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Correlation of Internet use for health care engagement purposes and HIV clinical outcomes among HIV-positive individuals using online social media

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Abstract

Our objective was to describe mobile telephone and Internet use and assess the correlation of Internet use for health care engagement (HCE) purposes and HIV clinical outcomes among HIV-positive individuals. We conducted a national survey using online social media to examine mobile telephone and Internet use, self-reported HIV viral load (VL; detectable versus undetectable), and antiretroviral adherence rating (excellent versus <excellent). Participants (N= 1,494) were asked about their Internet use for HCE purposes (including emailing health care providers, refilling medications online, or making medical appointments online). Approximately 95% of participants accessed the Internet nearly daily or daily in the past month (mean hours on Internet use per day= 5.2 hours) and 55.5% used the Internet for HCE purposes. Those who used the Internet for any HCE purposes had a 1.52-fold odds of reporting an undetectable VL (p= 0.009) and a 1.49-fold odds of reporting excellent adherence (p= 0.001). Although Internet access and use were similar across racial/ethnic, educational, and socioeconomic groups, disparities existed with the use of the Internet for HCE purposes among racial/ethnic minorities, those with low to moderate financial stability, lower education, and history of incarceration. Our data reveal that among HIV-positive users of online social media, use of the Internet for HCE purposes is associated with better self-reported virologic and adherence outcomes.

Key words or phrases

HIV; Internet; mobile telephone; health care engagement; online social media

Introduction

In the United States, it is estimated that 1.1 million people aged 13 years and older are living with HIV (PLWH) (CDC, 2013) and approximately 50,000 new cases of HIV occur each year (CDC, 2012a). Greater than 50% of those diagnosed with HIV are not engaged in

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medical care and only 25% of PLWH have suppressed virus (CDC, 2012b; Gardner, McLees, Steiner, Del Rio, & Burman, 2011). Poor engagement in HIV care has been associated with delayed initiation of antiretroviral (ARV) therapy and ARV non-adherence (Horstmann, Brown, Islam, Buck, & Agins, 2010; Mugavero, Amico, Horn, & Thompson, 2013), which is one of the strongest predictors of progression to AIDS and death (Bangsberg et al., 2001; Garcia de Olalla et al., 2002; Hogg et al., 2002).

Much research has been devoted to the development and evaluation of interventions designed to improve engagement in HIV care and ARV adherence (Amico, Harman, & Johnson, 2006; Simoni, Pearson, Pantalone, Marks, & Crepaz, 2006). However, due to the high cost, need for trained personnel, and limited reach and scalability of clinic-based interventions, researchers are increasingly examining mobile technologies and the Internet for behavioral interventions aimed at improving engagement in HIV care. The Internet is a major source of HIV-related information and PLWH are increasing using the Internet to access this information (Courtenay-Quirk et al., 2010). Prior research has shown that PLWH who used the Internet for health-related purposes were significantly less likely to be non-adherent to their ARV regimen in the past week (Kalichman et al., 2005) and Internet use has been associated with greater confidence in adhering to ARV medications (Kalichman, Benotsch, Weinhardt, Austin, & Luke, 2002).

Several studies have presented the importance of involvement of patients in their own care and the value of an informed patient (Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Joosten et al., 2008; Maly, Bourque, & Engelhardt, 1999; Perestelo-Perez, Gonzalez-Lorenzo, Perez-Ramos, Rivero-Santana, & Serrano-Aguilar, 2011). Additionally, individually-tailored self-care technology-based methods have the potential for improving engagement in care and enhanced ARV adherence (Saberi & Johnson, 2011). Prior research in integrated health care systems has shown that the use of patient electronic personal health records was associated with higher pharmacy-based refill adherence (McInnes et al., 2013; Silverberg et al., 2013). Given the rapid evolution of technology and the lack of data on use of the Internet for the purpose of engaging in health care (e.g., emailing health care providers, refilling medications online, and making medical appointments online) outside of a healthcare system, we conducted a survey to describe how PLWH are currently using mobile telephones and the Internet for health-related purposes and to examine the association between their use of the Internet for health care engagement (HCE) purposes and self-reported HIV clinical outcomes.

