Technology use and reasons to participate in online social networking websites for people living with HIV in the US

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Abstract

It is unknown if online social networking technologies are already highly integrated among some people living with HIV (PLWH) or have yet to be adopted. To fill this gap in understanding, 312 PLWH (84% male, 69% white) residing in the US completed on online survey in 2009 of their patterns of social networking and mobile phone use. Twenty-two persons also participated in one of two online focus groups. Results showed that 76% of participants with lower adherence to HIV medication used social networking websites/features at least once a week. Their ideal online social networking health websites included one that facilitated socializing with others (45% of participants) and relevant informational content (22%), although privacy was a barrier to use (26%). Texting (81%), and to a lesser extent mobile web-access (51%), was widely used among participants. Results support the potential reach of online social networking and text messaging intervention approaches.

Keywords

Introduction

Technology is increasingly used to improve adherence to antiretroviral therapy (ART) among people living with HIV (PLWH; 1–5). The Internet and other forms of new media (e.g., smart phone applications, text messaging) have the advantages of reaching persons in need of intervention across a wide geographic area and hidden populations who may be concerned about revealing their identities, as well as providing intervention in naturally-occurring contexts (6). Technology-based ART adherence interventions show promise across a number of technology platforms. For example, medication adherence among PLWH residing in the United States (US) who received a computer-administered ART adherence support intervention and remained "on protocol" was significantly higher than that of

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patients receiving standard of care at 18 months (7). In another use of technology, HIV-positive Africans randomized to receive a short message system (SMS, or "text") message once a week over their cell phones (with follow-up phone calls for those replying to the text that they need assistance) had significantly greater adherence to antiretroviral medications at 6 and 12 months than those receiving standard of care (3, 8).

Most existing technology-based ART adherence interventions operate at the individual level, with little or no social interaction between group members. However, peer-to-peer exchanges are a common way in which people living with chronic illness gain support and share health information (9). Some HIV-related interventions have taken advantage of social networking technology, including using online chatrooms to reduce sexual risk behavior among high-risk populations (10). Online social networking ART adherence interventions have yet to be evaluated, however, the ease of uptake and wide-scale dissemination of such interventions rests upon the familiarity and frequency of use of these technologies among PLWH. To date, we have not identified any studies that described the patterns of social networking and mobile phone use among PLWH.

In the broader population of adults living in the United States (US), online social networking features are widely used, as reflected in a recent (2010) report on social networking and mobile phone use among a representative sample of 3,001 US adults (11). Nearly three-quarters (74%) of respondents used the Internet, and 59% looked for information on one or more of 15 health topics (e.g., seeking information about a specific disease or medical problem; seeking information related to health insurance). Forty-six percent of adults used social networking sites, such as *Facebook* or *MySpace*; use of social networking websites was higher among adults who use the Internet (62%). Although 13% of adults went online to find other people who have similar health concerns, significantly more adults living with a chronic health condition did so compared to those not living with a chronic health condition (23% v. 15%). A relatively small percentage of adults posted comments or questions about health or medical issues (4%) or their experiences with a drug or medical treatment (3%), or joined a health-related group on a social networking site (4%). Among respondents with a cell phone, 9% had a software application on their phone to help them track or manage their health. Moreover, among cell phone owners, 70% send and receive texts and 17% used their cell phone to look up health or medical information. Taken together, the results of this study suggest that social networking and mobile technologies may be an important way for some persons living with chronic health conditions to better manage their health and healthcare.

While social networking and cell phone technology offer an attractive and far-reaching intervention medium for populations who use these technologies, it is presently unknown how common such use is in populations of PLWH in the US. To address this gap, the aims of this study included: 1) to determine if social networking websites are used by PLWH and which are most often used; 2) to understand the preferred features of an online social networking health website among PLWH with sub-optimal ART adherence, and reasons that would prevent them from using such a website; and 3) to assess mobile phone adoption and frequency of use among PLWH. Results could inform the development of technology-based HIV medication adherence interventions for PLWH.

