François-Xavier Bagnoud Center

Project Overview

Community Mobilization for a Women's Self-Care Health Promotion Campaign

Phase Two: Pilot-test of an Online Meeting Using Web 2.0 Tools vs. a Traditional In-Person Meeting Venue with Women Infected or Affected by HIV Infection

The project was a prospective, experimental, pilot study describing the differences in traditional in-person and online meetings for the development of a community mobilization campaign for self-care health promotion by women infected or affected by HIV infection.

In this study, women assigned to an online meeting group (n=7) or in-person meeting group (n=8) chose self-care health topics, developed health messages, and provided outreach and health promotion to women in the community on various self-care health topics.

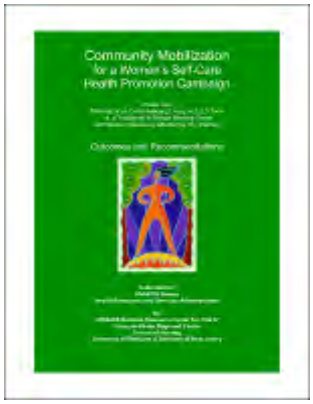
Community mobilization is a capacity-building process through which members of the community plan and carry out activities to improve community health.

Fourteen women outreached to 1,808 other women in the community on various self-care health topics in a one and one-half month time period. Both groups disseminated many effective self-care messages, and the self-care messages were diverse and reached broad and difficult-to-reach women in the community.

Women in the in-person group outreached to more women, and the cost of the in-person meeting was lower, but the success and benefits of the online meeting approach support the use of both approaches in future self-care promotion efforts like this.

The report on this pilot study was prepared in three sections to enable the reader to review the project by component:

Background and Methods



Outcomes and Recommendations

Participants and Their Outreach

The development of this report was supported by project 6 U69 HA10551-01-01 from the HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA). The report's contents are solely the responsibility of the authors and do not necessarily represent the official view of HAB or HRSA.

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Pilot-test of an Online Meeting Using Web 2.0 Tools
vs. a Traditional In-Person Meeting Venue
with Women Infected or Affected by HIV Infection

BACKGROUND AND METHODS

Submitted to:
HIV/AIDS Bureau
Health Resources and Services Administration

By
HIV/AIDS National Resource Center for Part D
François-Xavier Bagnoud Center
School of Nursing
University of Medicine & Dentistry of New Jersey

The HIV/AIDS National Resource Center (NRC) offers a range of services to HIV/AIDS healthcare educators and providers. For more information on NRC programs and services, contact: HIV/AIDS National Resource Center at François-Xavier Bagnoud Center, University of Medicine & Dentistry of New Jersey, 65 Bergen Street, 8th Floor, Newark, NJ 07101. Telephone: 973-972-9228; fax: 973-972-0397; e-mail: rothplpm@umdnj.edu or visit us at www.FXBCenter.org .

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With the assistance of
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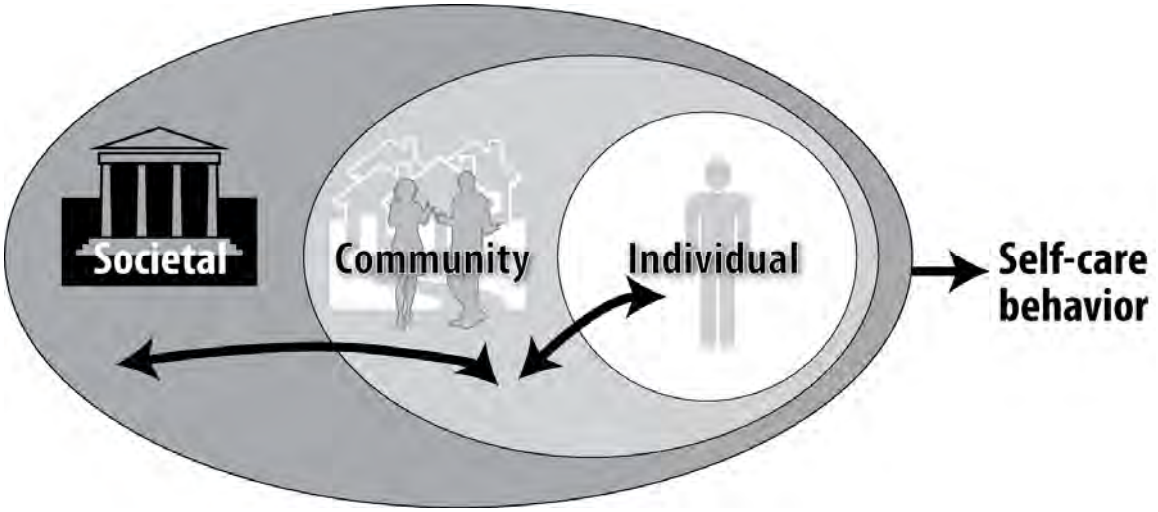
Introduction

In an effort to support healthcare systems and consumers, the U.S. Department of Health and Human Services (DHHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) identified self-management for women living with HIV as a development priority. As part of a cooperative agreement with HRSA HAB, the François-Xavier Bagnoud (FXB) Center, School of Nursing (SN), University of Medicine and Dentistry (UMDNJ) has completed a review of the self-management models literature and the first part (Phase I) of a research study to build upon or address gaps in existing knowledge. Phase I, the formative phase of this research study, was a survey undertaken to learn about and describe self-care behaviors of women in the Newark community living with HIV and to identify areas to intervene to promote self-care or self-management. The process phase (Phase II) of the study, which is described in this proposal, is the development and pilot test of strategies for a self-care intervention focused on health promotion. Future phases include the intervention phase (Phase III) – when the self-care intervention is scaled-up; and dissemination of the findings (Phase IV).

The literature in self-management research and education for women living with HIV has tended to focus on individual psychosocial variables such as self-efficacy. Thus, the FXB Center, National Resource Center (NRC) at UMDNJ designed the formative phase of the study, a community-based survey, to explore additional influences on self-care behavior such as social-environmental variables, interpersonal interactions between family, social networks, and health

care providers, community, and systems of care. The social ecological framework (Figure 1) was used to develop the self-care research.

Figure 1: Spheres of Influence on behavioral skills for self-care



The first phase of the self-care study provided evidence for areas to focus on for the subsequent phases of the self-care support and health promotion research. The participants in this first phase of the research were either from community-based sites or HIV-care sites. Interestingly, women from the HIV-care sites participated in significantly more self-care behaviors than the community sites (Table 1). This finding indicates that HIV-care systems may be more effectively engaging women in managing their health compared to the healthcare supports for women in the general community.

In addition to the increased frequency of self-care behavior for women from the HIV-care sites, the proportions of women from the HIV-care sites were also significantly higher for the ability to ask health care provider questions (self-advocacy) and for positive patient-provider relationships ($p < .01$). Positive patient-provider relationships were associated with self-care behavior. It is plausible that women living with HIV can provide a model for better self-

advocacy and patient-provider interaction which could be shared with other women in the community.

Table 1: Self-care Behaviors

Behavior	Overall		Community Respondents		HIV-care Respondents		P[a]
	n	%	n	%	n	%	
Attend Support Groups (n=430)	173	40.2	104	33.9	69	56.1	.000
Dentist (n=457)	190	41.6	128	39.0	62	48.1	.097
Exercise (n=457)	237	51.9	172	52.4	65	50.4	.771
Healthy Diet (n= 455)	285	62.6	198	60.4	87	68.5	.133
Medication Adherence (n=441)	333	75.5	228	71.0	105	87.5	.001
Mental Health Counseling (n= 314)	87	18.7	48	14.3	39	30.0	.001
Pap (n=433)	316	73.0	214	68.2	102	85.7	.000
Seek Follow-Up Medical Care (n=455)	350	76.9	232	70.9	118	92.2	.000
Seek Medical Care (n=435)	360	82.8	245	78.0	115	95.0	.000
Sleep 7-8 hours per night (n=442)	229	51.8	161	50.2	68	56.2	.304

[a] χ^2 test

While women from the HIV-care sites reported participating in more self-care behavior, women only reported 3 of the 10 positive self-care behaviors at least 75% of the time (Table 1). This indicates that there is a need for increased self-management support. Findings from the first phase also show that self-care behaviors were associated with multiple levels of influence. Substance abuse, an individual-level influence was reported significantly more by women from the HIV-care sites ($p < .01$). Depression was negatively associated with self-care. Food security (food availability) and the women's perceived ability to ask health-care providers questions (self-advocacy skill) were moderately associated with

self-care behavior. Community-level associations with self-care behavior included positive patient-provider relationships, religious support, and social support. Societal-level relationships included having access to medical care.

