Ethics Issues in Social Media–Based HIV Prevention in Low- and Middle-Income Countries

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Abstract: Questions have been raised regarding participants' safety and comfort when participating in e-health education programs. Although researchers have begun to explore this issue in the United States, little research has been conducted in low- and middle-income countries, where Internet and social media use is rapidly growing. This article reports on a quantitative study with Peruvian men who have sex with men who had previously participated in the Harnessing Online Peer Education (HOPE) program, a Facebook-based HIV education program. The survey assessed participants' ethics-relevant perspectives during recruitment, consent, intervention, and follow-up.

Keywords: ethics; men who have sex with men (MSM); social media; social networking technologies; HIV/AIDS

Introduction

The Internet has provided a platform to reach large numbers of individuals for health education because of its immense popularity and accessibility. As of January 2014, it was estimated that 87% of American adults are Internet users.[1] Many Internet users have used the Internet as their primary source for health-related information. According to a 2012 Internet use survey, as many as 72% of adult Internet users searched for health information online in the past year.[2] Moreover, half of the participants in the 2003 Health Information National Trends Survey ($n = 6,369$) indicated that they tended to look for health information online first before seeking medical advice from physicians.[3]

The growing demand of health information and healthcare access on the Internet encouraged many researchers to embrace the practice of e-health. E-health can be broadly defined as "the use of emerging information and communication technology, especially the Internet, to improve or enable health or health care."[4] Because of its interactivity and customizability, researchers have postulated that e-health education programs might help to better engage individuals than traditional methods of achieving desired behavioral change.[5,6] So far, e-health education programs have focused on a variety of health conditions, such as sexually transmitted infections (STIs), HIV, weight loss, eating disorders, poor nutrition, chronic disease and its management, and mental health issues.[7,8,9,10,11,12,13]

Social media are one of the fastest-growing Internet technologies. According to a recent survey, 74% of adult and 90% of young adult (aged 18–29) American Internet users use some form of social media.[14] In addition, social media use is also being explored in low- and middle-income countries (LMICs). A recent study found that the individuals in LMICs who use the Internet are avid social media users, and the percentages of social media users in some LMICs have bypassed those of high-income nations.[15] Peru is no exception. A 2014 survey suggested that

there are currently more than 12.4 million Peruvian Facebook users; this number represents 55% of Peru's population.[16]

Compared to other Internet technologies, social media are unique in that they connect people and establish virtual communities based on common interests, lifestyles, and activities.[17] These virtual communities can be effectively used to facilitate health education, because participants will be able to share their knowledge and experiences with one another.[18] This is particularly salient for stigmatized diseases, such as HIV and STIs, for which it is difficult to engage high-risk individuals in health education in person because of high levels of stigma and discrimination.[19,20]

Although many studies have evaluated the effectiveness of e-health education programs,[21,22,23,24,25,26,27] only a handful of studies have explored ethical issues regarding participants' safety and comfort. These studies have recounted several key ethical issues encountered by e-health researchers, such as autonomy, privacy, confidentiality, informed consent, and equity.[28,29,30,31,32,33,34,35] Only a few studies have assessed participants' perspectives on their experiences in e-health education programs. In general, participants reported a positive experience in the study and found the study content to be helpful.[36,37,38,39,40] However, no known research thus far has assessed, specifically, participants' perspectives on their experiences in social media–based e-health education programs. In addition, as increasing numbers of e-health programs are implemented in LMICs, there exists an urgent need for researchers to address the ethical issues in the global context.[41,42]

These ethical issues are particularly important when using social media for health education. The term "social media" refers to a variety of social networking sites that offer a multitude of services and ways to connect individuals. Each site has different terms and conditions and privacy settings. This requires researchers to stay up-to-date with how different social media sites are used in order to protect participants, particularly when working with vulnerable populations, such as men who have sex with men (MSM) and youth.[43,44] However, currently, little is known about participants' risks and benefits or privacy and confidentiality when participating in social media–based health education programs.

This study recontacted participants from a previous social media–based HIV education study to assess their experiences. Potential concerns include the following: (1) Did the participants understand the online consent forms? (2) How did the participants perceive the risks involved in participation? (3) What were the participants' perspectives on whether the benefits of participation outweighed the risks? (4) Did combining MSM at risk of HIV actually increase sexual risk by increasing the number of their sexual partners? And (5) what concerns did participants have regarding the privacy and confidentiality of their online communications? Through examining the ethical issues associated with using social media for HIV education, we hope to inform future e-health education programs regarding recruitment, informed consent, intervention, and follow-up.

