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The Association Between Age and Ethics-Related Issues in Using Social Media for HIV Prevention in Peru

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Abstract

Little research has focused on the ethical issues around using social media for HIV prevention in low- and middle-income countries (LMICs), such as Peru. This study surveyed participants from the HOPE social media HIV intervention in Peru to assess their experiences and perceptions of ethical issues in the study and the impact of age on their experiences and perceptions. This study found that, compared to younger participants, older participants were more likely to express higher levels of understanding of the consent form and trust that other participants were real. Older participants also reported being less likely to benefit in learning about their HIV status. Findings suggest that age plays a role in participants' experiences in a social media-based HIV intervention.

Keywords

Ethics; MSM; Peru; HIV/AIDS; Social media

Introduction

Social media and Internet use have become immensely popular. According to a recent survey in 2014, it was estimated that 74% of American adult Internet users use some form of social media (Pew Research Center, 2014). The use of social media is especially popular among youth online (ages 18 to 24), as approximately 90% of youth are social media users (Pew Research Center, 2014).

The popularity of social media has enabled these technologies to emerge as platforms for delivering health information to at-risk individuals. Social media and Internet-based studies to date have focused on health behaviors and health-related conditions, such as anxiety, insomnia, diabetes, physical activities, and nutrition (Cavallo et al., 2012; March, Spence, &

Donovan, 2009; Napolitano et al., 2003; Ritterband et al., 2009; Wantland, Portillo, Holzemer, Slaughter, & McGhee, 2004). In addition, pilot studies have shown promising results in using social media for prevention of stigmatized diseases, such as HIV prevention (Bull, Levine, Black, Schmiede, & Santelli, 2012; SD Young & Jaganath, 2013; S. D. Young et al., 2013). For example, in the Harnessing Online Peer Education (HOPE) study, African American and Latino MSM at-risk of HIV in the Facebook (intervention) group were twice as likely to request HIV home testing kits compared to the control group (SD Young & Jaganath, 2013; S. D. Young et al., 2013). Furthermore, the Just/us study provided youth (ages 18-24) at-risk of sexually transmitted infection (STI) prevention messages via Facebook. At 2 months, participants in the intervention group reported higher levels of condom use (Bull et al., 2012). However, both of these studies are based in the U.S.

Social media and Internet use is also increasing in Low and Middle Income Countries (LMICs), such as Peru. A recent study found that Internet users in LMICs are also avid social media users, and the percentages of social media users in several LMICs have exceeded the percentage in the U.S. (Rainie & Poushter, 2014). In Peru in 2009, for instance, 75% of Peruvian youth (ages 15 to 29) and 60% of Peruvian adult Internet users accessed social media ("New Media and Peru's Youth and Young Adults," 2009). Facebook is particularly popular. A recent local survey suggested that there are more than 12.4 million Peruvian Facebook users and the number of Facebook users represents 55% of Peru's population (Pereyra & Santillana, 2014). The rapid increase in social media use in Peru provides a new way to reach individuals at high-risk of HIV that bypasses traditional social barriers, such as stigma and homophobia. Ethical questions and concerns have been raised regarding participants' safety and comfort when participating in social-media based HIV interventions. A small number of studies have identified privacy and informed consent issues in using social media, suggesting that researchers should become familiar with current privacy settings on social media to help protect participants and educate them on how to improve their privacy (Bull et al., 2011; Sean Young, 2012). Additional research has urged researchers to take measures to ensure participants' understanding of informed consent and study process (Pequegnat et al., 2007; Rosser et al., 2009). Currently, no research has assessed participants' view on these ethical questions and concerns.

Although researchers have hypothesized that participants' demographic characteristics, such as age, might affect participants' experiences in social media-based HIV research (Moreno, Fost, & Christakis, 2008), few studies have explored this topic, and no known studies have assessed this issue among participants in LMICs, such as Peru. Age, in particular, may impact individuals' engagement in social media-based HIV interventions as participants might lose interest if they do not relate to or identify with the information or how it is provided. For example, MSM of different age groups often have different risk profiles. Data have shown that HIV is growing rapidly among young MSM aged 13 to 24 in comparison to other age groups (Centers for Disease Prevention and Control (CDC), 2014) and these youth were more likely to engage in HIV risk behaviors, such as unprotected anal intercourse and substance use, compared to their older counterparts (Broz et al., 2014; Hall, Byers, Ling, & Espinoza, 2007; Pappas & Halkitis, 2011). Therefore, interventions might need to tailor the information to address differences in individuals' risk behavior based on age. Second, social media is constantly changing (e.g. updates to the interface, terms and agreement, and general