Since self-care behavior was associated with multiple levels of influence the research findings support the hypothesis that self-care behavior has multiple influences at individual, community and societal levels. These findings also support areas to focus on for self-care support and health promotion in phase II of the study. These areas include increasing self-care capacity in the following ways; intervention to support access to food; substance abuse reduction, interventions to decrease depression and to increase social support, and interventions to increase access to health care and to improve patient-provider relationships. In addition, since the proportion of women reporting self-care practices were low for numerous other practices, areas of focus could also include sleep, nutrition, regular physical activity, promoting dental care, etc.

The findings from phase one of the research study underscore the need for self-care support and point to some specific areas to focus on for self-care interventions. In addition women from the HIV-care sites engaged in more self-care than women from the community sites, indicating that women living with HIV may be helpful for developing health promotion messages and education for self-management of health.

Health Promotion

Health promotion is the process of enabling people to increase control over and to improve their health. [1] Self-care or self-management is an area that can be focused upon for health promotion. There are numerous published

reports in HIV and health promotion efforts, and a select few related to self-management are described here. [2, 3] The Eban health promotion intervention was the comparison arm of an HIV risk reduction intervention.[3] The health promotion intervention included eight sessions focused on teaching African American couples that many health problems can be prevented by changing personal behaviors, including physical activity, eating habits, cigarette smoking, alcohol and drug use, and medication adherence. The health promotion intervention was tailored towards preventing health issues affecting the target population. Similarly, a pilot test of educational and behavioral intervention to improve sleep was conducted with a group of women living with HIV since sleep disturbance is a common complaint among persons living with HIV.[2] These two studies provide examples of health promotion efforts to increase self-care behaviors. Another strategy for health promotion includes enabling (with support and educational resources) the affected community to develop and diffuse health promotion messages. This approach allows individuals in the community to mobilize maximum numbers of people around common health initiatives.[4]

Community Mobilization for Health Promotion

As part of the community survey in the first phase of this study, when women were asked to share their suggestions for implementing self-management training, many of them suggested community-based approaches for education such as group meetings in community-based agencies or churches. Historically, community mobilization has involved communities responding to directions given by professionals to improve their health. More recently, community mobilization efforts have involved the community in the development

of the health intervention.[5] This community involvement in the development and implementation of research and education utilizes the assets of the community and capitalizes on their understanding of local norms, attitudes, and values of the community. The participatory role of Community Advisory Boards (CAB) in the first phase of this research project illustrated the tremendous value community involvement brings since their participation enhanced the methods and development of the study.

Community mobilization is a capacity-building process through which community individuals, groups or organizations plan, carry out, and evaluate activities on a participatory and sustained basis to improve their health.[5] This process empowers participants to be agents of change and is an efficient conduit for the provision of information to a broader group.[6] For example, a study evaluating the development of an HIV-peer education model for low-literacy rural communities in India reported training 174 community-based peer educators.[7] These 174 peer educators reached 30,000 people with health messages, provided 2051 HIV awareness programs, distributed 62,000 educational materials and 69,000 condoms, and referred 2844 people for services. The authors also indicate that the peer educators were empowered by the community mobilization efforts due to their increased social status as peer educators.

Educational messages created by a team of community members for other community members can result in more effective messages due to the assets and experience of the team – and the process is also empowering.[8] The active involvement of women affected or infected with HIV in addressing self-management health promotion in their community should result in the development of more effective health promotion messages that relate well to

women.[9] Involving women in the creation and implementation of the self-care health promotion education will also result in increased human and community capacity. In addition, this approach has the potential to reach large numbers of people, and the team may have rapport with and access to parts of the community that academic researchers or medical clinicians do not. Therefore, the next step of the self-care study is to develop a community outreach and mobilization educational effort to increase women's self-care for health.

Next Steps - Pilot-testing Strategies for Community Mobilization in Self-Care Health Promotion

New technologies such as mobile phones and the internet have rapidly become more accessible and present new opportunities for organizing and coordinating the development of self-care health promotion. A Pew internet study reported that 55% of adult Americans now have broadband internet connections, and 25% of low-income Americans – those whose household incomes are $20,000 annually or less – reported having broadband at home in April 2008.[10] In addition, the internet is widely used as source of health information – 78% of home broadband internet users look online for health information.[11] This indicates that even though the digital divide among poor communities still exists, a quarter of low-income Americans have fast internet connections with the bandwidth to enable videos or other internet applications, and many of these internet users access health information online. In addition, some cities in the US are gearing up to provide free wireless internet to increase accessibility. New technologies are widely used by the public, and interventions using information technologies may have greater reach, adoption,

implementation, and maintenance, and therefore greater public health impact.[12] Global health groups are also seizing upon new developments to improve their work. For example, an entrepreneurial, sex worker advocacy group has used innovative technologies such as mobile phones, blogs, and YouTube videos for information sharing among peers.[8]

Information and communication technologies are increasingly used for health education, and the efficacy is supported by the published literature. One semi-experimental and three randomized controlled trials have evaluated the effects of web-based education vs. traditional education or wait list for self-management in diabetes, epilepsy, chronic obstructive pulmonary disease, and depression.[13-16] Of these studies, both groups in each study showed improved outcomes, three had no differences between outcomes for the intervention and comparison group, and one study that looked an internet-based self-help for depression compared to participants on a waiting list reported that the internet-based self-help produced clinically and statistically significant effects. These findings indicate that online education provided the same benefit as traditional health education. None of the studies included cost-benefit analysis. An additional interview study described patients and caregivers concerns about internet-based self-care in a primary care setting.[17] Findings from this study indicate that health care providers are more cautious about online applications for managing health than patients. These studies provide evidence for the efficacy of online interventions. However, these online interventions are primarily based on the static, Web 1.0 platform for education delivery.

Web 2.0 is a generic term to describe the trend towards user-oriented content, whereby communities of individuals provide information.[18] This

approach is a paradigm shift from the static Web 1.0 format in which online content is passively browsed with little or no user contribution. Web 2.0 tools provide a bottom-up approach versus the traditional top-down approach of experts providing content. Examples of popular Web 2.0 websites and databases include: Wikipedia, an online encyclopedia; Flickr a photograph database; YouTube, a site for sharing amateur and professional videos; social networking sites such as Facebook, Friendster, and MySpace; GoogleDocs; WikSpace; and PatientsLikeMe a patient-driven database of experience and treatment testimonials.[18] There is published research about Web 2.0 applications in health and medicine including several reports and one study that provides evidence to support Web 2.0 applications for activism and health-related content development.[18-24] A published program report describes how an enterprising CAB developed an online substance abuse referral directory for providers.[20] A study evaluating PatientsLikeMe reported the benefits when patients share information and engage in dialogue about their health in an online community.[19] A review article of Web 2.0 or Health 2.0 or Medicine 2.0 examined 56 academic papers to develop a definition for these e-health approaches.[25] The published literature provides support for Web 2.0 applications and also provides information about some of the barriers and controversies in the field.

The internet is wildly popular, it has tremendous potential for public health efforts due to its reach and sustainability, and the Web 2.0 applications enable participants to contribute to planning and content development which is aligned with the community-participatory approach. Based on this, the FXB Center NRC is proposing to recruit women infected or affected by HIV to participate in a study comparing the traditional meeting approach to an online approach using Web 2.0

interactive tools to develop health promotion messages and community interventions. The purposes of both meeting venues are for women to meet in person or online to create self-care health promotion messages based on the findings from the first phase of the study, and to plan ways to disseminate these messages in their communities. We are proposing to test two approaches to community mobilization planning and action.

The in person-meetings or online forum is not intended for personal information-sharing to increase self-management of health, though self-care practices of participants may improve as a secondary outcome. The meetings are for community members to generate self-care messages and interventions for community dissemination. This distinction is emphasized because there is some controversy about privacy issues and Web 2.0 applications.[25] Participants in this pilot study will not be sharing personal-health information or even identifying themselves, they will be collaborating to develop interventions for the community. In addition, in the Web 2.0 group, steps will be taken to protect confidentiality with password protected enabled Web 2.0 tools or a private server host. The Web 2.0 participants will have more anonymity than the participants collaborating on the in-person meetings.

Problem Statement for Phase 2

Online meeting forums utilizing Web 2.0 applications have tremendous potential for community-participatory public health campaigns, but it is important to test the feasibility for this use with women infected or affected by HIV infection before a Web 2.0 community mobilization campaign is scaled-up.

Research Question

What are the differences between traditional meetings versus an online meeting forum utilizing Web 2.0 tools for women infected or affected by HIV when used as approaches to create self-care health promotion messages and community interventions?

Sub-questions:

1. What and how many health promotion messages were generated by each group and how are they similar or different?
2. What type and how many community interventions did each group plan and what are their similarities and differences?
3. What type and how many community encounters were reported by each group and what are the similarities and differences?
4. What are the reported barriers and benefits of each approach?
5. How cost-effective are these approaches for collaborative meeting?

