Internet Health Information Seeking Behavior and Antiretroviral Adherence in Persons Living with HIV/AIDS

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Abstract

While the Internet has the potential to educate persons living with HIV/AIDS (PLWHA), websites may contain inaccurate information and increase the risk of nonadherence with antiretroviral therapy (ART). The objectives of our study were to determine the extent to which PLWHA engage in Internet health information seeking behavior (IHISB) and to determine whether IHISB is associated with ART adherence. We conducted a survey of adult, English-speaking HIV-infected patients at four HIV outpatient clinic sites in the United States (Baltimore, Maryland; Detroit, Michigan; New York, and Portland, Oregon) between December 2004 and January 2006. We assessed IHISB by asking participants how much information they had received from the Internet since acquiring HIV. The main outcome was patient-reported ART adherence over the past three days. Data were available on IHISB for 433 patients, 334 of whom were on ART therapy. Patients had a mean age of 45 (standard error [SE] 0.45) years and were mostly male (66%), African American (58%), and had attained a high school degree (73%). Most (55%) reported no IHISB, 18% reported some, and 27% reported “a fair amount” or “a great deal.” Patients who reported higher versus lower levels of IHISB were significantly younger, had achieved a higher level of education, and had higher medication self-efficacy. In unadjusted analyses, higher IHISB was associated with ART adherence (odds ratio [OR], 2.96, 95% confidence interval [CI] 1.27–6.94). This association persisted after adjustment for age, gender, race, education, clinic site, and medication self-efficacy (adjusted odds ratio [AOR] 2.76, 95% CI 1.11–6.87). Our findings indicate that IHISB is positively associated with ART adherence even after controlling for potentially confounding variables. Future studies should investigate the ways in which Internet health information may promote medication adherence among PLWHA.

Introduction

THE INTERNET PROMISES to change HIV care. Internet-based health interventions have been proven to be successful in conditions such as diabetes, heart failure, obesity, and substance abuse, among others.^{1–7} In addition to medical applications delivered via the Internet, the Internet is becoming a major source of consumer health information. Surveys indicate that 64% of all Internet users in the United States engage in Internet health information seeking behavior

(IHISB) and that 4% of all Internet searches are health related.^{8,9} Studies have shown that persons living with HIV/AIDS (PLWHA) and their caregivers use the Internet to seek information about HIV.^{10,11} Internet HIV support groups have been shown to provide both emotional and informational support for PLWHA.¹² However, there are also studies suggesting Internet use may be associated with increased high-risk sexual behavior.^{13,14}

The vulnerability of some groups to inaccurate information is a potential threat to optimal antiretroviral therapy (ART)

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adherence. One study found that PLWHA—particularly those with lower incomes, lower educational attainment, poorer reading comprehension, and lower literacy levels—assign credibility to websites that medical professionals do not.¹⁵ Younger age is associated with both lower IHISB and lower adherence.^{16,17} Another study showed that PLWHA who use the Internet are more likely to believe that HIV treatments “do more harm than good” and that HIV does not cause AIDS.¹⁸ Therefore, websites have the potential to educate patients, but they may also contain inaccurate information and negatively impact adherence. Furthermore, if IHISB is beneficial, there is concern that disparities in Internet use could widen disparities in health outcomes, since low-income PLWHA are less likely to use the Internet.¹⁹ On the other hand, one study found that training patients in a community center improves IHISB both in frequency of use and in health information evaluation skills.²⁰ Thus, if IHISB is proven to be beneficial, it may be an important source of information and support for PLWHA.

Several studies found mixed results with respect to the association of IHISB with medication adherence. One study found that persons who had used the Internet were more likely to respond correctly to HIV knowledge questions, but were not more likely to report ART adherence, while another study found that Internet health information seekers reported higher ART adherence.^{21,22} Given the potential for Web-based information to both positively and negatively affect PLWHA, and the lack of empirical clarity about the influence of IHISB on ART adherence, we sought to determine the association between IHISB and ART adherence.