features) and people of different age groups use and experience social media differently. For example, while the 45-54-year old group is the fastest growing demographic group on Facebook (Cooper, 2013), adult social media users (18+) were less likely to contribute to social media content (e.g. posts, photos, and clips) than younger users (Pew Research Center, 2014). In addition, social media has greatly expanded individuals' social networks to include strangers (The Annenberg Public Policy Center, 2006). Younger individuals that grew up with social media (Pew Research Center, 2014) might be more comfortable with interacting with strangers online (The Annenberg Public Policy Center, 2006).

Based on these patterns in social media use, we hypothesized that older participants might express higher levels of distrust in the study than younger participants, and therefore might be more reluctant to share or post information in the social media group, including HIV-related information. If interventions cannot actively engage older participants, older participants may become indifferent and subsequently benefit less from study participation. To address these questions related to age and ethics, the study sought to re-contact participants from a previous social media-based HIV prevention study to assess the ethical issues associated with using social media for HIV prevention research and how age differences might be associated with their experiences in the study from recruitment, informed consent, intervention to follow-up.

Methods

Institutional Review Boards (IRBs) at (REMOVED FOR BLIND REVIEW) approved the study protocol for the original HOPE Peru study and the current study. The IRB approved the HOPE Peru study to follow up with participants one-year after the intervention, and the current study was approved as a modification to the follow-up. Participants received information about the study and completed informed consent online. The study adheres to the current recommendations on using social media in HIV research (Sean Young, 2012).

Based on the diffusion of innovations model, the HOPE Peru study was a 12-week HIV intervention that delivered peer-led HIV education over Facebook to increase HIV testing and prevention behaviors. All participants were recruited via the Internet (e.g., website banner ads, email lists, and Facebook ads), and eligible and consented participants were then randomized into one of the two conditions: an HIV intervention Facebook group and a standard of care control group (general health). The HOPE Peru study included 556 participants who were 1) male, 2) 18 years of age or older, 3) residents of Greater Lima, 4) current Facebook users 5) had had sex with a man in the past 12 months. Only MSM were included in the study, because the majority of the HIV epidemic in Peru is concentrated among MSM (Caceres & Mendoza, 2009; Sanchez et al., 2007; UNAIDS., 2010). Peer leaders were recruited using the same inclusion criteria, and were randomly assigned to the control or intervention group. Peer leaders are encouraged to engage the participants by sending messages, chats, and wall posts. Peer leaders in the intervention group were instructed to communicate about HIV prevention and testing, whereas peer leaders in the control group focused on exercising, healthy eating and maintaining a low-stress lifestyle. In June 2014, approximately one and a half years after the HOPE Peru study, MSM from the HOPE Peru study were re-contacted using email, social media, and phone, and invited to

complete a survey to assess their experiences in the social media HIV prevention study. This ethics-related follow-up study provided enough funding to recruit 221 participants from the HOPE Peru study. After the first 221 MSM (approximately 110 from each condition) from the HOPE Peru study (out of 556) completed surveys, we closed the study to further participation. All participants (intervention and control) completed the same survey. The participants were compensated with an equivalent of \$11 in Peruvian Sol.

Measures

The 40-item survey assessed study participants' experiences and perceptions of ethical issues in recruitment, informed consent, intervention, and follow-up/after intervention. The survey was developed by the investigators with input from the community advisory board. The survey has not yet been validated due to this research not having been previously conducted.

Basic Demographics—Basic Demographics included age, sexual identity, highest education attainment, and race/ethnicity. Using the median (31.0) and quartiles, participants were categorized into three different groups based on age: 1) 20-26, 2) 27-36, and 3) 37 and above.