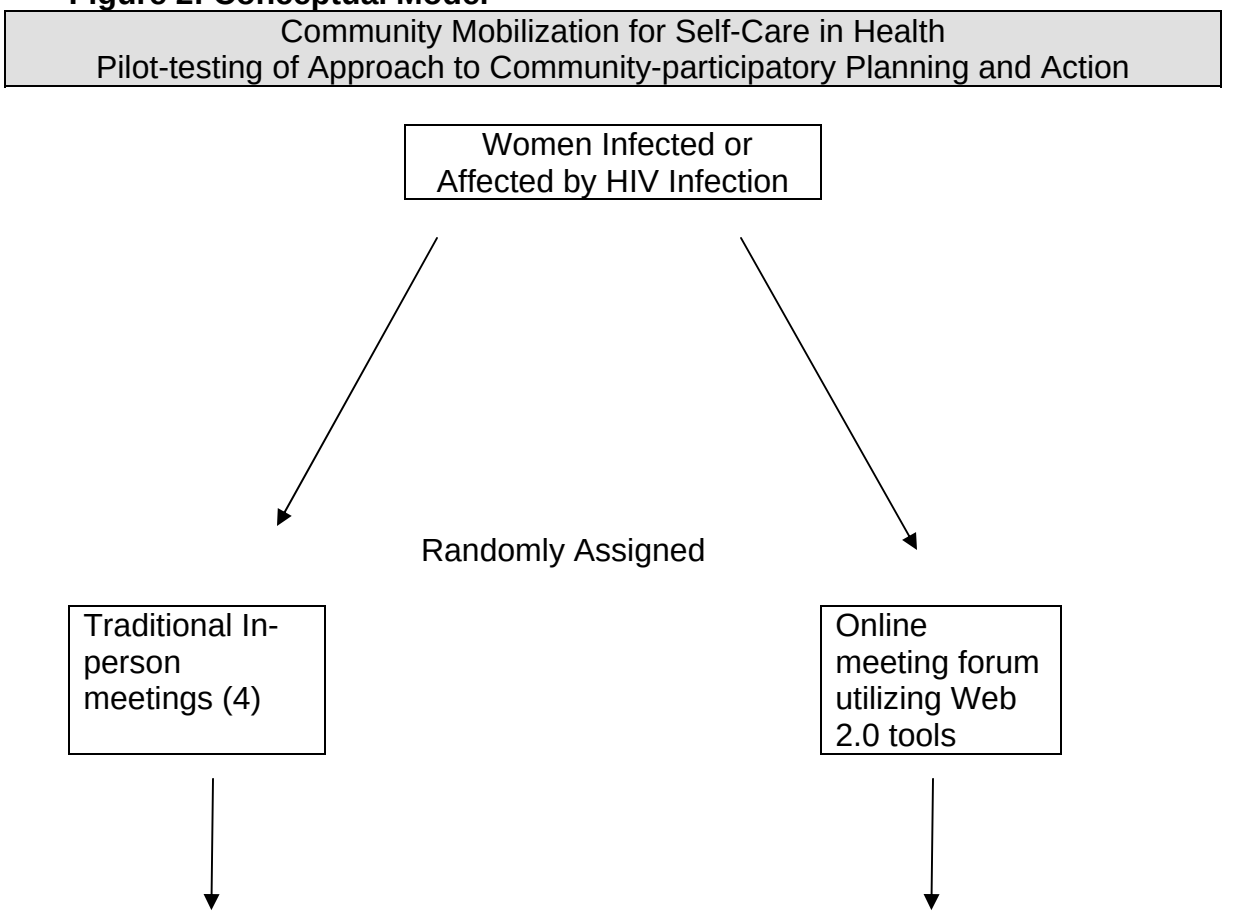
Independent variables: Traditional meetings and online meetings utilizing Web 2.0 tools

Dependent variables: community mobilization activities as measured by, health promotion messages, planned community encounters, actual community encounters, barriers and benefits to the approaches, cost-effectiveness

Hypotheses:

1. There will be no differences in community mobilization outcomes between the groups.
2. There will be no differences in the number of barriers for each group.
3. The online meeting forum will be more cost-effective.

Figure 2: Conceptual Model



Methods

Study Design

The study was a prospective, experimental, pilot study describing the differences in the effect and economics of traditional in-person and online meetings for the development of a community mobilization campaign for health promotion by women infected or affected by HIV infection. Forty-five women were invited to attend the information meeting about the study. Nineteen study participants ended up consenting to participate and were randomly assigned to the traditional in-person or online meeting group. After participants were assigned to groups, the traditional meeting group held four meetings to plan and to begin to carry out community mobilization efforts. Content and focus for the meetings are outlined in figure 3. The online meeting forum was available to participants for planning and action for the same time frame – three months. Both meeting forums were facilitated and observed by two or three FXB Center NRC research investigators with HIV, women's health, clinical nutrition, research, and public health expertise. A licensed clinical social worker was available for consultation and advisement on content development related to substance abuse, social support, depression, and self-advocacy. The licensed clinical social worker was also available if participants if they experienced psychosocial issues related to participating in the study, though none did. A Community Advisory Board (CAB) will be informed and consulted about the approach to the study. Institutional Review Board (IRB) approval will be obtained prior to any data collection.

Participants

Participants included nineteen women infected or affected by HIV infection and were recruited with flyers/announcements/posters at Ryan White Care Act Part C and D programs and HIV-care community agencies in the Newark, NJ area. Women were considered infected or affected by HIV if they frequent HIV-care settings such as Ryan White funded programs or community agencies that provide services for women and families living with HIV. HIV status was not obtained. Women in both groups received three fifty dollar gift cards to compensate them for their time.

Group Meetings

During the three month study time period the FXB Center NRC research investigators facilitated four in-person meetings and an online meeting forum based on the following facilitator objectives for the community mobilization campaign:

- To familiarize participants with the findings from phase one of the study and to the purpose of phase two of the study, described in this proposal.
- To orient all participants about the purpose of community mobilization for self-management of health: A capacity-building process through which women infected or affected by HIV plan and carry-out health promotion for women's self-care through a variety of strategies and venues in the community to get the word out.
- To facilitate discussion about the creation of self-management health promotion messages that community members will resonate

with. The potential messages were based upon findings from phase one of the study and included the following topics:

  - Nutrition
  - Regular physical activity
  - Sleep
  - Dental care
  - Food Access
  - Substance abuse treatment and prevention
  - Depression treatment and prevention
  - Social support
  - Accessing health care
  - Communicating with health-care providers
  - Self-advocacy

- To provide educational content and resources to support women in developing the health promotion messages and interventions that they decided to act on. The FXB NRC facilitators provided basic background information and monitored accuracy of information transfer between participants for each topic that was chosen by the women.
- To facilitate discussion about plans for dissemination of the health promotion messages in the community, including the types of message delivery e.g., word-of-mouth, phoning, texting, e-mailing, flyers, brochures, blogs, group meeting presentation, individual encounters, public announcements, etc., as well as the place or venue or target audience for distribution, e.g. Web, street

encounters, shelter, support group, beauty salon, church, etc. All content was reviewed by the FXB NRC research team and in some cases, the research team role-played with participants to allow participants to practice delivering their message, to help ensure the accuracy and appropriateness of the message and delivery, and to practice setting personal boundaries. The FXB Center NRC provided graphic design and reproduction support for written materials such as flyers, cards, and posters.

- To facilitate documentation and discussion about the type and number of community encounters. Community encounters could range from a conversation with a family member or someone on the street about the self-care behavior being promoted to a planned group discussion about the self-care behavior, to a flyer prominently placed in a beauty salon, etc. All of these encounters were captured, described, and enumerated.
- To evaluate the experience and to provide a forum for participants to discuss the experience.

Figure 3: Procedures Flow Chart

CAB Meeting

Present study and obtain feedback

↓

Obtain IRB Approval

↓

Recruitment

Create flyers, posters and distribute to UMDNJ ID Clinic, FXB Clinic, Hyacinth AIDS Foundation and to other places the CAB recommend

↓

Information, Group Assignment and Informed Consent Meeting

Provide overview of study and participant expectations, randomly assign participants to groups, provide information about the risks and benefits of participation and obtain written informed consent

↓

Facilitated by FXB Center NRC Research Investigators for 3 Months

Traditional Meeting 1:

- Present findings from phase 1 and purpose of phase 2
- Decide upon group chair person
- Decide upon health promotion messages to focus on

Traditional Meeting 2:

- Develop health promotion messages
- Plan community encounters
- Distribute notebook for documentation of encounters

Traditional Meeting 3:

- Report encounters
- Discuss progress
- Start meeting 2 activities again

Traditional Meeting 4:

- Report encounters
- Discuss progress
- Evaluation
- Evaluation Discussion
- Distribute gift cards

Online Meeting Forum with Web 2.0 Tools:

- Present findings from phase 1 and purpose of phase 2
- Decide upon group chair person
- Decide upon health promotion messages
- Develop health promotion messages
- Plan community encounters
- Present encounter documentation methods
- Blog about progress
- Evaluation
- Evaluation Discussion
- Distribute gift cards

Data Collection

The FXB NRC research investigators directly observed and documented the development of health promotion messages, community intervention planning, and the community encounters. Several logs were utilized to document processes of each approach. A log was kept to document barriers and benefits of both approaches. Expenses were tracked throughout. At the end of the study time period, the FXB NRC research investigators facilitated a written evaluation and evaluation discussion in both groups (Appendix 1 in Outcomes and Recommendations section of this report).