Methods

Study design

This was a cross-sectional study using baseline data from the Enhancing Communication and HIV Outcomes (ECHO) study, a multisite study examining potential sources of disparities in HIV care, conducted between December 2004 and January 2006. The design of the ECHO study has been previously published.^{23–26} Briefly, study subjects were HIV pro-

viders and their patients at four HIV outpatient clinic sites in the United States (Baltimore, Maryland; Detroit, Michigan; New York, and Portland, Oregon). Patients were eligible for inclusion if they were HIV-infected, 18 years or older, and English-speaking. Research assistants enrolled approximately 10 patients per participating provider from clinic waiting rooms. Patients gave informed consent, and, following the medical encounter, research assistants administered a 1-h interview that assessed demographic, social, and behavioral characteristics, including IHISB, ART adherence, health beliefs, and medication self-efficacy. The study received Institutional Review Board (IRB) approval from each of the four sites.

Measures

We measured IHISB, the independent variable in this study, using the following question: “Now I’m going to read you a list of sources that people sometimes use for information about HIV/AIDS diagnosis and treatment. For each source, please tell me how much information you have received since you first tested HIV-positive: the Internet?” (Examples of other sources listed were main HIV doctor, AIDS Service Organizations and personal acquaintances who have HIV/AIDS.)²⁷ Response options were: “none,” “some,” “fair amount,” and “great deal.” We examined the data distribution of frequency of IHISB. Based on a skewed distribution of the data, we combined the responses of “fair amount” and “great deal” into a single category.

Our outcome variable was ART adherence, restricted to those patients on ART. Patients listed each ART medication by name and regimen, and reported how many doses they had missed in the past 3 days.²⁸ We created a dichotomous measure of adherence that reflected whether or not the patient reported missing any dose within the past 3 days.²⁸

We collected information on age, gender, race/ethnicity, and educational attainment (highest level attained from the following choices: less than high school, high school degree, some college, college degree, or beyond college degree; Table 1) To measure patient race/ethnicity, we asked patients to

TABLE 1. STUDY SAMPLE

Patient characteristics	Internet health information seeking behavior			
	All, n = 433	None, n = 236	Some, n = 79	Fair amount/great deal, n = 118
Age (yrs)—mean (SE)	45 (0.45)	47 (0.59)	44 (1.2)	44 (0.86) ^a
Gender—n (%)				
Male	286 (66%)	144 (61%)	58 (73%)	84 (71%)
Female	147 (34%)	91 (39%)	21 (27%)	34 (29%)
Race—n (%)				
White	106 (24%)	51 (22%)	20 (25%)	35 (30%)
African American	254 (58%)	144 (61%)	47 (59%)	62 (53%)
Latino	62 (14%)	36 (15%)	10 (13%)	16 (14%)
Other	15 (3%)	5 (2%)	2 (3%)	5 (4%)
≥ High school degree—n (%)	317 (73%)	146 (62%)	70 (51%) ^b	98 (83%) ^b
High medication self-efficacy—n (%)	137 (32%)	63 (27%)	21 (27%)	53 (43%)
Positive ART health beliefs—n (%)	196 (46%)	115 (49%)	28 (37%)	53 (46%)
On ART—n (%)	334 (79%)	185 (78%)	59 (75%)	90 (76%)

^aWhen compared to “None” IHISB category, after controlling for site and accounting for clustering by provider, $p < 0.01$.

^bWhen compared to “None” IHISB category, after controlling for site and accounting for clustering by provider, $p < 0.001$. IHISB, health information seeking behavior; SE, standard error; ART, antiretroviral therapy.

identify: (1) whether they were Hispanic/Latino, or not and (2) to which racial group(s) they belonged. We then asked them to identify—from a list of options including white/Caucasian, black/African American, Hispanic/Latino, American Indian/Alaska Native, Asian, Pacific Islander/Native Hawaiian, or Other—a single, main racial/ethnic group with which they identified themselves. Our variables for patient race were derived from this question.