Methods

Study design

We conducted a cross-sectional study using an online survey among HIV-positive individuals using online social media to: 1) describe general mobile telephone and Internet use in this population; 2) examine the demographic correlates of those who used the Internet for HCE purposes, including emailing health care providers, refilling medications online, or making medical appointments online; and 3) evaluate the correlation of the use of the Internet for HCE purposes and self-reported ARV adherence and HIV viral load. The

University of California, San Francisco (UCSF) Committee on Human Research approved this study in April 2013.

Recruitment and participants

From May through August 2013, we implemented a campaign approach where participants were recruited through online social media, such as Facebook, Twitter, LinkedIn, Craigslist, or Tumblr. For survey programming, we used Qualtrics Research Suite (Qualtrics, Provo, UT), an online survey tool that allows researchers to build, distribute, and analyze online surveys in real-time. This survey was designed to automatically disqualify duplicate Internet Protocol (IP) addresses. Monetary incentives were not offered in order to minimize duplicate and false responses. However, to keep participants engaged, we inserted stimulating health facts, titled "Fun Facts", throughout the survey and asked an HIV-specific question at the beginning of the survey and provided the answer to the question after survey completion. Details of our research methodology have been previously reported (Yuan, Bare, Johnson, & Saberi, 2014).

Measurement and data collection

Demographics—These data included participants' age, race/ethnicity, sex at birth, sexual identity, perceived financial stability based on current income (high= "live comfortably", moderate= "can barely get by", or low= "cannot get by"), education, school and work status, any history of homelessness or living in a shelter, and any history of incarceration.

HIV clinical outcomes—Participants were asked about the date of their last HIV viral load test and whether it was detectable or undetectable, an assessment approach that has been previously validated with laboratory HIV viral load assay results (Kalichman, Rompa, & Cage, 2000). Participants' ability to adhere to ARVs over the past 30 days was assessed using a validated adherence rating scale (Lu et al., 2008) and categorized as "excellent" versus "less than excellent". This single item has been linked to more objective ARV adherence estimates, such as medication event monitoring systems (MEMS) (Lu et al., 2008).

Internet usage—Questions pertaining to Internet and mobile telephone usage were developed specifically for this study and were informed by the Pew Research Internet Project's (www.pewinternet.org) poll questions on mobile telephones and the Internet, as well as in consultation with collaborators working in the field of HIV and technology. Participants were asked about the frequency of Internet access, mean number of hours per day spent on the Internet using any device, and whether they used the Internet to: 1) send/receive emails to/from their health care providers, 2) refill medications, 3) schedule, cancel, or change an appointment, 4) look for health or medical information, 5) search for information about HIV or sexually transmitted diseases, 6) sign up to receive email updates or alerts about health or medical issues, 7) read someone else's commentary or experience about health or medical issues on an online news group, website or blog, 8) watch an online video about health or medical issues, 9) find others who might have health concerns or medical questions similar to theirs, 10) track their weight, diet or exercise routine online, 11) track any other health indicators (such as CD_4^+ cell count and HIV viral load) online, or 12)

post comments, questions, or information about health or medical issues on a social networking site, an online discussion (such as a listserv or other online group forum), or a blog. We asked participants about their trust in health information on the Internet and prior use of the Internet to ever find a sex partner.

Mobile telephone usage—Participants were asked about mobile telephone access or ownership and smartphone ownership. Among those with access to a mobile telephone, participants were asked if they ever used their mobile telephone to: 1) send/receive text messages to/from their health care providers, 2) remind them to take their medications, 3) remind them to keep their medical appointments, and 4) keep a list of questions to ask their medical providers. These health-related uses of the mobile telephone were designed to be complementary to the Internet usage list. Frequency of breaks in mobile telephone service in the past six months and the details of mobile telephone plans (i.e., limited/unlimited data/minutes) were examined. Participants were asked about the types of applications ("apps") they used on their mobile telephone. Examples of these apps include exercise/fitness, diet/weight management, HIV/STDs prevention and treatment, medication management (i.e., alerts, tracking, etc.), and general wellness (e.g., sleep, mood, smoking cessation, etc.).