Data Analysis and Description

All data except the expenses were entered in to NViVo 8. The number of health promotion messages and the number of encounters were enumerated. The discussions during in-person meetings, live chat sessions, and the evaluation forum provide a basis for the case descriptions, though these descriptions are subjective and based upon the research teams observations about each participant. The economic analysis entails a brief discussion about the cost-efficiency of the groups based on economic inputs and outcomes produced.

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By
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The HIV/AIDS National Resource Center (NRC) offers a range of services to HIV/AIDS healthcare educators and providers. For more information on NRC programs and services, contact: HIV/AIDS National Resource Center at François-Xavier Bagnoud Center, University of Medicine & Dentistry of New Jersey, 65 Bergen Street, 8th Floor, Newark, NJ 07101. Telephone: 973-972-9228; fax: 973-972-0397; e-mail: rothplpm@umdnj.edu or visit us at www.FXBCenter.org .

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OUTCOMES

After receiving Institutional Review Board (IRB) approval to proceed on February 16, 2009, forty-five women were recruited for the self-care study from HIV-care Part C and D sites and from HIV-care community agencies over the course of one month. On March 19, 2009 an information meeting was held for potential participants. During this meeting, potential volunteers were provided with an overview of the study and participant requirements. Women who were still interested remained for an orientation and to participate in the informed consent process.

Nineteen women signed consent to participate and were randomly assigned to an online or in-person meeting group. Three women who consented to join the study withdrew before participating in the study activity of online or in-person groups. Two of the three women told the principal investigator (PI) that they had too much going on at home, and the third did not provide a reason.

A total of 15 women took part in online or in-person groups. Two women did not complete all the activities of the study but are described in the sample. One of these women, assigned to the online group, developed a health topic but called the PI to explain that she could not longer participate do to overwhelming life events. A case description was developed for this participant, but her outcomes are not captured since she dropped out. The other woman, assigned to the in-person group, missed one of the four in-person meetings due to the death of her mother—this woman developed her health message and flyer, but did not report on distributing her message during the study time period. This

participant's work is represented in the case descriptions (Participants and Their Outcomes section) and findings since she had substantial participation.

HEALTH PROMOTION MESSAGES AND OUTREACH TO OTHER WOMEN

Women in both groups developed a health topic of their choice from a list of eleven areas. These eleven topic areas were based on the findings from the needs assessment in phase one of this research. Women in the in-person group were provided with written materials on each topic. The on-line group accessed the same resources on each topic within the online forum, though these women had access to additional information on the internet.

Women in both groups chose to develop topics in a variety of areas. Four topic areas were chosen in the online group and six were chosen in the in-person group. Type of outreach activity was similar for both groups. One woman from each group developed a session or class on their topic, a woman from the online group added content to existing group meetings, and the remaining thirteen women created flyers or cards to hand out to individual women for their outreach. An additional unique activity by one woman from the online group was an effort to organize an HIV-testing session for women at a predetermined time and location using a mobile testing van. A summary of the health promotion messages and outreach efforts is provided in Table 1.

TABLE 1**: SUMMARY OF HEALTH PROMOTION MESSAGES AND OUTREACH BY GROUP ASSIGNMENT**

Health Promotion Message	Group Assignment	Summary of Outreach Efforts to Women As Reported by Participants
HIV Testing	Online	▪ Encouraged high-risk women in local Newark neighborhood to get an HIV Test ▪ Organized HIV testing van ▪ Distributed 50 inspirational cards with date and time for scheduled HIV van testing
STDs/HPV/HIV	Online	▪ Conducted 4 outreach/educational session to women at various community HIV care programs in the Newark area; reached approximately 40 women ▪ Shared 40 inspirational cards ▪ Distributed handouts on STDs and HIV
Depression	Online	▪ Distributed 10 flyers at a group meeting on depression ▪ Posted 40 flyers in local stores and businesses (beauty salon, barber shop, drug store, corner store, Pathmark)
Food & Nutrition	Online	▪ Distributed 40 notebooks with content on nutrition tailored for older African-American women ▪ Practiced presenting materials at UMDNJ Toastmasters meeting ▪ Conducted session at AARP meeting ▪ After study period conducted a session at the National Council of Negro Women
Exercise & Physical Activity (1)	Online	▪ Shared information with 40 people including co-workers and people on the street ▪ Networked at community health fair in Newark ▪ Distributed English and Spanish flyers
Exercise & Physical Activity (2)	Online	▪ Distributed 50-70 flyers to family, friends, co-workers ▪ Posted information in local businesses (grocery store, hair salon)
Exercise & Physical Activity (3)	Online	▪ Developed flyer on ways to incorporate exercise into daily activities, especially for those dealing with leg aches and pains ▪ Reached out to staff and residents of a nursing facility ▪ Posted five posters in elevator and bulletin boards ▪ Distributed 100 flyer versions of the poster
Substance Abuse	In-person	▪ Handed out 325 flyers with listings of local substance abuse treatment centers ▪ Shared information at church, bus station in Irvington, NJ and local streets known with substance abuse activity

Health Promotion Message	Group Assignment	Summary of Outreach Efforts to Women As Reported by Participants
Sleep	In-person	▪ Planned to share information and distribute 50 flyers to residents of senior buildings ▪ # of flyers distributed was not reported
Depression	In-person	▪ Shared information at church, doctor's office, support group, shelter and local neighborhood in Newark and Bloomfield ▪ Distributed 80 flyers
Nutrition/Food labels (1)	In-person	▪ Distributed 100 flyers to local stores, drug store, doctor office, hair salon and a community recreation center
Nutrition/Food labels (2)	In-person	▪ Distributed 100 flyers ▪ Shared information with participants at VOICES conference ▪ Posted flyers in building
Exercise	In-person	▪ Handed out flyers to commuters at Newark Penn Station ▪ Posted flyers in local Laundromat ▪ Distributed total of 75 flyers
Oral health-Periodontal disease	In-person	▪ Distributed 180 flyers (14 via mail, 166 in-person) ▪ Gave 6 in-person group sessions ▪ Spoke with 14 women over the phone ▪ Outreach to Newark, NJ, Princeton, NJ, Philadelphia, Massachusetts and Georgia ▪ Newark locations: St. Michael's, Roseville Presbyterian Church, St. Claire's Women's Support group, Apostle House, NEMA Planning Council, FXB Women's Support Group, UMDNJ ID Clinic, Planned Parenthood
Oral health-General	In-person	▪ Distributed 553 flyers ▪ Shared information at 21 different locations in Newark: 9 Summit St., 25 Summit St., James St., Nesbitt Terr., Roselle Street, Norfolk St, Lyons Ave, Sunnyside Terr., S. Orange Ave, Bruce St., 153 Halsey St., Dialysis Treatment Center ▪ Also targeted Elizabeth and Kearny, NJ

All but one woman in the in-person group completed their planned outreach. The total number of women outreached to was substantial for both groups—fourteen women had outreach encounters with 1,808 other women in the community. The median number of women outreached to was 77, with a

minimum of 40 and a maximum of 553. Women in the in-person group outreached to more women (n = 1413) than the online group (n=395, p=.007).

BARRIERS AND BENEFITS OF BOTH MEETING APPROACHES

The barriers and benefits of both meeting approaches are summarized in Table 2. There are differing barriers and benefits for each type of meeting. Overall, group members of both approaches felt that their meeting venue worked, though several online participants communicated by phone when they were unable to use the online forum due to computer accessibility. This phone communication resulted in some deviation from the pure online approach, but was necessary to enable two online participants to continue their outreach efforts. In addition, all but two of the participants from the online group preferred picking up their gift cards in person (as opposed to receiving them in the mail). This unanticipated interaction allowed for the research team to communicate with these participants more than would be expected in a solely online environment.

TABLE 2**: BARRIERS AND BENEFITS OF THE ONLINE AND IN-PERSON MEETING APPROACHES**.