Recruitment items (n=11): Participants were asked to indicate whether they had ever participated in other online or HIV studies (online and offline). Using a 5-point Likert type scale, participants were asked to rate their comfort/discomfort levels in the recruitment procedure of the study, such as the idea of participating in the study (how comfortable were you about the idea of participating when you first read or heard about the study) and the banner ads used (if you were recruited online by clicking on a banner advertisement, how comfortable were you clicking on the advertisement). This study also assessed participants' comfort/discomfort levels regarding key characteristics of the study when they first heard about the study, such as Facebook-based (how comfortable were you that the study was entirely conducted on Facebook), HIV- and MSM-related (how comfortable were you that only MSM would be included in the study), and peer-led (how comfortable were you that peer health educators were going to educate you online).

Informed consent items (n=3): On a scale of 1 (did not understand at all) to 5 (completely understood), participants were asked to indicate how much they understood the consent form and study process. In addition, they were asked how similar/dissimilar was their experience participating in the study from their understanding of the study.

Intervention items (n=15): Using a 5-point Likert type scale, participants were asked to indicate their comfort/discomfort levels in study procedures including: 1) completing the baseline survey (how comfortable were you completing the survey), 2) being sent a Facebook group invitation, 3) joining a social media-based research study with a group of strangers, 4) seeing other people's discussions on the group wall, and 5) posting on the group wall. Participants were asked whether other group members' comments made them feel uncomfortable (did people in the group post anything that made you uncomfortable). Participants were also asked to rate their trust in other participants and researchers (how

much did you trust that the other people in the group were telling the truth in their posts/how much did you trust that the investigators were telling the truth about the study), and their belief that other group members and researchers making posts were real people (how much did you trust that the other people in the group were real). Lastly, participants were asked whether they had met up (did you meet up with other members of the group) or had sex with other participants in the study (did you meet new sexual partners as a result of joining the group).

Post-intervention follow up items (n=21): Using a 5-point Likert type scale (very negatively to very positively), participants were asked how much they benefited in the following areas as results of their participation: 1) learning more about health (as a result of your participation in the study, how much have you benefited in learning more about health), 2) learning more about sexual health, 3) gaining new friends, 4) feeling closer to MSM community, 5) feeling better about yourself, 6) learning about HIV status, 7) improving HIV care, 8) learning where to receive sexual health services, 9) gaining a job, 10) learning about research, 11) increasing trust in other people, and 12) increasing trust in research. The survey also asked the participants whether they would have still participated in the study (if they could go back in time) and whether they would recommend this type of study to their friends. They were also asked whether the study had changed their behaviors, such as maintaining a healthy lifestyle (compared to before you joined the study, how much more likely are you to maintain a healthy lifestyle), practicing safe sex, getting regular HIV tests, and participating in research studies.

Ethics-related items (n=15): The study included 15 ethics-related items. Participants were asked about privacy issues (how concerned were you that your behavior online would be tracked by companies such as Google or Facebook if you click on the ad to participate), informed consent, comfort levels in study procedures (completing the baseline survey, having to accept an invitation to join the Facebook group and etc.), unintended consequences (meeting sexual partners or discomfort from others' posts), and trust in other participants and researchers.

Analysis

All analysis was conducted using R statistical software (version 3.1.0). 10 participants were excluded from the study, because they were missing basic demographic information (n=211). Logistic and cumulative logit regression models for binary and ordinal outcomes, respectively, were used to evaluate the association between age groups and ethics outcomes. The final model adjusted for education levels, prior HIV research experience, and group assignment (control vs. intervention). Only significant results were included in the tables.

Results

Basic demographics (Table 1)

Roughly equal numbers of participants were from the control (51.7%) and the intervention (48.3%) groups. Participants were mostly gay (88%), college and above educated (63.6%), and of mixed race (72.4%). The age of the participants ranged from 20 to 54, and the mean

age was 31.82 (st. dev. = 7.68). More than a quarter of participants had prior HIV research experience (32.7%).