Methods

This study is part of an ongoing research program to develop an online social networking HIV medication adherence intervention for PLWH. It included an online survey of 387 PLWH conducted between July and November, 2009 to assess theoretically grounded and empirically derived risk factors for poor adherence to HIV medication, examine social networking and mobile phone adoption and usage, and illuminate facilitators and barriers of

using an online social networking health website (Study 1). In addition, we conducted two online focus groups consisting of 22 participants who completed the online survey in April 2010 to provide more detailed information about reasons for using or not using social networking health websites (Study 2).

Participants and Procedures

Inclusion criteria for the online survey were: 18 years of age or older, English speaking (as the survey was conducted in English), self-reported HIV-positive status, and residence in the United States (including one of its territories or on a military base). Participants were recruited in several ways. Persons interested in the study could access the survey via banner advertisements placed on websites or e-mail newsletters on informational websites targeting people affected or infected with HIV (constituting 53.5% of persons enrolled in the study) or from *Facebook* (12.8%). Some participants enrolled in the study from an invitation-to-screen e-mail sent to persons who had participated in previous studies and requested notification of new study opportunities (4.5%). A small number found information about the study on the university website from an online search (1.6%). Finally, we contacted AIDS Service Organizations (ASOs) to hand out fliers and postcards with information about the study to potential participants that directed them to the online survey to be screened for inclusion in the study (27.6%).

To enroll, participants needed to provide a valid e-mail address to access the screening questionnaire. We sent an e-mail to the address provided by the potential participant containing a direct link to the screening survey. After answering the screening questions, participants who did not meet inclusion criteria received a message notifying them of their ineligibility and thanking them for their time and interest in the study. Eligible participants were provided an overview of the study and were invited to consent in accordance with procedures approved by the [author institution] Institutional Review Board. Persons meeting eligibility requirements, providing informed consent, and who answered at least one question of the survey were considered enrolled in the study. Multiple security measures were used to block repeated attempts to screen for eligibility, including cookies placed in browsers, e-mail address screening, and IP address screening. Participants who completed the online survey were reimbursed $25 for their time through their choice of a mailed check (77% of participants) or an Amazon.com© e-gift certificate (23% of participants).

Participants who completed the online survey and reported less than 95% adherence to antiretroviral medication were sent an e-mail message in April, 2010 asking them if they would be interested in participating in one of two planned online focus group. Sixty-four persons responded to the e-mail stating that they would be interested in participating in the online focus groups. The first 44 persons who responded to the invitation were sent information about how to access the focus groups during the scheduled time and told admission into the online focus group would be capped to the first 12 persons who entered the chat room. The last 20 persons who responded to the invitation were put on a waiting list. Three research team members conducted the online focus groups. The principal investigator directed the moderator on which questions to post, but did not directly interact with focus group participants. The project coordinator was the moderator of the focus groups, guiding the discussion and posting questions. A research assistant assisted with group management and periodically copied and pasted the text from the conversation into a word processing document. Focus groups lasted approximately one and a half hours. Participants were paid $25 with a mailed check as reimbursement for their time.

Measures

The online survey totaled 170 items, with branching and skip patterns guiding participants to only those items relevant to their life situation (e.g., if a participant reported that they did not have a mobile phone, they were not asked for the number of text messages they sent in the past month).

Measures assessed socio-demographic characteristics, 30-day ART adherence (with a drop down menu from 0–100% adherence in the past 30 days), utilization of online social networking websites, and mobile phone features and plan. Socio-demographic characteristics included age (in years); education (in years); gender (male, female, transgender male, transgender female); race (African American, White, Asian or Asian American; American Indian or Alaskan Native; or Native Hawaiian or other Pacific Islander) and ethnicity (Hispanic or Latino/Latina); sexual orientation (five-point scale from only having sex with men to only having sex with women); years living with HIV, residency (5 response options ranging from rural area to downtown or central district of a large size city); and income (in US$10,000 increments to $100,000). Where appropriate, an "other" option was provided in which participants could write in their response.

To assess the use of social networking websites, participants were asked to indicate which of the following websites or features they use at least once a week: *Bebo*, *The Body.com Connect* bulletin boards, *Facebook*, *LinkedIn*, *MySpace*, *Poz.com* community section blogs or forums, or *Xanga*. In addition, participants were asked if they used other social networking websites at least once a week, with an option to write in which other social networking websites or features they used (although no participants wrote in a response). Next, participants were asked to write a brief response to the questions, "What would prevent you from actively participating in a social networking health website for people living with HIV?" and "Imagine your ideal social networking health website for people living with HIV…how would you describe it?"