	Barriers	Benefits
Online Group	No face to face value of interacting with participants	Participants can work anytime – more flexibility
	Library hours limited time online for participants without a home computer	Provides opportunity for ongoing communication between research team and participants
	Hard to gauge participant progress if not documenting online or contacting research team	Decreased demand for printing background/support materials
	Limited interaction among participants, especially for those without a computer at home and/or not able to log in during one of the live chat sessions	More resources and information available through website links
	Some participants had difficulty expressing themselves in writing online	Some participants said that the online environment enabled them to participate since they did not have to leave work or find child care.
		One participant said that she preferred the autonomy of working online
In-person Group	Time constraints on in-person meetings	Better gauge of body language, enthusiasm, uncertainty about the discussion and ideas
	Transportation cost and planning	Face to face value of interacting with participants
	Increased demand and time for printing background/support materials	Participants were able to connect in real time
	Meeting room logistics	Participants able to provide live support to each other
	Extra personnel for note-taking	Forced (captive audience) to learn about peers health topic and outreach
		Participants enthusiasm fueled other participants

COST COMPARISON OF MEETING APPROACH

For the two and one half month time study period, the in-person group cost approximately $282.00 per person and the online group cost about $366.00 per person. These costs include the $150 gift card each participant received,

transportation, materials, and web-site development. The cost per person does not include the research team's time before, during, or after the study time period, nor does it include the material reproduction costs for flyers, posters, mailing, telephone, and so forth. While the in-person, per person cost was lower, this may not hold true if meetings needed to be held offsite and space needed to be rented for meetings.

PARTICIPANT EVALUATIONS

The participant evaluation allowed women to provide feedback about their involvement and to offer suggestions for future studies. Appendix 1 provides detailed evaluation findings, and a brief summary is provided here.

Participants in both meeting venues felt that their health messages and community outreach were successful. All of the women were able to develop the messages. Each woman (n=14) who completed the evaluation stated that they were able to participate in the development of health promotion messages that women would be able to understand and respond to. In addition, all but one person disseminated their self-care message into their community.

Eighty-eight percent of the women in the in-person group, as compared to 40% of the women in the online group, reported that it was easy to document their community encounters. The difference may be attributed to the barriers of limited computer skills and routine access to the internet.

Participants also stated that this type of research study and community mobilization should continue. Women suggested that the study time should be lengthened to allow for more time to disseminate messages in the community and that it be expanded to include more women.

The majority of the participants expressed that participation in the study was valuable. They provided many reasons, but the fulfillment of helping other women learn to take care of their health was among the top reasons listed. Several women also mentioned that while working with their group and sharing with women in the community, they also learned more about healthy habits and self-care for themselves. While women participants' self-efficacy was not a formally measured outcome, it was apparent that the study had many positive effects on the women. Statements like "I did not realize I can help other women and it felt great to do it" underscore the importance of their work and highlight the need for self-efficacy to be included as an outcome measure in future work.

RECOMMENDATIONS

Volunteers in this study participated in an online or in-person meeting venue to develop and disseminate self-care health messages to other women in the community. This process is called community mobilization. Community mobilization is a capacity-building process through which members of the community plan and carry out activities to improve community health. [1] Findings from this study are similar to other community mobilization efforts because they showed that the process is an efficient conduit for the provision of information from a smaller group of community members to a broader group. [2, 3] Fourteen women outreached to 1,808 other women in the community on various self-care health topics in a one and one-half month time period.

The process of community mobilization has also been touted for empowering participants to be agents of change.[1, 2, 4] This pilot-phase did not specifically measure self-efficacy changes for women participants, but the women's voiced sentiments during discussions, live chats, and evaluations that definitely support the notion that women are empowered by the process—maybe due to their increased social status as peer educators as reported by others. [2] Half of the women spontaneously shared that the experience either improved their own self-care or their self-efficacy and belief in themselves to help others, even though they were not specifically asked about this. The effects of community outreach on the women who carry out the outreach should be measured in future endeavors.

Another benefit of participatory community mobilization is that educational messages created by community members for other community members can result in more effective, culturally appropriate messages that relate well and connect to the target audience. [5] This pilot study did not measure how well outreached women related to the messages, but most women participants chose topics they had personal experience with or felt were important for other women to focus on, and developed their messages in ways they thought that the women targeted for outreach would understand. For example, one woman created a poem that read:

"Knowledge is Power, Save Your Life,
Take the Time, It Don't Cost a Dime,
Prevention & Testing are the Keys,
You can Live a Long Healthy Life w/HIV,
Get Tested & You will See,
Take it From Me!".

She wanted the poem printed on a business-size card so that women could put it in a pocket, and the date, time, and location of the HIV testing van were printed on the back of the card. Another woman targeted her entire presentation on food labeling for older African American women like herself. Other women brought knowledge and expertise of their community that would be difficult information for an academic or community agency to acquire. For example, one woman focusing on substance abuse treatment knew of specific locations to outreach to women at-risk. Another woman living in a shelter knew many women in the shelter to outreach to about treatment for depression. Most of these women would probably be hard to reach for a non-shelter resident. Women outreached to other women in similar or familiar circumstances to their own. This is clearly advantageous since women know their target population but precaution should also be taken when women work in the community. The study team spent time with the women participants reinforcing the need for boundaries and safety, and this should be part of future community mobilization efforts.

It is clear that both the in-person on online meeting approaches resulted in successful community mobilization by participants in each group, so the approach for the future is not clear cut. Both groups disseminated many effective self-care messages, and the self-care messages were diverse and reached broad and difficult-to-reach women in the community. Women in the in-person group outreached to more women, and the cost of the in-person meeting was lower, but the success and benefits of the online meeting participants cannot be overlooked.

Since both groups achieved success, it is recommended that women should be offered both approaches in the next phase of the project. Women who

prefer the flexibility and autonomy of working online can participate in the online group (with some changes to facilitate more live discussions by phone or web) and women who do not have access to the internet can also participate in the in-person approach to community mobilization. This solution will allow for greater participation and will allow development of training manuals for each type of meeting approach to community mobilization that can be used by Part D programs. Including both approaches for more self-care community outreach will also allow the approaches to be tested in a greater number of women and varying contexts.

APPENDIX 1

Community Mobilization for Women's Self-Care Promotion
Evaluation Findings

INTRODUCTION

Facilitators of this research study disseminated an evaluation questionnaire at the conclusion of the 3 month study period. The goal of the survey was to collect feedback about the experiences the women had participating in this study as well as obtain input about improving and expanding future studies.

METHODS AND RESPONDENTS

Women in the online group were provided a link to an online evaluation. Members of the in-person group were asked to fill out a paper questionnaire during the last face to face meeting. Fourteen women completed the survey, 6 from the online group and 8 from the in- person group.

- CLARITY OF GROUP DIRECTIONS

  One hundred percent of women from both groups indicated that the directions for their group were clear and understandable.

- PARTICIPATION

  Online
  When asked how often they logged into the online work group and communicated during the three month period, 33% of the women stated that they logged in on average of 2-3 times per week; 17% logged in 4-5 times per week or 1 time per week; 33% stated that they did not have an average weekly log in time.

  Thirty-three percent (2 respondents) indicated that they did experience problems using the online meeting tool. Some of the reasons for problems encountered included:

- My computer skills are very rusty. I hadn't been in front of a computer screen for over 5 years. I wasn't familiar with any of the features such as the chat room, inviting people in and even sending an e-mail.
- I only use Microsoft WORD, so I had to learn more computer skills.
- The timing was bad for me

In-person
Eight-eight percent of the women in the in-person group attended all four meetings. One participant attended 3 meetings only. No one experienced any difficulties with attending the meetings.

- DISCUSSION AND PLANNING

When asked if there was enough time for discussion and planning to disseminate the self-care health promotion messages, 100% of the women in the online group agreed that they had enough time and 86% of the women in the in-person group felt that they had enough time. Due to family matters, one participant in the in-person group expressed that she would have liked more time to develop her flyer.

Reasons that contributed to having enough time were the availability of resources to assist the women in developing their health messages, and the supportiveness of the facilitators to offer feedback and suggestions. One woman wrote that “there wasn’t any problem with research and graphics, the resources were plentiful.”

- DEVELOPMENT AND DISSEMINATION

One hundred percent of women from both groups felt that they were able to participate in the development of health promotion messages that women would be able to understand and respond to. 100% of the respondents from both groups also indicated that they were able to disseminate self-care messages in the community.

Online

Selected comments about development and dissemination:

- My message was clear and to the point. The majority of the women I spoke with responded in a positive manner. I even had dialogue with a few of them. I only had one serious rejection and that was my first encounter, but I was not deterred.
- I talked about my topic as a part of general conversation and exchanged ideas and thoughts with women. One woman told me that my presentation was unique and I will follow-up to see how they are using the notebooks I created for them.
- My message was welcome information to the women who reviewed it.
- I handed out cards with a message on the front stating that you can live a long, basically healthy life with HIV but only if you know that you are infected. I also had the date and time at which the NJCRI testing van would be available in my community.
- I was able to spread my message with the help of the group administrators through event postings and at my work.