Analysis

Initially, we used descriptive statistics to characterize our study sample's demographics, self-reported HIV clinical outcomes (ARV adherence, HIV viral load, and CD_4^+ cell count), and use of mobile telephones and the Internet. The HCE variable was created by summing responses to questions regarding Internet use for sending/receiving emails to/from health care providers, refilling medications online, and scheduling, canceling, or changing an appointment online. Next, using bivariate logistic regression, we examined the demographic correlates of those who used the Internet for HCE purposes. Next, we evaluated the association between the use of the Internet for HCE purposes and ARV adherence (excellent versus less than excellent) and HIV viral load (detectable versus undetectable) in two logistic regression models (one per outcome). Lastly, we conducted multivariable logistic regressions to examine these associations while controlling for any demographic variable which had a p-value< 0.25 in its association with ARV adherence or HIV viral load. We implemented backward elimination until all remaining variables had a p-value< 0.05 (Hosmer & Lemeshow, 2000). We used Stata version 13.1 (StatCorp LP, College Station, TX) for our analyses.

Results

Table 1 summarizes demographic information for our survey respondents (N= 1,494), who were mainly male, White, and self-identified as homosexual/gay. Approximately 67% of participants reported excellent ARV adherence in the past 30 days, 85% reported an undetectable HIV viral load, and 43% reported a CD_4^+ cell count of 500–999 cells/mm^3.

The usage of mobile telephones and the Internet are summarized in Tables 2 and 3. A large majority of participants (94.9%) accessed the Internet on a daily or nearly daily basis and reported a mean 5.2 hours per day spent on the Internet. Approximately 55% of participants used the Internet for HCE purposes, with the majority sending/receiving emails to/from their

health care providers. Approximately 72% of participants owned a smartphone and few (9.2%) had any breaks in service in the past six months. Approximately 17% used the mobile telephone as a reminder device and medication management mobile apps were used by 5.4% of participants.

Despite lack of difference among racial/ethnic groups in their access to the Internet or frequency in use (all p-values> 0.17), in bivariate analyses, African-Americans and Latinos had a statistically significant lower odds of using the Internet for HCE purposes compared to White participants (African-American odds ratio [OR]= 0.63, 95% confidence interval [CI]= 0.42–0.94, p= 0.02; Latino OR= 0.67, 95% CI= 0.47–0.94, p= 0.02; other race OR= 0.75, 95% CI= 0.48–1.17, p= 0.20; overall p= 0.02). Additionally, perceived financial stability (moderate stability OR= 0.58, 95% CI= 0.45–0.74, p< 0.001; low stability OR= 0.52, 95% CI= 0.36–0.74, p< 0.001; overall p< 0.0001, compared to high stability), education ("any college experience" OR= 1.60, 95% CI=1.23–2.07, p< 0.001; "higher than college degree" OR= 2.66, 95% CI=1.88–3.76, p< 0.001; overall p< 0.0001, compared to "high school degree or less"), and history of incarceration (OR= 0.53, 95% CI= 0.40–0.70, p< 0.001) were associated with a lower odds of using the Internet for HCE purposes.

Use of the Internet for HCE purposes was associated with higher odds of reporting excellent ARV adherence (OR= 1.49, 95% CI= 1.17–1.91, p= 0.001) and undetectable HIV viral load (OR= 1.52, 95% CI= 1.11–2.09, p= 0.009). In the multivariable logistic regression for the self-reported adherence outcome, reporting excellent adherence was correlated with higher odds of Internet use for HCE purposes (OR= 1.31, p= 0.04), while controlling for age (OR= 1.02, p= 0.01), sex at birth (female OR= 0.39, p= 0.001), education ("any college experience" OR= 1.17, p= 0.29; "higher than college degree" OR= 2.02, p= 0.001; overall p= 0.003, compared to "higher school education or less"), history of homelessness or living in a shelter (OR= 0.66, p= 0.01), and history of incarceration (OR= 0.72, p= 0.04). In this model, race/ethnicity, sexual identity, perceived financial stability, and school and work status were not statistically significant and were eliminated from the model. In the multivariable regression analysis for the self-reported virologic outcome, reporting an undetectable HIV viral load was significantly associated with use of the Internet for HCE purposes (OR= 1.49, p= 0.02), while controlling for age (OR= 1.04, p< 0.001) and race/ethnicity (African-American OR= 0.63, p= 0.08; Latino OR= 1.88, p= 0.03; other race OR= 0.92, p= 0.78; overall p= 0.03, compared to White). In this model, all demographic variables except age and race/ethnicity were not statistically significant and were eliminated from the model.

