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Harnessing Online Peer Education (HOPE): Integrating C-POL and Social Media to Train Peer Leaders in HIV Prevention

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Abstract

Novel methods, such as Internet-based interventions, are needed to combat the spread of HIV. While past initiatives have used the Internet to promote HIV prevention, the growing popularity, decreasing digital divide, and multi-functionality of social networking sites, such as Facebook, make this an ideal time to develop innovative ways to use online social networking sites to scale HIV prevention interventions among high-risk groups. The UCLA HOPE [Harnessing Online Peer Education] study is a longitudinal experimental study to evaluate the feasibility, acceptability, and preliminary effectiveness of using social media for peer-led HIV prevention, specifically among African American and Latino Men who have Sex with Men (MSM). No curriculum currently exists to train peer leaders in delivering culturally aware HIV prevention messages using social media. Training was created that adapted the Community Popular Opinion Leader (C-POL) model, for use on social networking sites. Peer leaders are recruited who represent the target population and have experience with both social media and community outreach. The curriculum contains the following elements: discussion and role playing exercises to integrate basic knowledge of HIV/AIDS, awareness of sociocultural HIV/AIDS issues in the age of technology, and communication methods for training peer leaders in effective, interactive social media-based HIV prevention. Ethical issues related to Facebook and health interventions are integrated throughout the sessions. Training outcomes have been developed for long-term assessment of retention and efficacy. This is the first C-POL curriculum that has been adapted for use on social networking websites. Although this curriculum has been used to target African American and Latino MSM, it has been created to allow generalization to other high-risk groups.

Keywords

HIV prevention; social networking; facebook; c-pol; popular opinion leader

Introduction

The Internet has emerged as a popular setting for MSM to seek sexual partners. An online survey of MSM found that 82% had used the Internet to find a sexual partner (Chiasson et al., 2007). MSM cite that they are able to find sexual partners without fear of discrimination (Chiasson et al., 2007; Kim, Kent, McFarland, & Klausner, 2001; Ross, Rosser, & Stanton,

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2004). Furthermore, MSM are more likely to negotiate sexual preferences and disclose HIV status on the Internet (Bolding, Davis, Hart, Sherr, & Elford, 2005; Carballo-Diéguez, Miner, Dolezal, Rosser, & Jacoby 2006; Liao, Millett, & Marks, 2006). However, Men who use the Internet to seek Sex with Men (MISM) are more likely to engage in UAI and have multiple sex partners (Benotsch, Kalichman, & Cage, 2002; Carballo-Diéguez et al., 2006; Chiasson et al., 2007; Kim et al., 2001; Liao et al., 2006; McFarlane, Bull, & Rietmeijer, 2000). MISM are therefore a population at-risk for sexually transmitted infections (STIs) and HIV/AIDS.

Since MISM are at risk for HIV/AIDS, yet may be more open to discuss sexual issues without fear of stigma, there is an opportunity to use the Internet to promote HIV prevention. The Internet provides a cost-effective method to reach MSM across a wide geographic range, including those who are not close to HIV services (Bowen, Williams, Daniel, & Clayton, 2008). An online survey of men who visited gay chat sites had favorable views towards health care workers using the sites (Bolding, Davis, Sherr, Hart, & Elford, 2004). Interventions that utilize online education modules have shown significant decreases in UAI (Bowen et al., 2008; Chiasson, Shaw, Humberstone, Hirshfield, & Hartel, 2009; Rosser et al., 2010). Taken together, the Internet appears to be an effective method of delivering HIV prevention.

While current online HIV prevention research has been on predominantly Caucasian participants, the majority of risk in the United States falls on African-American and Latino MSM (CDC, 2007). Cultural barriers in the African American and Latino communities provide additional challenges to HIV prevention, including difficulty in discussing issues such as homosexuality, drug use, or sex outside of marriage (Gonzalez et al., 2009; Laurencin, Christensen, & Taylor, 2008; Williams 2003). Gender roles (such as the Latino concept of “machismo”) may motivate sexual risk behavior and create stigma that prevents discussion and HIV testing (Gonzalez et al., 2009; Jarama, Kennamer, Poppen, Hendricks, & Bradford, 2005; Operario, Smith, & Kegeles, 2008). In addition, lower socioeconomic status may limit an individual’s access to healthcare and HIV services (Gonzalez et al., 2009; Laurencin et al., 2008; Loue, 2006).