Mobile phone technology and use was assessed in several ways. First, participants were asked to report what kind of phone they had, with options including smart phone brands (defined as "A smart phone allows easy Internet browsing and may have other capabilities beyond voice calls and text messaging."; e.g., iPhone, Blackberry), a mobile phone without smart phone features, or no mobile phone. Participants who reported using a mobile phone were asked whether they had an unlimited data plan, the frequency with which they accessed the Internet using their mobile phone, and the number of text messages they send in an average month (0, 1–20, 21–50, 51–100, 101–200, 201–500, more than 500).

Questions for the online focus groups were developed from responses to the open-ended questions in Study 1. Themes identified in Study 1 were described to participants in the online focus groups and they were asked to clarify the meaning of those themes (e.g., "Privacy in an online environment was important to many people. When you speak of your concern for privacy in an online social networking health website, which concerns are the most important to you?")

Analyses

These analyses include only those participants who self-reported to be currently on ART (n=312 of the 387 eligible respondents). Socio-demographic factors were collapsed into the categories shown in Table I. Adherence to ART was recoded as 95% or higher to define "higher" adherence or less than 95% to define "lower" adherence since the optimal virologic outcomes are associated with high levels of adherence and 95% represents a common cut-off point in the field (12, 13). Responses indicating that a participant used a type of known smart phone (e.g., iPhone®) were coded as having a mobile device with smart phone

features. Responses of "other" on the type of mobile device were recoded as having a mobile phone with smart phone features if the participant also indicated that s/he also accessed the Internet on her or his phone. Responses of "other" on the type of mobile device were recoded as having a mobile phone without smart phone features if the participant also indicated that s/he did not access the Internet on her or his phone.

Differences in socio-demographic characteristics, social networking variables, and mobile phone use factors were examined by adherence level (<95% v. 95% or greater) to determine whether PLWH reporting lower adherence had different intervention needs than those with higher adherence levels. Group differences were examined with t test, chi-square or Fisher's exact (FE) test. Open-ended responses to questions asking participants to describe their ideal social networking website for PLWH and barriers to participating in a social networking website were read and coded into themes. Only those themes relevant to PLWH with suboptimal ART adherence (<95% adherence) are presented as they would be the target for medication adherence interventions.

Focus group results were used to supplement and clarify the themes that emerged in Study 1. Transcripts of the online focus groups were read line-by-line to identify grammatical segments (the units of analysis for text coding) referencing one of the topics. Grammatical segments that provided greater clarification to the themes identified in the online survey were selected to supplement understanding of the underlying themes. All quotes in text were taken from the online focus groups, while example quotes for themes from the online survey are shown in the table.

Results

Socio-demographic Characteristics

Socio-demographic factors for the total sample of participants completing the online survey, and by self-reported adherence level, are shown in Table I. The average age was 43 years. Most participants were male (84%), white (69%), gay-identified (75%), had some college or higher education (average number of years of education was 15), made less than $30,000 per year (51%), and had been living with HIV for more than 3 years (73%). A higher percentage of participants who self-reported as non-white (i.e., Black, Hispanic, or another race/ethnicity; χ^2[3, n=311] = 10.66, $p<.05$), fewer years of education (t[310]=3.04, $p<.01$), living in a downtown or central district of a large city or a small town (χ^2[3, n=312] = 16.97, $p<.01$), lower income (χ^2[3, N=306] = 16.58, $p<.01$), and having government subsidized insurance (χ^2[1, n=311] = 4.35, $p<.05$) were in the less than 95% adherence group.

The mean age of the 22 online focus group participants was 46 years. Similar to Study 1, most participants were male (91%), white (82%), gay (81%), and earned less than $30,000 in the previous year (53%).

Social networking website use

Three fourths of participants (76%) used an online social networking website or feature at least once a week. Participants who did not use social networking websites at least once a week were slightly older (45 years old vs. 42 years old; t[309]=2.17, $p=.03$). However, the overall use of social networking websites did not otherwise differ by gender, race, sexual orientation, residency, income, or education. Likewise, no significant differences in overall online social networking website use was detected between those with lower (79%) or higher (73%) ART adherence.