Binary association between age and ethics outcome (Table 2)

Approximately 30% of participants had prior experience with online studies. Individuals over 37 years of age (40%) were more likely to have had participated in an online study before in comparison to the 20-26 group (18.5%, $p=0.016$). Roughly 13.8% of individuals aged 20-26 expressed that they did not understand or felt neutral about the consent form and study process in comparison to 13% and 7.3% in the 27-36, and 37+ groups. The different levels of understanding between the 37+ and 20-26 groups were significant (0.024). Participants aged 37 or above were also more trusting towards other participants in the group (61.8% vs. 40.8%) and the investigators of the study (77.8% vs. 64.0%) than the younger participants, aged 20-26 ($p = 0.023, 0.014$). Participants in the 27 to 36 group benefited less from the study in learning about sexual health than participants in the 20 to 26 group (64% vs. 85.7%, $p = 0.025$). Throughout the study, older participants (37+) reported learning less about HIV status (51.9% vs. 80%) and HIV care (58.2% vs. 82%) in comparison to participants aged 20 to 26 ($p = 0.010, 0.026$). No differences were found in other recruitment, informed consent, intervention, and follow up outcomes.

Adjusted odds ratios (AORs) for age on ethics outcomes (Table 3)

In comparison to younger participants aged 20-26, older participants (37+) were 2.24 ($p = 0.0063$) and 2.00 ($p = 0.0050$) times more likely to express higher levels of understanding of the consent form and study process and higher levels of trust in the other participants in the group, respectively. In addition, older individuals aged 37 and above benefited significantly less in learning about HIV status (aOR = 0.41) as a result of participating in the study than the 20 to 26 group ($p = 0.022$).

Discussion

To the best of our knowledge, this is the first paper that looks at the impact of age in ethics-related experience among participants in a social media-based HIV study, as well as the first paper to look at this among participants in an LMIC. Contrary to our hypothesis, we found that, compared to younger participants, older participants were more likely to trust that other people in the group were real participants and not study personnel or fake profiles. In working with young adults (ages 16-22), Byron et al. identified young people's self-presentation as a main challenge in using social media for sexual health promotion (Byron, Albury, & Evers, 2013). Although young social media users share information about themselves frequently on social media (Madden et al., 2013), each action (posts, photos, comments, and etc.) is carefully planned to enhance their self-presentation online and to avoid potential embarrassment or drama (Byron et al., 2013). Therefore, younger participants might be more hesitant to share sensitive or personal information that might negatively impact their self-presentation. Future social media-based HIV interventions should focus on building trust among participants, especially younger individuals, as this can help individuals to talk freely about their sensitive experiences and questions.

This study also found that older participants, aged 37 or above, tended to understand the consent form and study process more thoroughly than younger participants after adjusting for their prior HIV research experience. While the study assessed participants' prior HIV research experience, we did not assess if participants had participated in any research studies in the past. One possible explanation is that older participants might be more experienced with research studies, and therefore, understood the informed consent more thoroughly. Future research needs to take participants' prior research experience into consideration in order to tailor the information.

Another key finding was that older participants (37+) tended to benefit less from the study in terms of learning about HIV status compared to younger participants aged 20 to 26. Research has shown that older individuals tend to spend less time on social media in comparison to their younger counterparts (Nielsen Holdings N.V., 2012). Because of financial, career, and familial obligations, older participants might have limited time to browse and invest in the intervention group. Future research could focus on identifying the different types of posts/discussions to best engage participants with different levels of time commitment, such as personal stories, video clips, private messages, and in-depth questions. Peer leaders should also be trained to take these life events and experiences into consideration when interacting with participants of different age groups.

The study is limited by recall bias. The ethics-related questions were assessed approximately 1.5 years after the study. Future studies should consider incorporating ethics-related questions into regular assessment to monitor ethical issues throughout the study. In addition, the survey used in the study has not yet been validated, and future research is needed to validate the survey. The results of the study also call for more qualitative research to understand participants' experiences that we were not able to identify in a quantitative survey. Lastly, this study might lack generalizability outside of Peru, Peruvian MSM, and HIV studies.

Social media use is increasing at an astonishing rate globally (Rainie & Poushter, 2014). Using existing and popular social media technologies, to reach large numbers of at-risk individuals rapidly in LMICs might be a sustainable and cost-effective alternative to deliver health education. In this study, participants in general expressed low levels of concern about privacy, study procedures, and key characteristics. However, issues regarding informed consent and trust building remain challenging in using social media for HIV prevention. To ensure participants' safety in using social media for HIV prevention, more research is needed to gain further understanding of participants' ethics-related experiences.