Discussion

Through our survey of HIV-positive users of online social media, we showed that using the Internet for HCE purposes (i.e., to email health care providers, refill medications online, and make medical appointments online) was associated with better self-reported virologic and ARV adherence outcomes, even after controlling for other potential confounders. Despite lack of difference in access or frequency in use, there are racial/ethnic, educational, and economic disparities in the use of the Internet for HCE purposes, such that African Americans and Latinos, those with lower perceived financial stability, lower education, and

any history of incarceration were less likely to report using the Internet for these purposes. Given the favorable association between the use of the Internet for HCE purposes and self-reported HIV clinical outcomes, it is important to further examine these disparities and study methods of diminishing the gap in the use of technology to improve treatment outcomes and engagement in care.

A large proportion of participants owned a smartphone, subscribed to mobile telephone plans with unlimited data and minutes, and spent a substantial amount of time on the Internet. Therefore, interventions that use the participant's own smartphones or require the use of online programs are likely to be feasible in terms of capability for regular use. Despite the ubiquity of text messaging (Lenhart, 2010), participants did not commonly use this method to contact their health care providers. This mode of communication can potentially be an effective way of improving HIV clinical outcomes and engaging patients in their own care (Finitsis, Pellowski, & Johnson, 2014; Horvath, Azman, Kennedy, & Rutherford, 2012; Mbuagbaw et al., 2013). Therefore, future studies should examine successful clinic protocols and cost-effective methods of implementing text messaging in clinical care. Additionally, future research should explore opportunities to leverage text messaging technology while being mindful of potentials risks associated with loss of privacy and confidentiality inherent in those approaches. Lastly, given that few individuals in our study reported the use of medication management apps, it is important to examine such currently available apps in order to improve their use in research and clinical practice.

Other noteworthy results included the high level of trust in information found on the Internet and the large percentage of participants who had used the Internet to find sex partners in the past. To minimize propagation of inaccurate or incomplete information, we believe that it may be helpful for clinicians to provide patients with reputable websites where they can find up to date information about HIV care. Additionally, there is extensive research on the use of the Internet to meet sex partners and increased risk behavior, especially among men who have sex with other men (Chiasson et al., 2007; Grov, 2006; Liau, Millett, & Marks, 2006). Therefore, clinicians may consider asking patients about finding sex partners on the Internet, informing patients of the risks in trusting information provided by potential partners about their HIV/STD status, and offering further counseling on safer sex practices in this regard.

Our study provides valuable information concerning the use of mobile telephones and the Internet in HIV-positive users of online social media and the proportional relationship between using the Internet for HCE purposes and self-reported HIV clinical outcomes. However, this study has several limitations. We used a cross-sectional study design with which causality cannot be established and results may be confounded by other unmeasured variables such as participants' personality traits and level of proactivity and vigilance in health care. Therefore, future research should examine the impact of an intervention to promote Internet use for HCE purposes on objectively assessed HIV clinical outcomes. Given that we sampled users of online social media, our results may not be generalizable to the general HIV-positive population living in the US. However, the advantage of Internet-based surveys is the ability to access wide geographic regions and potentially gather data on hidden populations who may be concerned about revealing their identities due to perceived HIV-related stigma (Marcus, Schmidt, Hamouda, & Bochow, 2009). Other limitations

include the possibility of duplicate or false responses; however, given that we provided non-monetary incentives and the survey automatically disqualified duplicate IP addresses, we believe that the chance of these occurrences are low. Lastly, a disadvantage of self-reported data is that respondents tend to over-estimate adherence due to social desirability bias and/or self-denial. However, we used a previously validated approach to ask participants about viral suppression (Kalichman et al., 2000).

In conclusion, the findings generated by this study offer insight into the potential beneficial association between the uses of technology-based approaches to improving HIV clinical outcomes among PLWH. Of particular note is that although Internet access and use was comparable across racial/ethnic, educational, and socioeconomic groups, African Americans, Latinos, and those with lower education and socioeconomic status may not use the technology in ways that may optimize health, i.e., for health care engagement purposes. Future research is needed to better understand how technology can be further harnessed to optimize HIV clinical outcomes and how to foster motivation and self-efficacy for increased engagement in HIV care through the use of technology.