It has been suggested that these ethnicities have not been represented in these studies due to disparities in Internet access (Viswanath & Kreuter, 2007). However, a recent survey has shown no apparent ethnic differences in social media use (Chou, Hunt, Beckjord, Moser, & Hesse, 2009). Moreover, as Internet access increases among these ethnicities, studies have shown that they are also at risk for HIV. The Men’s INternet Sex (MINTS) study was an online survey to evaluate Latino MSM use of the Internet to seek sexual partners. It showed that 98.5% had used the Internet to find a sexual partner, of which 43% had UAI (Rosser et al., 2009a). The second phase of the study, MINTS-II, evaluated sexual risk across several ethnicities, and showed a significantly increased risk among African American MSM to have UAI (Rosser et al., 2009b).

The UCLA HOPE (Harnessing Online Peer Education) study seeks to determine the acceptability, feasibility, and preliminary effectiveness of using online social networks (Facebook.com) to scale the Community Popular Opinion Leader (C-POL) model to increase HIV prevention among high-risk populations, with a focus on African American and Latino men who have sex with men (MSM). Participants join an online Facebook group related to HIV prevention and interact with community peer leaders trained in the fundamentals of HIV prevention and behavior change over a 12-week period. The data collected from this study are compared to results from previous studies of community-based testing to preliminarily determine whether social networks can be used to scale community-based HIV prevention methods.

While previous Internet studies have used a “Web 1.0” interface, the HOPE study uses the “Web 2.0” format on Facebook. In “Web 1.0,” the communication is one-way; that is, the user is a passive participant who receives the information from a single source (Thackeray, Neiger, Hanson & McKenzie, 2008). However, in “Web 2.0” there is two-way communication, in which the users have greater control over their content and experience, and have the capability to connect to others over the Internet for advice and support. Websites include blogs, wikis and social networking such as Facebook and Twitter. The result is an “architecture of participation,” in which social networking creates a dynamic experience where users are engaged and site retention is high (Bennett & Glasgow, 2009). Social media sites are largely visited by youth, those most at risk of STI/HIV infection (Young & Rice, 2011; Rice, Monro, Adhikari, & Young, 2010). Facebook receives exceedingly more visits in a month than gay websites, the CDC or HIV testing sites (Rietmeijer & McFarlane, 2009). With such statistics, surprisingly there is a lack of research pertaining to health promotion on social media sites (Bennett & Glasgow, 2009; Rietmeijer & McFarlane, 2009). Facebook has become an expansive online social community, and the HOPE study seeks to utilize this opportunity for HIV prevention.

To train peer leaders in the HOPE study, a new curriculum was created that focused on how to utilize social media websites for outreach to at-risk populations. We describe here the components of the curriculum and the method of evaluation.

Training Elements

Training of peer leaders is based on the Community Popular Opinion Leader (C-POL) model, in which influential members in a community can motivate change in behavior (Rogers, 1962). They can serve to legitimize a given intervention, provide feedback to outreach programs, act as role models, deliver health messages, and remain active in the community, adding stability to the intervention (Valente & Pumpuang, 2007). The C-POL approach has been extensively utilized and studied in HIV prevention both domestically and internationally (Amirkhanian et al., 2005; Jones et al., 2008; Kelly et al., 1991; Kelly et al., 1997; Kelly et al., 2006; McQuiston & Uribe, 2001; NIMH Collaborative HIV/STD Prevention Trial Group, 2010). While C-POL studies have traditionally targeted white MSM, more recent studies have adapted the C-POL method for Latino and African-American populations by including training that emphasized cultural barriers to HIV prevention (Jones et al., 2008; McQuiston & Uribe, 2001; Somerville, Diaz, Davis, Coleman, & Taveras, 2006). The HOPE study is the first to adapt the C-POL method to social networking sites.

Peer leader training for the HOPE Study required a curriculum that was not only culturally sensitive, but that also included role playing and educational modules that demonstrate how to maximize the potential of social media sites to deliver HIV prevention messages. Since the study “setting” is Facebook, all role-playing is completed on peer leader Facebook group pages to create a realistic experience. In this and other C-POL studies, the goal is for POLs to feel comfortable initiating everyday conversations about a sensitive topic like HIV/AIDS, while reinforcing the importance of their efforts. To do so, this requires interactive discussion, modeling, role-play and repetition (NIMH Collaborative HIV/STD Prevention Trial Group, 2007).