Methods

Institutional review boards (IRBs) at Epicentro (Lima, Peru) and the University of California, Los Angeles (UCLA) approved the study protocol. Participants completed an online informed consent form.

The social media–based HIV education study on which the current study was founded—the HOPE Peru study—was a 12-week, Facebook-based intervention designed to deliver peer-led HIV education to increase HIV testing and preventive behaviors. The study included an intervention group for HIV-related discussions and a control group in which participants received general health information. The HOPE study included 556 MSM, and all participants (1) were male, (2) were 18 years of age or older, (3) had had sex with a man in the past 12 months, (4) were Lima residents, and (5) were current Facebook users. The participants were recruited online using banner ads, email lists, and Facebook ads. The study adheres to the current recommendations on using social media in HIV research.[45]

In June 2014, approximately one and a half years after initiation of the HOPE study, HOPE Peru participants were recontacted via email, social media, and phone and were asked if they would like to complete a survey to assess their experience with the social media–based HIV education study. Interested participants provided their informed consent online and were compensated for their participation with a payment equivalent to $11. After 211 participants agreed to complete the survey, we closed the opportunity for further survey completion.

Measures

The survey assessed the ethics-relevant experiences of MSM who had participated in the HOPE study with regard to recruitment, informed consent, intervention, and follow-up or intervention afterward.

Basic Demographics

The participants were asked to provide basic demographic information on their age, sexual identity (gay, bisexual, and heterosexual/other), educational attainment (secondary, vocational, university, and above), and race/ethnicity (native Peruvian, white, black, mixed, and Asian).

Recruitment Items (n = 11)

Participants were asked to indicate whether they had ever participated in HIV or online studies other than the HOPE study. In addition, participants were asked to rate their level of comfort/discomfort on a five-point Likert-type scale in regard to banner ads, online privacy (e.g., how concerned were you that your behavior online would be tracked by companies such as Google or Facebook if you clicked on the ad to participate?), and the characteristics of the study (e.g., the fact that it was online, HIV and MSM related, and Facebook based).

Consent Items (n = 3)

Participants were asked to indicate on a scale of one (did not at all understand) to five (completely understood) their understanding of the consent form. Moreover, participants were asked to rate how similar or different their experience participating in the study was to or from the description provided in the consent form.

*Intervention Items (*n = 15)

Using a five-point Likert-type scale, the survey assessed the comfort levels of different aspects of the intervention, such as whether the participants were initially comfortable joining the Facebook group and posting and reading discussion topics. Participants were also asked to rate their trust in fellow participants, in the validity of group members' posts (how much did you trust that the other people in the group were telling the truth in their posts?), and in the researchers (how much did you trust that the investigators were telling the truth about the study?). In addition, participants were asked to identify if they have met up with or had sex (including unprotected sex) with other participants in the group.

*Postintervention Follow-Up Items (*n = 21)

Participants were asked to indicate on a five-point Likert scale the extent to which they benefited in the following areas as a result of participating in the study: (1) health, (2) sexual health, (3) friendship, (4) connection to the MSM community, (5) self-esteem, (6) HIV testing knowledge, (7) HIV care knowledge, (8) knowledge of the availability of sexual health services, (9) job opportunities, (10) understanding of research studies, (11) trust in other people, and (12) trust in research studies. In addition, participants were asked, retrospectively, if they would participate in the study again and if they would recommend the study to a friend.

Analysis

All analysis was conducted using R.

Results

Basic Demographics

MSM respondents were predominately gay (88%), university educated (58.9%), and mestizos, or of mixed racial background. The age of the participants ranged from 20 to 54, and the mean age was 31.8.

Recruitment

Most participants learned about the study online (58.3%) and had not participated in an HIV (67.3%) or online (70.5%) study before. The majority of participants (> 80%) expressed that they were indifferent to or comfortable with the idea of participating in the study and the online banner ads used for recruitment. Out of all the study characteristics, participants were most uncomfortable with the fact that the study was conducted over Facebook (15.3%). In addition, 13% of participants also indicated that they were uncomfortable with the idea that they were being asked to join a Facebook group with strangers.

Informed Consent

Close to 90% of participants indicated that they understood or completely understood the consent form. In addition, almost 72% of participants thought that the

study was similar to what they had expected based on the consent process. Almost 11% of participants thought the consent process was missing information that they needed to know about the study beforehand.