In-person

Selected comments about development and dissemination:

- Very positive [feedback] if subject didn't pertain to them, they knew someone that it did.
- It was important to speak in layman's terms
- Health is life, if you know about health, it can help you.
- I think it is important to be reminded of your health.
- [I was to develop a health message] because of their unfamiliarity with proper oral health
- [I was successful] because I am familiar with the various areas and age ranges [I targeted]
- I needed more time because there were other subjects that wanted this service

- DOCUMENTING ENCOUNTERS

Online

Forty-percent of the women in the online group stated they were able to easily document their encounters online. When asked why or why not, participants reported:

- Unfortunately, it was not as easy as I had anticipated in getting to and from the library. Basically, I went only once a week. I was only allowed a half hour at a time and sometimes I took me half that time to get to the website and figure out where to type my message and how to send it. It definitely would have been easier if I would have had a computer at home.
- Personal issues did not leave me enough time to do this.
- Yes, because it was online, I didn't have to wait to share what happened.

In-person

About 88% percent of the women from the in-person group felt that they were able to easily track their community encounters in the notebook provided to them. When asked why or why not, participants reported:

- I called and made appointments for my presentations.
- I had good encounters everywhere I went.
- I used a tracking system

The next group of question allowed the participants to provide open ended feedback about working on this project and their recommendations for future projects.

Q: Was it beneficial for you to participate in this group?

Online

- It helped me feel like I was doing something to help other women struggling with the idea of even getting tested. Because I am a long-term survivor I feel I can be helpful to new comers. They are clearly able to see that with proper care you can live a long time.
- Yes I was able to speak to women to help them understand that exercise and nutrition are partners.
- While I was unable to participate regularly with the group, I am happy that I was able to prepare and distribute information that will help others.
- I went to get a couple of checkups that I may not have gotten because I was a participant in this study.

In-person

- Interest in the community and women caring for themselves
- I was able to get out of the house and talk to people.
- Very educated, informed and nice to share ideas
- We helped people
- I have learned more about eating healthy myself
- It was enlightening and fulfilling

Q: What did you like most about working in this group?

Online

- My interaction with the community was definitely my favorite part. I love talking to people. And the group of women I was trying to reach are near and dear to my heart. Been there, done that. I was clearly trying to save them some unnecessary pain and suffering.
- Talking about health issue
- I enjoyed the convenience of logging on anytime of the day
- Personal issues did not leave me enough time to do this
- Dr P was accessible and everything was online which enabled me to log on whenever I got a chance
- The commitment the women had

In-person

- The diversity of women
- Listen to how people develop their different ideas.
- That it was all about women
- That we were able to start caring for ourselves more
- Respectful and motivated
- Talking
- Developing messages and receiving insight

Q: What did you like least about working in this group?

Online

- The fact that I didn't have a computer at home so I couldn't participate in the chat discussions and I couldn't even view the other women's ideas because I didn't know how.
- I wasn't able to actually chat with the other women that were participating in this online group.

In-person

- Not enough time (study period)
- It could have been a longer time.
- No dislikes

Q: What strategies would help improve this type of project?

Online

- Well, in my particular case, if all persons lived up to their end of the deal it would have been totally successful. But since the van wasn't there that I said would be I couldn't tell if I had reached anyone.
- None, just spread it more
- I know how to work alone and independently so I had no problems, however, if you can't work alone and independently, you may have some problems with doing the research.

In-person

- More time (study period)
- If more people participate to develop more topics
- Having more meetings
- Just continue it

Q: Please share your suggestions for self-care health promotion activities in the future.

Online

- None. I fear that people's concern about this disease isn't as strong as it used to be because we are trying to promote it as a manageable disease.
- We need more self-care health promotion activities in the future because obesity and other disease are increasing every year.
- I have none at this time.
- Women have to come to terms about the importance of self-care. I think using social networking is a great idea to get the CORRECT information out to women

In-person

- Take care of yourself
- Should be done on a broader scale

Q: Do you think we should expand this work to other places in the country?

Online

- Definitely. Especially in countries where HIV meds are not available.
- Yes (multiple responses)

In-person (verbally asked to participants)

- All women agreed that this project should be expanded

Q: If so, do you have suggestions for how we can support women to do this in other communities?

Online

- Getting more women to be more involved with this. Women connect with women.
- Getting in contact with female community and district leaders might help to find a way to reach out to the women in their areas.
- [Enroll] a whole lot of females. I will tell them

In-person (verbally asked to participants)

- Have existing participants bring/recruit other women into the next project
- Have 5-6 months worth of meetings
- Have more meetings to report on results
- Have UMDNJ or community agency number listed on flyers and monitors outcomes (i.e., if number provided have agency track the total of new calls or inquires about services)
- Let each participant create a standard flyer
- Utilize the groups power to increase promotion

Q: Would you consider participation in similar self-care promotion activities in the future?

Online

- Absolutely. I would like to become more active in helping out. It as much of a benefit to me as it is to the women I'm trying to reach.
- I had fun. I learned what I was capable to do, and learn from them.

In-person

- Yes, it is important for me to be positive and conductive in the community
- Because it helps to educate women about health
- The group was a good idea for us. I wish I could start my own group
- I enjoyed the challenge
- It helped the community
- It was very helpful to the community
- I feel it helps with educating those who otherwise would be ignored

Q: Please provide any additional comments you wish to share.

Online

- Dr. P was a real help. She was very supportive at times when I became a bit discouraged because of my lack of knowledge of the updated software. She encouraged me to keep on and if I couldn't get to the library she told me it was all right to use the phone. She really made me feel like I had something to contribute. She even gave me Kleenex when needed. Thanks, Dr. P. And when things didn't go as planned and NJCRI let me down on their part of the whole thing, she was just as mad as I was. She really cares about getting the message out to women and will not tolerate people dropping the ball when dealing with people's lives. She gets the fact that you have to get them while you can and any time they are again let down from the system, it's just another reinforcement that people don't really care. That they are dispensable.

- In researching information for others, I discovered information useful for me.

In-person

- The promotion opened up a lot of eyes (and mine) to important issues. there should be more seminars or bigger ones to implement these health issues
- Thank you for your patience. I found the facilitators to be organized and kind and able to direct the group in a professional manner
- This program helped people on the street and my life
- This program can be very helpful because of the different parts of the study
- This group program should be done on a broader scale

CONCLUSIONS

Both methods of meeting, either online or in-person appeared to have been a useful way to organize women and assist them with developing health promotion messages. Women in both groups were successfully in developing a health promotion message, sharing it in their community, documenting encounters and reporting back on their experience.

The online forum posed challenges for women who had limited computer skills and routine access the internet. In these instances, those participants would call the facilitators with updates on how their community mobilization was progressing. The facilitators would either assist them with their online issues or make documentation online on behalf of the participant.

The in-person group was very vocal and open with sharing ideas and being supportive to the other women in the group. The face-to-face interaction allowed for real-time sharing. This was limited in the online group, especially for those without a computer at home and/or not able to log in during one of the live chat sessions.

Both groups expressed that their participation in the study was valuable. It offered a structured avenue to assist other women in the community, as well as enhanced the self-learning and in some instances the self-care of the participant themselves.

It was stated more clearly in the in-person group that the study period could have been longer. Feedback from the questionnaire suggested a 5-6 month study period would have been beneficial for allowing more time to disseminated health messages, document encounters and any outcomes they were able to capture.

It is evident from both groups that this type of project should continue and expand to engage more women. Since both approaches to meeting for community mobilization were successful, next steps could include a hybrid or both approaches.

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Community Mobilization
for a Women's Self-Care Health Promotion Campaign

Phase Two:
Pilot-test of an Online Meeting Using Web 2.0 Tools vs. a Traditional In-Person Meeting Venue with Women Infected or Affected by HIV Infection

PARTICIPANTS AND THEIR OUTREACH

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HIV/AIDS Bureau
Health Resources and Services Administration

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Introduction

This component of the report describes each participant and their outreach efforts. The case description summaries were developed by the principal investigator and were reviewed and edited by a co-investigator, both of whom met with women online and during the in-person meetings. The summaries are based upon the researcher's observations, in-person and phone discussions with women, live chats with women, and participants' discussion of the project evaluation questions. Case descriptions were developed for the purpose of providing insights into the two meeting approaches to mobilize women by telling the stories of the participants' outreach experiences and products. The case descriptions should not be considered formal "research findings". These are presented in the "Findings and Recommendations" section.

The style and content of the case descriptions highlight the unique aspects of each participant, and are intended to most effectively portray each of the women and their community mobilization outreach. Although demographic information was not collected, the women from the Newark community who volunteered to participate in this study were diverse in age, life experiences and culture. This was a strength when carrying out community outreach, since women targeted varying topics and target populations.

Online Participants

Anna

Having participated in other HIV-advocacy capacities, Anna joined the study as a seasoned supporter of HIV-related issues in the Newark community. Anna's ability to articulate her own needs and to advocate for the needs of others made her an ideal candidate for the women's self-care health promotion.