As shown in Table II, the most widely used social networking website was *Facebook*, used by 62% of participants in this sample. The next most common social networking websites or features were *Poz.com* community forums (28%), *My Space* (21%), and *The Body.com* community forums (11%). Fewer participants reported using other types of social networking websites, such as *LinkedIn*. There were no differences in the use of specific social networking websites or features between participants with lower and higher adherence to HIV medications, with the exception that lower adherers were more likely to use *MySpace* (26% v. 16%).

Ideal online social networking health website and barriers to use

Themes that emerged from the open-ended questions in the online survey are shown in Table III. Forty-five percent of participants reported that their ideal social networking website would be one that allowed them to connect with other people in a variety of different ways, such as message boards and chatrooms. A desire to connect with others living with HIV was clearly expressed: "A lot of us feel the need to know we are not alone" (on-line focus group participant [OFGP] 20). The look and feel of *Facebook* was often brought up as the best example of an online social networking website in both the online survey and the online focus groups. One participant stated, "I think it would be easier to have something similar to *Facebook* but more informational…" (OFGP10). Another said: "I agree that the *Facebook* model is the best I could come up with. One that has real pictures of us, warts and all…" (OFGP13).

On the other hand, 14% of participants in the online survey reported that they would not like to participate in an online social networking health website for PLWH. When asked why someone would not want to participate in a social networking website, the two primary reasons given were beliefs that such sites can be exclusionary and being disinterested if someone already has a face-to-face social outlet:

> "Most of the social networking sites I have tried …have turned "clicky" and exclusive…not inclusive." (OFGP8)

> "Cause they have a social life in their own personal life. Where some people [sic.] only outlet is through the Internet. I just moved to where I live and this is my social life for now" (OFGP22)

Privacy concerns were common (26% of responses) when participants were asked what would prevent them personally from engaging in an online social networking health website. This concern was clearly reflected in statements by online focus group participants:

> "The web can be a place of anonymity and deceit, so you have to be mindful of the info you share and whom it is shared [with]." (OFGP9)

> "Most people I know that do not use *Facebook* cite privacy grounds" (OFGP15)

Of concern was stigma surrounding HIV and the potential for one's HIV status to be revealed via the Internet to co-workers, friends, or family: "Whether or not we are out [i.e., open about one's HIV status] to the world about our status is irrelevant…it is a sensitive issue that can be used against someone in employment, housing and who knows what else…" (OFGP5). Stigma was clearly a common and painful experience, exemplified by one participant's comment: "I live in a small town and the stigma here is unbearable" (OFGP14). Concerns about privacy varied across participants, with some believing that their privacy would ever be fully protected online: "Even with all the supposed controls, someone, somewhere has access to the file and password keys" (OFGP7). Other participants appeared less concerned about privacy: "It seems that 'privacy' in an Internet setting is casual at best, it is not a big realistic concern for me personally" (OFGP8). Regardless of their personal

beliefs about privacy, PLWH in the online focus groups all believed that users of a social networking website should have a high level of control over how private or public to make their identity, as demonstrated in the following exchange:

> OFGP6: "One could be as honest or as private in a profile if one was required to be set up."

> OFGP10: "Though I think it should be at the participants' discretion"

Despite the need for privacy, some participants in the online survey (13%) recognized the need for social networking spaces to be monitored. As noted by a participant: "[A social networking website should be]… monitored so that it doesn't become a dumping ground for negative comments." (OFGP5). Thirteen percent of responses to the question about what would prevent the participant from engaging in an online social networking health website were related to concern about negativity in online spaces, as well as the potential for abusive or hostile users. A focus group participant noted, "There should be some monitoring to prevent bullying or annoying behavior" (OFGP9). Another stated: "For me the reasoning to have it monitor [sic] is so that it keeps people who are only there to cause trouble. It's okay to have discussion but not ones filled with hate" (OFGP22). Although there was widespread belief that a social networking space should be monitored, there did not appear to be consensus on how closely such spaces should be monitored.