Intervention

In general, participants were comfortable with the study procedures, such as completing the baseline survey, posting on Facebook groups, having other group members talk to them online, and seeing other people's discussion topics. A small percentage of participants were uncomfortable with having to accept an invitation to join the Facebook group (14.9%) and with joining the group and seeing other people in the group (15.4%). Seventy-eight participants indicated that they posted content on the group wall (38.6%), and 10.2% indicated that people in the group posted something that made them uncomfortable. Study participants trusted the researchers (65.2%) more than they trusted other study group members (51.2%). Only 30 people met up with other members of the group (15%), and only 4 people met new sexual partners as a result of joining the group (2%). Among those who met new sexual partners as a result of joining the group, only 1 person engaged in unprotected sex. Moreover, slightly more than a quarter of participants wished that something about the study had been done differently (33.2%).

Postintervention Follow-Up

As a result of participating in the study, more than half of participants indicated that they benefited positively in learning about health and sexual health, feeling better about themselves, learning about HIV, improving HIV care, learning where to receive sexual health services, and developing increased trust in research. In addition, a large number of participants thought the study did not affect them in gaining new friends (67.3%), feeling closer to the MSM community (45.4%), gaining a job (73.3%), learning about research (44.2%), and developing increased trust in other people (44.4%). Close to all of the participants indicated that they would have still participated in the study (93.4%) and that they would recommend the study to their friends (93.4%). Most participants said that, after participating in the study, they were more likely or much more likely to maintain a healthy lifestyle, have safe sex, get tested for HIV regularly, and participate in research studies.

Discussion

Although a small number of studies have discussed the ethical challenges encountered in using e-health education programs,[46,47,48,49,50,51,52,53] to the best of our knowledge, this is the first study from any LMIC to quantitatively assess the safety and comfort of a longitudinal, social media–based HIV education program from participants' perspectives. Although most participants found online communities to be generally acceptable for use in HIV education, some participants were concerned about the use of Facebook and about joining a Facebook group with strangers. Individuals might be hesitant to participate in HIV-related social media–based studies out of fear that sensitive HIV-related and sexual information might permeate into their preexisting online social networks. For example, they might fear that accepting an invitation to the study group would result in

this information showing up on their friends' newsfeeds. Previous studies have also addressed this issue and have urged researchers to become familiar with privacy settings, such as private versus public groups and sharing settings on social media.[54,55] Future researchers need to actively address privacy issues in recruitment and during intervention to ensure that participants are comfortable with their involvement in social media and e-health education programs.

Although many studies expressed concerns over electronic/online informed consent,[56,57] this study found that most participants understood the consent form and felt that the study matched the descriptions in the consent form. However, some participants thought that the consent document was missing information that they needed to know beforehand. In addition, a small proportion of participants also expressed discomfort with other group members' posts. In online informed consent, participants are often confined to the information provided, without further opportunities to ask for clarification. To provide participants with a thorough understanding of the study, previous studies have suggested that e-health education programs should allow participants to preview the content of the study,[58,59] for example, by providing information such as a snapshot of the program and discussion topics.

Participants reported that participation in the study improved their knowledge about HIV and health-related behaviors and attitudes. In developing this study, some researchers had expressed the concern that using online communities for HIV and sexual health education might actually increase participants' sexual risk. However, only a very small number of participants ($n = 4$) met new sexual partners through the study, and, among them, 1 individual engaged in unprotected sex with sexual partners met through the group. This finding suggests that the concern that social media–based HIV prevention communities could actually increase sexual risk might be an unnecessary fear.

This study is limited by the time delay between when the original study took place and when participants were asked to complete surveys on their study participation (approximately one and a half years); by the difficulty of generalizing these results outside of Peru, Peruvian MSM, and HIV prevention studies; and by the fact that the survey's quantitative nature made it difficult to identify specific details. Future research can attempt to use qualitative interviews to gain a more thorough understanding of the ethics-related issues identified in this analysis.

Internet use, including participation in social media, is increasing rapidly worldwide and might provide a sustainable and cost-effective alternative for global health education. Although this study focused on HIV and Facebook, some of the issues identified from participants' perspectives can be of cross-platform importance. It is recommended that future e-health education programs include ethics-related questions as part of the regular assessment to further understand the ethical issues involved in using information and communication technologies for health education.

Notes

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