After a few phone calls to help Anna access the online site, she was able to use the site independently. She wanted to reach out to other women about dental health and came up with some ideas, but did not develop her topic. About 2-3 weeks into the study, Anna contacted the PI to explain that she wanted to withdraw from the study due to issues going on at home. Anna's choice to end participation was respected, and she was withdrawn from the study. The loss of her participation was keenly felt since she had such potential to outreach to women about their self-care.

Chig

Chig, a vibrant, young woman, is a student and has a job. Early on in the study, she relayed that she is "really interested in exercise and physical activity"; she identified this topic for her outreach efforts. Chig needed prompting to participate in the online group (the PI called and e-mailed her), but was able to navigate and operate within the online environment successfully. Her first few drafts of her content required substantial revision by the study team for accuracy and appropriate graphics. Chig was open to feedback, and the final product, an informational flyer, was mutually agreed upon.

Chig distributed 70 flyers about physical activity to family, friends, coworkers, and community residents. She visited hair salons and a grocery store, and conducted outreach on the street. She chose to distribute her message on warm days when women would be out. She mostly spoke with women individually, but sometimes ended up speaking with groups of women.

Chig relayed that she thought that her outreach efforts were worthwhile because "women were interested and asked questions." She felt that her message helped motivate women to begin exercising or to exercise more. She also reported that women asked for additional flyers so that they could pass the information on to their network of female friends and family. Chig commented that there should be more woman-to-woman community outreach like this and that her success was largely due to her positive message and her ability to connect with women about a health message.

Chig reached out to many women about increasing physical activity, decreasing meal portion size, and keeping a positive attitude. She believes that her message

impacted many women, and she also shared that she learned about some of her own unique strengths in communicating and connecting with women regarding taking care of their health.

CJ

CJ joined the study with resolve and determination to help older African American women like herself and to personally grow. She asked a few carefully chosen questions during the information meeting and carried herself with quiet dignity and watchful eyes.

CJ did not have a home computer, but was not upset about being randomized into the online group. She quickly challenged any age-related stereotypes about technology use by stating that she was pleased about the online placement. She accessed the internet in the library, was able to use the online site to capacity, and participated regularly in online asynchronous discussions and one of the live chat (synchronous discussion) sessions.

CJ's chosen topic was food labeling and nutrition. Her efforts were tremendous, in the realm of extraordinary from the perspective of the study team. In fact, at certain points during the study there was concern that CJ committed too much time to the study. The PI spoke with CJ about this, and CJ assured the team that she wanted to commit a lot of time because she saw it as a growth opportunity. CJ's outreach was so exceptional that the following description does not convey the extent of what she accomplished.

CJ spent most of the first 2 months developing her topic. She asked many content-related questions in the online forum and offered support to other women online. Much of her time was spent investigating existing materials, including the USDA's Food Guidelines and Pyramid. Her efforts including learning about these guidelines and creating sample menus which incorporated foods she knows older African American women in her community eat. She even went to the grocery store to take photographs of these foods for incorporation into her sample menus. CJ became more and more energized as she learned more about food labeling and nutrition.

Her communication online began to include aspects of her own evolution during this process. She started to relate her content to the struggles she and her peers faced during the 60's. Basically, she began to see that women her age need to advocate for their health now as they advocated for their equality during the civil rights movement. Most of her content related nutrition and health advocacy back to a time women her age recall — she even rewrote the lyrics to the song "Sugar Pie Honey Bunch" by the Temptations to include a nutrition and health message. She also focused on detail and wanted an Afro-centric theme, including a Sankofa, an African symbol of wisdom, on the title page of her content.

CJ's content on nutrition and health is extensive. The study team answered questions, led CJ to resources, assisted with some of the technical content

development and “word-smithing”, but by-in-large, CJ developed the content and used materials created by the USDA and FDA. At one point she recognized that she had developed too much content and decided not to reproduce the sample menus for her women's groups.

Toastmasters, a communication and leadership group, served as CJ' practice forum for her presentation. The Toastmaster advisors provided CJ with feedback about her presentation skills. The study team attended this presentation and stood with the rest of the Toastmaster participants during the standing ovation. CJ's presentation was relevant, interesting and inspiring — she managed to captivate and involve the audience while teaching basic principles of nutrition labeling in the context of self-advocacy. CJ also took the time to prepare many visual aids for her presentation.

After the success of Toastmasters, CJ went on to provide a group education session to twenty women at the American Association for Retired Persons (AARP). She plans to return to the AARP for a follow-up session. She also provided a second session to twenty women at the National Council of Negro Women after the study time period. CJ remarked that the study was like a "college course" since she worked so hard and learned so much. No doubt, CJ will continue to provide leadership in this capacity for others.

Deedee

When Deedee began developing her topic she explained that she wanted to reach out to "working girls", that is, prostitutes, to talk them about the importance of HIV testing. She shared that she is HIV-infected and a former “working girl”. She knows these women in her community and already speaks with them on a regular basis. When discussing her proposed plan, Deedee appeared sheepish and asked if the idea "was good enough." The research team assured DeeDee that her outreach plans were excellent since she targeted a high-risk population that is difficult to reach with education. From this, a partnership was born.

Deedee was in the online group and while she did not complain, it was obvious that she would have preferred to be in the in-person group. The study team asked her to remain in the online group and she respectfully agreed. Deedee came in for one online overview session since she missed this during the information meeting, and from then on accessed the online group via the library. The library access was a significant barrier for Deedee since she needed assistance and the library she uses limits time and assistance on the computers. Deedee began calling the study team instead of communicating in the online forum.

Despite the difficulties with online access, Deedee took charge of her topic and outreach planning. She called community agencies to obtain schedules for their mobile HIV-testing vans and began observing the mobile testing vans in her community. She noted that the vans did not always stick to schedule, so she called one of the agencies to see if she could schedule a time for women to come for HIV testing.

Deedee also developed a poem that she wanted printed on something of business card size. Reportedly, working girls don't carry purses so the written information needed to be small enough to fit in a pocket. After confirming the HIV testing van time and location, Deedee also wanted this information printed on the cards. Deedee spoke with women and distributed 50 cards over the course of several weeks, late at night or early in the morning when she knew she would encounter women before or after work.

Unfortunately, when the day and time arrived for the HIV-testing van to come to the planned destination, the van did not show up. Deedee telephoned the van community agency and they told her that they had scheduling problems. This outcome was very discouraging for Deedee since she had done significant legwork and coordinated the HIV-testing van with the community agency. She also expressed dismay for women who may have gathered courage to go for testing only to discover the testing van was not there.

The research team worked with DeeDee to draft a letter to the community agency. This seemed to help her resume her positive attitude and she remarked that her efforts were not in vain since she spoke with so many women — "maybe they will go for testing some other time". Despite the failure of the HIV-testing van, Deedee seemed to find the community outreach project rewarding and remarked that "it felt good to use her brain again."

Louana

Louana joined the study and was randomly assigned to the online group. She was very inquisitive during the information session and asked many good questions.

Louana works for a community agency focused on HIV, and decided that she wanted to expand her community outreach education efforts for HIV-infected women and/or women at risk to include sexually transmitted diseases (STD) prevention. Louana explored some resources online, but ended up networking with her health educator colleagues to find materials about STDs, including information specifically about human Papilloma virus (HPV). She also created an inspirational message which she distributed during the meetings at the community agency and in various locations in Newark. She worked along side a health educator from the community agency for each group meeting. Louana relayed that working with the educator would be ongoing after the study period.

Despite good oral communication skills, Louana had difficulty expressing herself in writing online. The study team learned about her self-care message and community encounters by phone or in-person when she and her husband came to campus to pick up gift cards. The online environment was a barrier for communication but it did not prevent Louana from her productivity with this project. She wrote that "it was very successful" and "it was awesome" about her

group meetings. She also expressed interest in networking more with the other women in the study.

Martha

Martha, an online group participant, chose to target her peers, middle aged and older women, with information about physical activity. Since Martha spends time at her sister's nursing home, she decided that she wanted to create a health message for the female staff and residents. Martha spoke with the staff and residents about the kind of information they wanted to hear more about. After taking their advice, Martha decided to focus on the benefits of activity.

She created a poster with content about changing routines to include safe activity. The poster was placed in elevators and on bulletin boards at the nursing home. Reportedly, several staff members also asked for copies of the poster for use outside the nursing home.

During the study time period Martha needed affirmation to continue and communicated minimally online. Her life events seemed to be overwhelming her, but she ended up persisting and expressed gratitude for being nudged. She relayed that the experience of trying to help other women was very positive and that she believes she was able to help women — she also said she "never helped anyone before" and that the activity felt good.

Shakira

“Be at your best!” This was the message that Sharkira chose to develop about physical activity and exercise. Sharkira, a young, working mother, created an English and Spanish flyer with information for women about how to increase daily activity and nutrition recommendations. Sharkira explored the USDA's food and nutrition information to create her content.