Training peer leaders in the HOPE study involved the following elements (Figure 1):

- (1) Recruitment
- (2) Knowledge
- (3) Social Context

- (4) Communication
- (5) Ethics

Recruitment

In order to obtain C-POLs, criteria for peer leaders in the HOPE Study are:

- (1) Male
- (2) Over 18 years old
- (3) African American or Latino
- (4) Has had sex with a man in the last 12 months
- (5) Lives in Los Angeles area
- (6) Experience using Facebook
- (7) Experience as a POL or ability to be a leader in their community
- (8) Interest is using social networking to educate others about health

Recruitment occurs online and by contacting community outreach organizations. Facebook and Myspace groups related to health outreach are asked to post fliers describing the study and eligibility criteria. Community-based outreach organizations are given similar fliers to distribute. Peer leaders are randomly assigned to either a Facebook group that would discuss topics in HIV/AIDS, or a control group that discussed general health topics.

Knowledge

In the first session, peer leaders are taught core facts about their group's topic. Peer leaders in the HIV/AIDS group learn about HIV/AIDS prevalence in the MSM community, methods of transmission, prevention strategies, and myths around HIV/AIDS. Peer leaders in the control arm are taught about topics in general health, including nutrition, benefits of exercise, mental health and substance abuse. Both groups also receive instruction on home-based HIV testing kits that are available to all participants.

Role playing in the knowledge session seeks to teach peer leaders how to translate technical information into basic ideas suitable for social media. Each peer leader posts on the Facebook Wall a fact that they learned during the educational module. It is emphasized that Wall posts are a useful tool for providing general information available to all members in a group. Throughout the exercise, peer leaders can read each other's posts to gain ideas and help each other create effective messages. In addition, peer leaders are asked to post five website links related to facts in HIV/AIDS or general health. The goal is to empower peer leaders to take advantage of useful sources on the Internet to share with the group while creating a list of trusted websites for accurate information about their topics (Young, 2011).

Social Context

This session focuses on stigma and the cultural barriers to prevention. Peer leaders learn about the basic epidemiology facing Latino and African American MSM, the unique cultural obstacles, and the consequences of stigma. They then discuss how to have a conversation with a person that is both sensitive to stigma and culture. In particular, the training attends to how social media (compared to offline communication) can be used to facilitate communication about stigmatizing or sensitive topics. Peer leaders in the control arm are taught about the general health risks of African Americans and Latinos, including diabetes, hypertension and obesity.

Before the session begins, the group is asked to utilize the “Group Chat” feature on Facebook. The training coordinator then begins a sentence “Javier, who works at the LGBT center, was walking down the street when he bumped into his friend. Javier asked how he was doing.” Each peer leader is then asked to provide a sentence to continue the story. The story, as created by the group, explores issues related to stigma and culture that the friend was having because he is a Latino MSM. This exercise seeks to encourage the topic of culture in their discussions and build comfort in addressing these issues, while describing how the chat feature can be utilized for more sensitive conversations. The session ends with one-on-one Facebook chats between peer leaders to reinforce these concepts.

Communication

The creation of effective health promotion messages is key to the C-POL method. Prior to this session, peer leaders are asked to try to initiate a conversation with current Facebook friends about HIV/AIDS prevention. During discussion, peer leaders talk about obstacles and receive feedback from the group. They then brainstorm methods to initiate a conversation and build trust with members in the Facebook group. Moreover, they practice “Facebook etiquette,” such as proper language, use of emoticons, and when to Wall post versus send a message (Figure 2).

With these ideas, peer leaders are asked to enter the Facebook group page and list short messages that can be used to attract participants’ attention and initiate further discussion (Table 1). This exercise seeks to build comfort in initiating conversations with the participants while encouraging the peer leaders to collaborate throughout the study to communicate health messages effectively.