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Table 1

Demographics of survey participants

Demographics		**Total N= 1,494**	**Users of Internet for HCE (N=687)**	**Non-users of Internet for HCE (N=561)**
Mean age, years (SD)		45.6 (11.4)	46.8 (11.0)	45.7 (11.2)
Sex at birth, N (%)				
	Male	1,338 (89.6)	653 (95.1)	527 (93.9)
	Female	80 (5.4)	32 (4.7)	33 (5.9)
	Missing	76 (5.1)	2 (0.3)	1 (0.2)
Race, N (%)				
	White	1,013 (67.8)	522 (76.0)	382 (68.1)
	Latino	182 (12.2)	72 (10.5)	79 (14.1)
	African-American/Black	126 (8.4)	50 (7.3)	58 (10.3)
	Other	103 (6.9)	43 (6.3)	42 (7.5)
	Missing	70 (4.7)	0	0
Sexual identification, N (%)				
	Homosexual/gay	1,225 (82.0)	606 (88.2)	476 (84.9)
	Heterosexual	94 (6.3)	40 (5.8)	39 (7.0)
	Other	92 (6.2)	38 (5.5)	43 (7.7)
	Missing	83 (5.6)	3 (0.4)	3 (0.5)
Perceived financial stability, N (%)				
	Live comfortably	531 (35.5)	299 (43.5)	166 (29.6)
	Can barely get by	642 (43.0)	293 (42.7)	281 (50.1)
	Cannot get by	195 (13.0)	81 (11.8)	87 (15.5)
	Missing	126 (8.4)	14 (2.0)	27 (4.8)
Education, N (%)				
	High school degree or less	430 (28.8)	166 (24.2)	204 (36.4)
	Any college experience	725 (48.5)	361 (52.6)	278 (49.6)
	Higher than college degree	253 (16.9)	158 (23.0)	73 (13.0)
	Missing	86 (5.8)	2 (0.3)	6 (1.1)
School, N (%)				
	Full-time or part-time	176 (11.8)	86 (12.5)	52 (9.3)
	Not in school	1,238 (82.9)	601 (87.5)	504 (89.8)
	Missing	80 (5.4)	0	5 (0.9)
Work, N (%)				
	Full-time	630 (42.2)	316 (46.0)	233 (41.5)
	Part-time	194 (13.0)	93 (13.5)	69 (12.3)
	Other	549 (36.8)	268 (39.0)	233 (41.5)
	Missing	121 (8.1)	10 (1.5)	26 (4.6)

Demographics		**Total N= 1,494**	**Users of Internet for HCE (N=687)**	**Non-users of Internet for HCE (N=561)**
Ever been homeless or lived in shelter, N (%)				
	Yes	278 (18.6)	130 (18.9)	116 (20.7)
	No	1,133 (75.8)	554 (80.6)	441 (78.6)
	Missing	83 (5.6)	3 (0.4)	4 (0.7)
Ever incarcerated, N (%)				
	Yes	304 (20.4)	115 (16.7)	154 (27.5)
	No	1,113 (74.5)	570 (83.0)	405 (72.2)
	Missing	77 (5.2)	2 (0.3)	2 (0.4)
Self-reported CD_4^+ cell count, N (%)				
	Don't know	283 (18.9)	118 (17.2)	139 (24.8)
	< 200 cells/mm^3	62 (4.2)	29 (4.2)	29 (5.2)
	200–349 cells/mm^3	105 (7.0)	55 (8.0)	43 (7.7)
	350–499 cells/mm^3	161 (10.8)	102 (14.9)	55 (9.8)
	500–999 cells/mm^3	544 (36.4)	302 (44.0)	226 (40.3)
	≥ 1000 cells/mm^3	119 (8.0)	64 (9.3)	53 (9.5)
	Missing	220 (14.7)	17 (2.5)	16 (2.9)
Self-reported HIV RNA, N (%)				
	Undetectable	1,068 (71.5)	584 (85.0)	437 (77.9)
	Detectable	191 (12.8)	86 (12.5)	98 (17.5)
	Missing	235 (15.7)	17 (2.5)	26 (4.6)
Taking ARV medications, N (%)		1,383 (92.6)	651 (94.8)	519 (92.5)
	Missing	0	0	0
ARV adherence rating in past 30 days, N (%)				
	Less than excellent	409 (33.6)	192 (28.0)	200 (35.7)
	Excellent	810 (66.5)	457 (66.5)	319 (56.9)
	Missing	275 (18.4)	38 (5.5)	42 (7.5)