Participants in the online survey identified relevant HIV information (22% of all responses) and addressing the emotional needs of PLWH (16% of all responses) as key components of their ideal social networking website. Focus group participants identified many areas of interest related to HIV, including new medications, a registry of healthcare professionals, nutrition, Medicare updates, and side effects of medications. Although some participants believed that in-person counseling was better than online counseling, others recognized that Internet mental health resources fill an important gap in underserved areas (e.g., rural areas) and for people who do not feel comfortable leaving their home: "I live with social anxiety/ phobia…I think weekly online support groups would be helpful…not everyone wants to deal with people especially if you're extremely shy…" (OFGP11).

PLWH in the online survey stated a preference to socialize with others similar to themselves (11%), with 2% of participants noting that their inability to find similar persons prevented them from engaging in online social networking health websites. In the focus group, one participant stated that similar others included "an individual living with HIV/AIDS who can share experiences and offer solutions that they may have learned to manage the disease" (OFGP9). Most online focus group members agreed: "We need more networking for poz [HIV-positive] individuals" (OFGP19).

Fewer participants in the online survey stated that their ideal website included having one that contained expert advice (8%), one that is easy to use (7%) and one that is personalized and interactive (6%). On the other hand, not having enough time (9%), lack of access to a computer or Internet connection (6%), a website that is difficult to navigate (4%), and cost associated with membership (3%) were identified barriers that would prevent some participants from utilizing an online social networking health website.

Mobile phone use

An equal percentage of participants in this sample reported having a mobile phone with smart phone features (43.9%) and a mobile phone without smart phone features (43.6%). The remainder did not have a mobile phone (12.6%; Table II). More participants reporting lower adherence to their HIV medications did not own a mobile phone than those reporting higher adherence (16.0% v. 8.8%; χ^2[2, n=310] = 11.04, p<.01); however those with lower

adherence who owned a mobile phone were more likely to have one that had smart phone features compared to those with higher adherence (49.1% v. 38.1%; χ^2[2, N=310] = 11.04, $p<.01$). Mobile phone ownership and type also varied by demographic characteristics. Participants who owned a mobile phone without smartphone features were older (M=44.2 years) than those who owned a mobile phone with smart phone features (M=38.8 years; F(2,309)=9.92, p<.000). More women than men (23.4% v. 10.7%, respectively) did not own a mobile phone (FE=.031). Finally, a higher proportion of African American (59.5%) and Latino/a (60.0%) participants owned mobile phones with smart phone features than white participants (37.6%; FE=.002), as did wealthier participants compared to the poorest participants (66.7% of participants who earned $90,000 or more owned a mobile phone with smart phone features v. 37.8% of participants who earned less than $30,000; FE=.006). Mobile phone ownership and type did not differ by sexual orientation, residence, or education.

Among participants who owned a mobile phone, approximately half (49.1%) did not have an unlimited data plan and access the Internet on their phone. However, 61% (74/122) of those with an unlimited data plan frequently accessed the Internet using their phone. Among those with a mobile phone, participants with lower ART adherence reported accessing the Internet on their mobile phone more frequently than those reporting higher adherence to their medication (χ^2[4, N=265] = 9.32, $p<.05$).

Of those with a mobile phone, 46% (124/271) sent/received more than 50 text messages in the last month. Among those with a mobile phone, participants with lower ART adherence generally reported utilizing text messaging more frequently than those reporting higher adherence to their medication (χ^2[6, N=271] = 14.12, $p<.05$).

Discussion

The results of this study provide important insights into the potential acceptability and design of online social networking ART adherence interventions. Three main conclusions can be drawn. First, most PLWH responding to this survey used social networking sites regularly, including most of those reporting lower ART adherence using such websites weekly. Second, a sizable proportion of participants with lower ART adherence indicated that their ideal online social networking health website should meet their social and informational needs, suggesting that these features may contribute to the overall success of online adherence interventions. Third, texting, and to a lesser extent web-access via mobile technologies, is widely used among Internet-using PLWHA. Hence, interventions targeting this population which integrates texting and mobile phone technologies should have high acceptability. Each of these is discussed in more detail below.