Ethics

The use of social media in health promotion has led to new ethical considerations that must be integrated into training and study protocol to ensure proper protection and support of peer leaders and participants. A recent case report outlined the potential ethical issues of using Facebook for HIV prevention (Bull et al., 2011). This included informed consent, comprehension of procedures, equity given a potential “digital divide” to internet access, confidentiality, and HIPAA data security.

These topics are addressed throughout the training process for the HOPE study. Prior to the first session, all peer leaders complete informed consent, and the study procedure is revisited during the introductory training session to ensure comprehension. While equity may remain an issue in Internet access, we have minimized the divide by focusing on populations that are considered to have decreased access. Confidentiality and privacy are central challenges on Facebook, with concerns of viewing private information, hacking, and changing privacy rules. The Facebook groups created for the study are customized to be “Secret,” so that the group cannot be found by search, members must be invited to join, and the group affiliation is not listed on a peer leader or participant’s profile page (Figure 2). In addition, participants are allowed to change their profile name or create a separate profile for the study to maintain anonymity. Importantly, peer leaders are instructed during the training to conduct all communication either on the group wall or in private messages and chats, and are given the responsibility to delete comments that are offensive to others or reveal private information. In addition, administrative staff monitors the group pages and have weekly discussions with peer leaders to ensure that privacy is upheld. Peer leaders and participants are notified when there are any changes in privacy settings by Facebook. All identifying data for the study complies with HIPAA regulations and storage of data is encrypted, firewall, and password protected. While more ethical issues will emerge as online research continues, we have sought to address major ethical concerns both in the training and study methods.

Evaluation

At the conclusion of the training, each peer leader should:

- Develop proficiency in basic facts about HIV, with definite knowledge of the routes of transmission and methods of prevention
- Be comfortable using Facebook, including writing a wall post, changing their status, writing a message, posting a link, and using the chat function
- Understand that stigma and cultural traditions can create barriers in HIV prevention, and know how to approach those topics in a sensitive way
- Learn basic communication skills to initiate conversations related to HIV/AIDS
- Understand their role as a leader and responsibilities to regularly communicate with the members of the group

The HOPE training has been developed to allow for both quantitative and qualitative methods of evaluation. Prior to the training, peer leaders complete a questionnaire that includes past experience with Facebook features (Wall posts, chat, messaging and sharing a link) and a series of true/false questions related to HIV/AIDS and general health to evaluate knowledge. Comfort in using Facebook features and discussion of topics in sexual and general health is assessed using 5-point Likert scales (1 = very uncomfortable, 5 = very comfortable). After the training, the peer leaders complete the same questionnaire to evaluate changes in knowledge and comfort level. If peer leaders score above 70% in knowledge and are at least “comfortable” (score of 4 on Likert scale) in all categories, peer leaders receive certification and are assigned to a Facebook group.

To evaluate whether skills from the training are utilized throughout the study, peer leaders are asked to log their activities (i.e. wall post, message or chat). In addition, they are asked to indicate whether a given conversation is related to knowledge, stigma, or cultural context. Qualitative evaluation of Facebook wall discussions and interviews with peer leaders can provide further evidence of whether specific modalities from the training were utilized. As the HOPE study continues, the goal is to correlate the training outcomes with behavioral outcomes among participants, in order to determine the efficacy of the training in preparing peer leaders to initiate and effectively deliver HIV prevention messages on Facebook.

Conclusion

The Harnessing Online Peer Education (HOPE) study seeks to assess the feasibility, acceptability, and preliminary efficacy of using online social networks as a platform for delivering peer-led HIV prevention, with a particular focus on African American and Latino MSM. The primary stage of the study involves training peer leaders in effective HIV prevention communication, cultural awareness, and the role that technology can play in reducing stigma, and the use of the social networking site Facebook. As this is the first study to use Facebook for a peer-led HIV prevention intervention, we have described the creation of a new training curriculum that adapts the evidence-based Community Popular Opinion Leader (C-POL) method of HIV prevention to Facebook. To do so, we recruited peer leaders that matched the study population and had experience with both social networking and outreach. We then applied didactic discussions on knowledge, social context and communication to role playing exercises that occur entirely on Facebook. Concomitantly, we created a control arm that focuses on general health topics. In both groups, ethical considerations were emphasized to assure consent, comprehension of the study, equity and importantly privacy and confidentiality.