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Table 1

Basic Demographics among Peruvian MSM who participated in a social media-based HIV prevention study, Greater Lima Peru

		Participants (n=211)	
		n	%
Group	Intervention	102	48.3
	Control	109	51.7
Age	Mean (st. dev.)	31.82	7.68
Sexual identity	Gay	169	88
	Bisexual	20	10.4
	Heterosexual/others	3	1.6
Educational attainment	Secondary	11	5.7
	Institution	52	27.1
	Vocational training	7	3.6
	University	113	58.9
	Above	9	4.7
Race	Native Peruvian	1	0.6
	White	36	20.7
	Black	8	4.6
	Mixed	126	72.4
	Asian	3	1.7
Prior HIV research experience	Yes	69	32.7
	No	142	67.3

Table 2

Binary association between age and ethics outcome

Outcomes	Total (N=211)		20-26 (n=56)		27-36 (n=80)		37+ (n=55)		P-value
	n	%	n	%	n	%	n	%	
Had you ever participated in an online study before this one?	61	29.5	10	18.5	23	29.1	22	40.0	0.016*
No	146	70.5	44	81.5	56	70.9	33	60.0	
How much did you understand the consent form and study process?	1	0.5	0	0	1	1.3	0	0	0.024*
Did not at all understand	3	1.5	1	2.0	2	2.6	0	0	
Did not understand	19	9.4	6	11.8	7	9.1	4	7.3	
Neutral	64	31.7	19	37.3	25	32.5	12	21.8	
Understood	115	56.9	25	49.0	42	54.5	39	70.9	
Completely understood	2	1.0	0	0	1	1.3	1	1.8	0.023*
Did not trust at all	3	1.5	1	2.0	2	2.6	0	0	
Did not trust	92	46.2	28	57.1	36	47.4	20	36.4	
Neutral	55	27.6	12	24.5	22	28.9	16	29.1	
Trusted	47	23.6	8	16.3	15	19.7	18	32.7	
Completely trusted	0	0	0	0	0	0	0	0	0.014*
Did not trust at all	3	1.5	2	4	0	0	1	1.9	
Did not trust	66	33.5	16	32.0	35	46.7	11	20.4	
Neutral	47	23.9	18	36.0	11	14.7	12	22.2	
Trusted	81	41.1	14	28.0	29	38.7	30	55.6	
Completely trusted	0	0	0	0	0	0	0	0	0.025**
Very negatively	1	0.5	0	0	1	1.4	0	0	
Negatively	54	28.0	7	14.3	25	34.2	18	33.3	
Neutral	78	40.4	23	46.9	27	37.0	19	35.2	
Positively	60	31.1	19	38.8	20	27.4	17	31.5	
Very positively	0	0	0	0	0	0	0	0	0.010*
Very negatively	1	0.5	0	0	1	1.4	0	0	
Negatively									

Outcomes	Total (N=211)		20-26 (n=56)		27-36 (n=80)		37+ (n=55)		P-value
	n	%	n	%	n	%	n	%	
Neutral	58	29.7	10	20.0	20	27.0	26	48.1	
Positively	73	37.4	20	40.0	30	40.5	13	24.1	
Very positively	63	32.3	20	40.0	23	31.1	15	27.8	
Very negatively	1	0.5	0	0	1	1.4	0	0	0.026*
Negatively	2	1.0	0	0	2	2.7	0	0	
Neutral	50	25.4	9	1.8	16	21.6	23	41.8	
Positively	79	40.1	20	40.0	35	47.3	15	27.3	
Very positively	65	33.0	21	42.0	20	27.0	17	30.9	

As a result of your participation, how much have you benefited in improving HIV care?

* Significant differences between 37+ and 18-26

** Significant differences between 27-36 and 18-26

Table 3

Adjusted odds ratios (AORs) for age on ethics outcomes

Outcomes*	Group	AORs	95% Confidence Interval		P-value
			Lower	Upper	
How much did you understand the consent form and study process?	27-36	1.30	0.64	2.62	0.47
	37+	3.24	1.41	7.70	0.0063
How much did you trust that the other people in the group were real?	27-36	1.05	0.53	2.07	0.89
	37+	3.00	1.41	6.55	0.0050
As a result of your participation, how much have you benefited in learning about HIV status?	27-36	0.73	0.37	1.43	0.36
	37+	0.41	0.19	0.87	0.022

* All models adjusted for educational attainment, prior HIV research experience, and group assignment (control vs. intervention), and used 20-26 group as reference group

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