A higher percentage of participants in this study (76%) used social networking websites or features regularly (at least once a week) compared to a representative sample of adults who use the Internet in the US (62%)(11). The difference in online social networking website use in this sample and the US sample may be partly due to sampling differences and item wording. However, the high percentage of PLWH who reported online social network use in this study does suggest that many PLWH are familiar with the look and features of social networking websites. *Facebook* was the most highly utilized social networking website, despite only a small percentage of the sample recruited via *Facebook*. The widespread use of social networking websites and the features identified as important by PLWH in this study indicates that future technology-based interventions that contain similar features are likely to be acceptable to PLWH who use the Internet. Offline social support interventions have been used regularly to increase medication adherence among PLWH (14). The results of this study support the development of online social support interventions with social networking

capabilities modeled after widely-used social networking websites, especially for PLWH who are already using the Internet.

Many participants in this study expressed the need to talk with others about their fears and concerns and socialize with other PLWH, which has also been demonstrated in prior studies (15, 16). Despite this need, some PLWH fail to obtain social support (17), which may adversely impact ART adherence (18). That many PLWH use online social networking websites or features regularly suggests the potential for such websites to be used to provide either general support or specific support for concerns about HIV.

When asked about their ideal social networking health website, participants in reported that it would be one that provides opportunities to socialize and to enhance their emotional well-being through interacting with similar individuals. Future online social networking interventions should facilitate interactions between participants to quickly build group cohesion and to establish a supportive environment to address emotional wellbeing. However, it may be challenging to develop group cohesion, while maintaining high levels of privacy. Privacy concerns in online venues were expressed by PLWH in a prior study (15) and are supported by the results of this study. Group cohesion, on the one hand, relies on group members believing that they know each other and hence involves disclosure of personal information. Privacy, on the other hand, relies on participants' beliefs that their personal information is secure with the amount of disclosure under their complete control. Further research is needed to identify how to encourage social interaction, disclosure, and group support in an intervention setting, while addressing privacy concerns. Incorporating these features into a website that also provides information relevant to the needs of PLWH who may be struggling to maintain adequate adherence to ART lays the groundwork for the success of online social networking adherence interventions.

Although there is limited research on online adherence interventions, mobile phone adherence interventions using text messaging are becoming more common(5, 6) and have shown promising results (8). However, most text messaging interventions have been conducted outside the US and little information is available about the uptake of mobile phones and texting among PLWH in the US. While 35% of Americans are reported to have a smart phone that provides mobile access to the Internet (19), 42.3% of PLWHA in this study reported having smart phones. While most PLWH in this study have mobile phones, only about half of those with phones access the Internet on their mobile phone. Interestingly, participants with lower adherence tended were more highly represented in the small group of PLWH who reported not owning a mobile phone; however, among the larger group of participants who owned mobile phones, persons reporting lower adherence accessed the Internet more often from the phone.

Text messaging was common, with over 80% of PLWH in this study sending one or more texts in the previous month. Based on current usage, while many PLWH may be able or willing to access adherence interventions through the Internet on their mobile phone, there are some who may not be able (e.g., among people who cannot afford a mobile phone or data charges) or willing to do so. On the other hand, adherence messages and tools developed at this moment that utilize texts would likely reach a much broader sample of PLWH given current technology use patterns. Providing adherence interventions in a variety of technology formats (Internet, mobile Internet or smart phone applications, and texting) may be optimal to reach to PLWH, but will likely come at increased cost for development.

Study Limitations

The results of this study should be considered in the context of several limitations. First, a convenience sampling strategy was used to recruit participants. The results are unlikely to