The creation of this curriculum is also meant as a tool for others interested in using social media in health promotion. Social networking sites such as Facebook are gaining immense popularity, and greater efforts should be made to utilize these sites for HIV prevention among a wide population. We hope that this guide creates a framework for how to deliver HIV prevention using social networking, and serves as the impetus for additional social-media based interventions.

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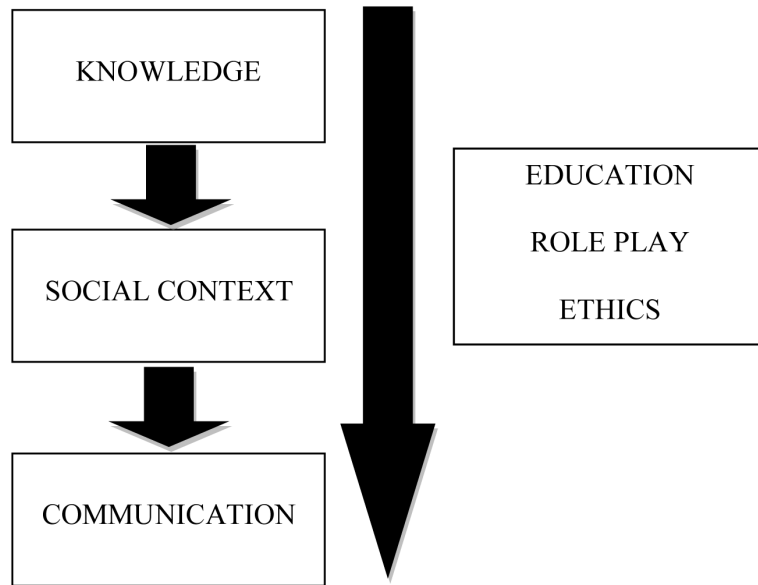


Figure 1. Elements of HOPE peer leader training. Short arrow signifies transition to next session, and long arrow indicates a component that is utilized in every session.

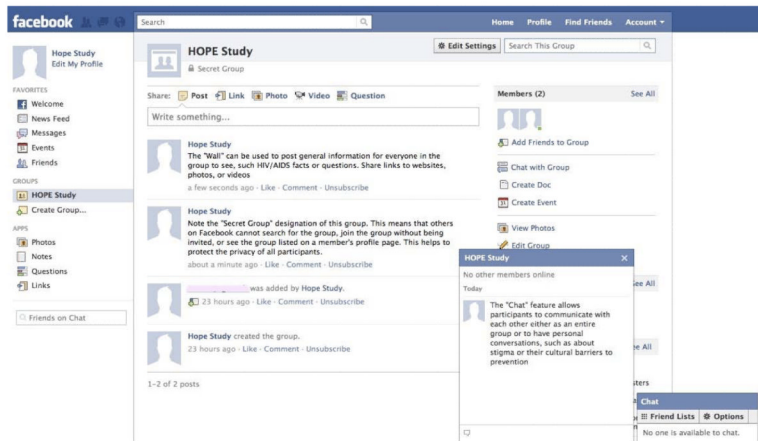


Figure 2.
Examples of how features on Facebook can be used for HIV/AIDS prevention and education

Table 1

Translating key concepts into Facebook messages. Examples of how the major educational elements can be adapted to the more casual setting of a social networking site such as Facebook.

Topic	Key Concepts	Examples of Facebook Posts
Knowledge	Epidemiology, Signs and Symptoms, Testing, Treatment and Prevention Methods	<p><u>Wall post:</u> Who can list the ways you can transmit HIV?</p> <p><u>Sharing a Link:</u> I just found this amazing video talking about HIV symptoms, check it out!</p>
Social Context	Challenges to HIV Prevention, Epidemiology of High Risk Groups, Cultural Barriers, Stigma	<p><u>Wall Post:</u> Sometimes it's really hard to tell people I'm gay. Anyone else feel the same way?</p> <p><u>Chat:</u> Hi, I saw on the wall that you're having a hard time with your family, do you want to talk about it?</p>
Communication	How to Initiate a Conversation, Online Etiquette	<p><u>Wall Post:</u> I've finally started this great exercise routine, send me a message if you want to find out more!</p> <p><u>Chat:</u> Do you have a partner? I'd love to learn about him!</p>