ARV: antiretroviral; SD: standard deviation

Table 2

Description of Internet usage among study participants

Mean number of hours per day on Internet, hours (SD)		5.2 (4.3)[a]
	Missing (%)	320 (21.4)
Frequency of Internet access in past month, N (%)		
	Daily	1,084 (72.6)
	Nearly every day	96 (6.4)
	3 or 4 times a week	29 (1.9)
	Once or twice a week	13 (0.9)
	2 or 3 times a month or less frequently	9 (0.6)
	Never	12 (0.8)
	Missing	251 (16.8)
Internet use for any health-related purposes, N (%)[a]		1,063 (85.2)
	Look for health or medical information	694 (55.6)
	Send/receive emails to/from your HCP[b]	513 (41.1)
	Search for information about HIV or STDs	511 (41.0)
	Read someone else's commentary or experience about health or medical issues	467 (37.4)
	Refill medications[b]	407 (32.6)
	Post comments, questions, or information about health or medical issues on social networking site	346 (27.7)
	Watch a video about health or medical issues	298 (23.9)
	Schedule, cancel, or change appointment[b]	295 (23.6)
	Find others who have similar health concerns	249 (20.0)
	Sign up to receive email updates or alerts about health or medical issues	211 (16.9)
	Track weight, diet, or exercise routine online	146 (11.7)
	Track CD_4^+ cell count or viral load	127 (10.2)
Internet use for HCE purposes[c], N (%)		
	Yes	687 (46.0)
	No	561 (37.6)
	Missing	246 (16.5)
Trust of health information on Internet, N (%)		
	Just about always	80 (5.4)
	Most of the time	465 (31.1)
	Some of the time	558 (37.4)
	Never	32 (2.1)
	Missing	359 (24.0)

Ever use Internet to find sex partner, N (%)		
	Yes	903 (60.4)
	No	327 (21.9)
	Missing	264 (17.7)

HCE: healthcare engagement; HCP: healthcare provider; SD: standard deviation; STDs: sexually transmitted disease

[a] From total N= 1,248 Internet users

[b] Variables summed to calculate use of Internet for HCE purposes

[c] HCE: including emailing HCP, refilling medications online, or making medical appointments online

Table 3

Description of mobile telephone usage among study participants

Have access to mobile telephone, N (%)		1,221 (96.2)
	Missing	225 (15.1)
Own mobile telephone, N (%)[a]		1,160 (91.4)
Own smartphone, N (%)[a]		907 (71.5)
Type of mobile telephone data/minute plans, N (%)[a]		
	Limited minutes and data	313 (24.7)
	Unlimited minutes and data	508 (40.0)
	Unlimited minutes and limited data	196 (15.5)
	Limited minutes and unlimited data	133 (10.5)
	Missing	119 (9.4)
Any breaks in mobile telephone service in past 6 months, N (%)[a]		115 (9.1)
	Missing	24 (1.9)
Use mobile telephone for any health-related purposes, N (%)[a]		
	Reminder to keep medical appointments	506 (39.9)
	Send/receive text messages to/from your HCP	225 (17.7)
	Reminder to take medications	218 (17.2)
	Keep a list of questions to ask HCP	169 (13.3)
Types of mobile health apps, N (%)[b]		
	Exercise, fitness	182 (20.1)
	Diet, calorie counter, weight management	117 (12.9)
	Medication management	67 (7.4)
	HIV/STD prevention, care or treatment	63 (7.0)
	Wellness	55 (6.1)

HCP: healthcare provider; STDs: sexually transmitted disease

[a] From total N= 1,269 individuals with access to mobile telephone

[b] From total N= 907 individuals who owned a smartphone