represent all PLWH, particularly since participants for this study were primarily white, well educated, and recruited online. It should be remembered that this sample is likely to be more technologically savvy than the general population of PLWH. In addition, participants recruited in this survey may not be representative of PLWH who respond to online surveys or those who are less computer literate, since they were required to read and respond to the survey and the focus group through text. Second, participants were asked to respond to a relatively small number of technology use questions. Because of survey length limitations and concerns about over-burdening participants, we did not ask in-depth questions about their Internet use, ways they use social networking websites to seek support in general or for issues concerning HIV, or psychosocial factors related to technology adoption and use (e.g., technology use self-efficacy and health literacy). Future studies may benefit from examining these and other technology-use factors. Third, we used a 95% adherence cut point to compare group differences in technology, although it is possible that the findings may be different if another cut-off level was used (e.g., < 80% adherence v. higher). We did not explore group differences at lower adherence levels given that too few participants reported very low adherence levels and based on current practices in adherence research, although investigating such differences may be worthwhile in future studies. Finally, participants responded to the online survey in 2009 and the focus groups in 2010. Although the data fill an important gap in literature, these technologies are in rapid evolution, with technology adoption increasing. It will be important to continue to monitor technology availability and adoption among PLWH to provide current information on these factors and inform the field of technology-based adherence interventions.

Conclusions

The results of this study support the potential reach and uptake of online social networking intervention approaches. Such interventions may be most attractive if they encourage social interaction, provide a virtual space that is supportive and welcoming, while placing a strong emphasis on privacy and flexibility to allow users to decide how private or public to make their personal information. Providing a range of technology options – from a website, to mobile access, to text messaging features – is optimal to address the needs of a broad cross-section of PLWH who are diverse in their adoption and use of different technologies. Future studies are needed to determine the extent to which the associations between technology use and ART adherence may be moderated by a range of other factors, as well as studies to examine the feasibility and acceptability of this approach to adherence interventions.

Acknowledgments

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Table I

Demographic characteristics (*n*=312)

		Total (n=312)	95% + Adherence (n=148)	< 95% Adherence (n=164)	Sig.[c]
		Mean (SD[a])	Mean (SD)	Mean (SD)	
Age	Years	43.1 (9.8)	43.3 (9.7)	42.8 (9.8)	0.62
Education	Years	15.1 (2.7)	15.6 (2.9)	14.6 (2.4)	0.003
		Column %	Row %	Row%	
Gender	Male	84.0	47.3	52.7	0.57
	Female	15.0	50.0	50.0	
	Transgender	1.0	0.0	100.0	
Race/Ethnicity	Black	13.8	27.9	72.1	0.01
	White	68.8	53.3	46.7	
	Hispanic	12.9	42.5	57.5	
	Other	4.5	35.7	64.3	
Sexual Orient.	Gay/Homosexual	74.8	46.7	53.3	0.11
	Straight/Heterosexual	19.1	57.6	42.4	
	Bisexual	6.2	31.6	68.4	
Residency	Rural/Small Town	15.4	43.8	56.3	.001
	Medium city	26.6	55.4	44.6	
	Large city	37.2	55.2	44.8	
	Downtown	20.8	26.2	73.9	
Income (US$)	0–30,000	51.3	38.2	61.8	.001
	30,001–60,000	25.5	50.0	50.0	
	60,001–90,000	12.4	52.6	55.2	
	90,001+	10.8	75.8	47.4	
Insurance [b]	None	4.2	30.8	69.2	0.27
	Employer Insurance	32.2	57.0	43.0	0.02
	Individual plan	13.2	48.8	51.2	0.89

	Total (n=312)	95% + Adherence (n=148)	< 95% Adherence (n=164)	Sig.[c]
Government Subsidized	40.8	40.2	59.8	0.04
Ryan White	31.9	43.4	56.6	0.40
Years Lived with HIV 1–3	26.9	59.0	41.0	0.10
4–8	25.4	51.2	48.8	
9–15	23.3	41.6	58.4	
More than 15	24.4	40.9	59.1	

[a]
standard deviation;

[b]Percentage that have this type of insurance, not mutually exclusive;

[c]From t-test or chi-square analysis

Table II

Social network and mobile phone adoption utilization among people living with HIV