Sharkira distributed 60 flyers to coworkers, friends, acquaintances, and strangers she met during a community health fair. She also took the initiative to attend several nutrition and health sessions at the community health event so that she felt better prepared to speak with women about her topic.

Sharkira had no difficulty using the online environment and relayed that the flexibility of the online work enabled her to fit this into her busy life. She took advantage of the resources posted in the online environment and was able to communicate well in writing on the discussion board. She only attended one of the four live chat sessions, but when the research team and Sharkira happened to be online at the same time they utilized the live chat feature to communicate.

The research team knew Sharkira from her participation on the Community Advisory Board and were well aware of her capabilities. Sharkira has natural

leadership tendencies and participation in this project provided her with more information and the ability to create a flyer, which enabled her to speak more knowledgably to women about nutrition and exercise. It is also notable that while she is not Spanish speaking herself, she was the only participant in both groups to request a Spanish version of her content.

Veronica

Veronica breezed through the online work group. She took charge of the task of creating a health message early on, and was able to utilize the online environment without difficulty and with mastery. If she had questions about the process or topic she sought clarification and moved ahead.

She chose to develop a message about depression. Her focus was on signs, symptoms, and treatment of depression and she chose to provide information about a local depression treatment center. At first Veronica tried to organize a meeting for women to attend. The meeting was not well-attended, and Veronica realized that she needed to change her focus and target audience. Henceforth she began to post her flyers in beauty salons, barber shops, Pathmark, and corner stores. She also distributed the remaining of the fifty flyers at her depression support group.

Veronica was by far the most independent participant. She requested clarification a few times, but was able to proceed and participate in the process with minimal input from the research team. The down-side of this is that the research team does not know too much about Veronica's personal experience or perceptions about her outreach efforts. She also did not complete the program evaluation. So, this participant was very autonomous and handled the online environment with ease, but we don't know as much compared to the other participants about the experience.

In-Person Participants

Alba

After nearly a month of refusing to leave her home upon learning her HIV status, Alba joined the study due to encouragement from an FXB outreach worker. Alba was assigned to the in-person group and agreed to participate with trepidation.

She decided to focus on physical activity because she believes in the benefits of regular exercise. Alba's demeanor is reserved so she decided she would be most comfortable giving people flyers as opposed to facilitating a group encounter with women. She and her son regularly take the train from Newark to New York where her sister lives, so she targeted Penn Station, Newark for her flyers. She also wanted to take some flyers to her sister's church so a version of her flyer was created without local information (the Newark Parks and Recreation Office number). She distributed 75 flyers to women.

Alba said she did end up engaging in discussion about exercise with some women. Over the course of study she became increasingly more comfortable during the group meeting, though never verbose. At the end of the study Alba relayed that she thought the activity was positive since she spread a health message to other women, but she also explained that the activity forced her to go out and interact with other people. She believes that the experience was positive for herself and other women and affirmed these words with a quiet, yet determined smile.

Aniqua

Aniqua was assigned to the in-person group and quickly assumed a leadership role in discussion during meetings. Aniqua's charismatic personality was an excellent fit for this project and she distributed 300 flyers with information about substance abuse treatment programs in the area.

Aniqua targeted bus stations and other locations where she knows women go to get high. She also distributed her flyers at her church, where she says family members struggle with loved ones substance abuse. During our role-playing at in-person meetings, Aniqua showed the research team that she was prepared to leave a situation if the woman did not want information. Aniqua also showed us that she was in a healthy place in terms of her own substance abuse and that she did not feel vulnerable when exposed to women who are not in recovery. The research team discussed boundary setting with the participants at length, and Aniqua’s experience highlights the importance of this issue for lay persons outreach.

Aniqua's participation was productive on many levels. She took charge of her topic and managed to distribute information about local treatment programs far and wide. She was philosophical about women that rejected her message stating that "women need to deal with certain issues when they are ready." She relayed that in general she did not know if the women she outreached to went for treatment, but that she did serendipitously run into one woman who proudly told her that she had called one of the treatment centers. Aniqua's impact on the in-person group dynamic is also of note — her enthusiasm and character helped other women to focus on their topic and outreach planning.

Beatrice

Beatrice is well known to the research team due to role on two Community Advisory Boards. Early in the study she partnered with a young woman, also in the in-person group, whom she wanted to mentor along for this project. So, she and Nay Nay (see later summary) developed their health message for women together, but they disseminated the message in different forums.

They chose to speak with women about food labeling, and disseminated materials created by the USDA. Beatrice and Nay Nay used the study meeting time to discuss food labeling. The research team observed them practicing to ensure that they had a basic understanding of food labeling.

Beatrice chose to target doctors offices, corner stores, hair salons, and pharmacies. She left stacks of flyers at each of these locations. She received positive feedback from store owners and the women she spoke with; she distributed 200 flyers. Belinda was not as enthusiastic about the project as some of the other participants but she provided leadership by mentoring Nay Nay.

Jane

Jane participated in the in-person group with unsurpassed commitment. She chose to outreach to women on dental health and created extensive content, visual aids, and programming to support her topic. Her outreach efforts were vast and varied. She distributed 180 packets of information. Some of her distribution involved leaving information or posting her flyers, other outreach involved providing presentations to women in shelters, HIV support groups, and Planned Parenthood.

Jane endured a brief hospitalization during the study time period and needed to cancel two presentations, but planned to carry out these presentations after the study time period. She also relayed that two groups asked her to prepare an article on dental health for their newsletters.

Jane's quiet and unassuming leadership was impressive. When she carried out presentations, participants requested more information and outreach in other venues. She was in demand. This activity provided Jane with a platform and she

seized the opportunity and carried it out to the fullest. Her productivity was remarkable, and many women learned about the importance of dental health due to her efforts.

Nay Nay

Nay Nay, a young woman, worked with Beatrice, an older, more experienced woman, to develop their message on food labeling. Nay Nay, is well-known to the research team since childhood. Her participation in the project illustrated how she has transitioned into adulthood. For example, during one of the in-person meetings Nay Nay was at the VOICES conference in Washington, DC. The research team did not request that she telephone in to the project meeting, but she did so on her own initiative.

Nay Nay distributed 50 flyers to peers at VOICES or at corner stores and her building in Newark. She relayed that she was self-conscious about providing information about food labeling, but did it nevertheless.

Nay Nay was responsible, but did not exhibit the same kind of enthusiasm as peers in this project. However, it is noteworthy that Nay Nay experienced a personal transformational moment for her own health when she finally really understood how to read a food label.

Rachael

Rachael, an in-person group member, chose sleep as her topic. Her target audience was seniors in the center she resides in and other senior centers in the community. Rachael approached the study with a reserve and confidence. She provided quiet direction and encouragement to her peers in the group.

Unfortunately, Rachael's mother died during the study time period. Priorities changed and Rachael did not finish developing her topic. The research team went ahead and produced a flyer based on feedback Rachael provided during one of the early meetings, but Rachael still wanted some changes made.

Changes were made to Rachael's flyer as she requested, and 50 copies of the final product were mailed to Rachael after the last in-person meeting. Rachael completed the program evaluation at the last meeting but she did not report on the distribution of the flyers that were mailed.

Rene

Rene's case was a stark reminder of the personal nature of community. Project participants were not asked to provide or share any personal information. In many cases, however, the dissemination of a health message led to an

understanding of the women's community since many women chose to deliver their messages near their homes or chose messages near and dear to their heart.

For example, women were not asked for an address, they simply had to confirm that they lived in the Newark vicinity. In Rene's case, in one of the in-person meetings, we learned that she was living in a shelter. We learned this because we did ask participants where they were planning to disseminate the health messages and Aniqua chose to disclose that the shelter was in her dissemination plan since she lived there.

Rene chose to develop a message about depression and suicide prevention. She admittedly joined the study simply for the stipend, but the change in Rene during the course of the study was the most profound. At the beginning of the study Rene was distant and emanated anger and distrust. By the end of the study she readily participated in lively and productive discussion at group meetings. Rene discovered that she could easily outreach and engage women in discussion about depression and was proud of her effort and leadership.

Rene distributed 80 flyers to various locations throughout the Newark vicinity. She relayed that some women responded to her in a more positive way than she expected. She also requested that the research team contact her again if the study is replicated.

Yolanda

Yolanda participated in the in-person group and chose dental health as her topic. Her outreach was extensive as she distributed 560 flyers and materials. She targeted 21 different locations for her outreach to women of all ages, including her dialysis center and dialysis support group.

Yolanda took this project very seriously. Early on, she relayed that she preferred distributing materials as opposed to conducting group education. Though, she worked closely with Jane, another participant focusing on dental health, to develop her message. They also shared materials.

Yolanda commitment to the project was remarkable. She never complained but it was obvious that she struggled with her own health issues. She was very organized and detail oriented and made the project a priority despite personal health issues that could hinder many.