		Total	95% + Adherence (n=148)	< 95% Adherence (n=164)	Sig.
		n (col %)	Col %	Col %	
Social Networking Websites & Features Used at least Once per Week	Facebook	192 (61.7)	87 (59.2)	105 (64.0)	0.38
	Poz.com Forums	87 (28.0)	42 (28.6)	45 (27.4)	0.82
	My Space	66 (21.2)	24 (16.3)	42 (25.6)	0.05
	The Body Forums	33 (10.6)	20 (13.6)	13 (7.9)	0.11
	LinkedIn	29 (9.3)	11 (7.5)	18 (11.0)	0.33
	Bebo	4 (1.3)	2 (1.2)	2 (1.2)	1.00
	Xanga	2 (0.6)	0 (0)	2 (1.2)	0.50
	Other	34 (10.9)	12 (8.2)	22 (13.4)	0.14
	None	74 (23.8)	39 (26.5)	35 (21.3)	0.28
Mobile Phone Type (*missing = 2*)	No mobile phone	39 (12.6)	13 (8.8)	26 (16.0)	0.01
	Mobile phone without smart phone features	135 (43.6)	78 (53.1)	57 (35.0)	
	Mobile phone with smart phone features	136 (43.9)	56 (38.1)	80 (49.1)	
Mobile Phone Plan (*missing = 8*)	Unlimited data – Often	74 (27.9)	35 (26.7)	39 (29.1)	0.05
	Unlimited data – Occasionally	25 (9.4)	8 (6.1)	17 (12.7)	
	Unlimited data – Rarely	23 (8.7)	8 (6.1)	15 (11.2)	
	No Unlimited Plan – Access Internet on Phone	13 (4.9)	5 (3.8)	8 (6.0)	
	No Unlimited Plan – Do not Access Internet on Phone	130 (49.1)	75 (57.3)	55 (41.0)	
Text messages sent/received per month (*missing = 2*)	0	50 (18.5)	22 (16.3)	28 (20.6)	0.03
	1–20	63 (23.3)	41 (30.4)	22 (16.2)	
	21–50	34 (12.6)	19 (14.1)	15 (11.0)	
	51–100	26 (9.6)	9 (6.7)	17 (12.5)	
	101–200	31 (11.4)	17 (12.6)	14 (10.3)	
	201–500	35 (12.9)	17 (12.6)	18 (13.2)	
	More than 500	32 (11.8)	10 (7.4)	22 (16.2)	

Table III

Ideal social networking website features and barriers to participating in a social networking health website described by people living with HIV who report less than 95% adherence to antiretroviral medications

Theme Title	Ideal Social Networking Website (*n*=135)		Barriers to Participating in a Social Networking Website (*n*=155)	
	%	**Example Quotes**	**%**	**Example Quotes**
Social	45	"One with multiple components such as health message boards, general message boards, ability to befriend people nearby, ability to live an 'openly HIV positive' life" [AND] "like *Facebook*"	14	"That is not how I would want to interact with folks on a social level."
Information	22	"One that introduces the reality of other diseases that will develop with prolonged, continued use of HIV meds, Ex: heart failure, cancer, leukemia, etc."		[NO THEME]
Emotional wellbeing	16	"HIV poz people who are looking to enjoy life not think about dying." [AND] "Friendly, Nonthreatening, Supportive, Colorful"		[NO THEME]
Welcoming but monitored space	13	"I guess it would have to be realistic and honest. I wouldn't want to feel inferior or less than because I don't comply 100%."	13	"Abusive users" [AND] "negative information and feedback"
Special Interest Groups	11	"easy links to identify people like me (duration of treatment, drugs taking, topics covered, side-effect experienced and dealt with)"	2	"lack of viable networking partners (my own age, status, location, interests, etc.)"
Privacy/Confidentiality	10	"A safe place. A secure place. A place where you can choose who knows/sees your profile and who doesn't."	26	"Fear of disclosure of status to potential employers and professional colleagues"
Expert advice	8	"medically sound information/advice"		[NO THEME]
Ease of Use	7	"easy to use and friendly, a lot of options on what to do"	4	"If the site is complicated to navigate."
Personalized/Interactive	6	"It would have a personal health dashboard. Information there could also be tracked off-line on my computer. (It also should be able to be shared with my health-care providers if I chose - including emergent health care providers.) Dashboard links to typical things such as updates about self … It needs to motivate me to act... it should be interactive with my mobile life."		[NO THEME]
Time		[NO THEME]	9	"I generally find it takes too much time to be involved on online networking sites."
Lack of Access		[NO THEME]	6	"Not having access to a computer."
Cost		[NO THEME]	3	"Charging for access to the site."
I don't know/other	21		2	