To evaluate the possibility that any observed association between IHISB and ART adherence was explained by other patient characteristics that might be associated with both IHISB and adherence, we examined additional variables as potential confounders: beliefs about ART and self-efficacy in managing HIV medication regimens. We constructed a measure of ART-related health beliefs using five items addressing the respondent's beliefs about ART [(1) HIV drugs will improve my health; (2) HIV drugs will help me have fewer symptoms; (3) HIV drugs will keep me alive longer; (4) I will get sick if I don't take my HIV drugs; (5) It is important that I take all doses of my HIV medicine]. Because the data distribution was heavily skewed toward positive responses we dichotomized responses between those who responded "strongly agree" to all five statements and those who did not. For medication self-efficacy, we used a validated 6-item self-efficacy scale regarding management of HIV medications.²⁹ Scores on the medication self-efficacy scale ranged from 1 to 10, with higher scores indicating greater medication self-efficacy. Because the distribution was heavily skewed toward the highest scores, we dichotomized responses between those who scored 10 and those who did not.

Statistical analysis

We used bivariate multinomial logistic regression to test the association of socio-demographic and behavioral characteristics with IHISB. We then used logistic regression to test the association of IHISB with ART adherence in both unadjusted and adjusted analyses. We included potentially confounding sociodemographic and behavioral covariates in multivariate models if the covariate was significant at a *p* value of 0.10 in bivariate analysis or conceptually related to either IHISB or ART adherence. All reported analyses controlled for site as a fixed effect and accounted for clustering by provider using generalized estimating equations to produce standard error estimates.

Results

Study sample

Of 617 eligible patients, 435 (73%) agreed to participate and completed all study procedures. The most common reasons for patient refusal were not enough time to complete the interview (*n*=106), not feeling well (*n*=22), and not being interested (*n*=13). Data on IHISB were available for 433 patients.

Study sample characteristics and frequency of IHISB are shown in Table 1.

Respondents had a mean age of 45 years. Most of the respondents were male (66%) and had a high school degree (73%). Fifty-eight percent were African American and 24% were non-Hispanic white. More than half of respondents (55%) reported no IHISB, while 18% reported some IHISB and 27% reported "a fair amount" or "a great deal" of IHISB. Compared to those with no IHISB, those reporting a fair amount/great deal of IHISB were more likely to have a high school education (*p*=0.001). Younger patient age was also associated with IHISB; on average, those reporting a fair amount/great deal IHISB were 3 years younger (*p*=0.004).

Higher medication self-efficacy was associated with a higher likelihood of IHISB (*p*=0.000) in bivariate analyses. There was no significant association between IHISB and ART-related health beliefs.

IHISB Adherence

Associations between IHISB and ART adherence are shown in Table 2. Those who reported a fair amount/great deal of IHISB had a nearly threefold greater odds of adherence than those who reported none (OR 2.91, 95% CI 1.22–6.95). This association persisted after adjustment for age, gender, race, and education (AOR 3.13, 95% CI 1.31–7.45). After additional adjustment for medication self-efficacy, IHISB remained significantly associated with ART adherence (AOR 2.76, 95% CI 1.11–6.87).

Discussion

In this sample of patients engaged in HIV care, nearly half reported IHISB. Those who accessed the Internet for health information a "fair amount" or a "great deal" were more

TABLE 2. ASSOCIATION OF INTERNET HEALTH INFORMATION SEEKING BEHAVIOR WITH ART ADHERENCE

IHISB	Adherent ^a (%)	Unadjusted OR ^b (95% CI) n=334	Adjusted OR ^c (95% CI) n=333	Adjusted OR ^d (95% CI) n=333
None	148 (80%)	Reference	Reference	Reference
Some	44 (75%)	0.73 (0.30–1.78)	0.71 (0.27–1.88)	0.74 (0.26–2.13)
Fair amount/great deal	83 (92%)	2.91 (1.22–6.95) ^e	3.13 (1.31–7.45) ^f	2.76 (1.11–6.87) ^e

^a Among patients on ART.

^b Adjusted for clinic site and accounting for clustering by provider.

^c Adjusted for age, gender, race, education, clinic site, and accounting for clustering by provider.

^d Adjusted for medication self-efficacy, age, gender, race, education, clinic site, and accounting for clustering by provider.

^e *p*<0.05.

^f *p*<0.01.

OR, odds ratio; CI, confidence interval; ART, antiretroviral therapy; IHISB, Internet health information seeking behavior.

likely than nonusers to report that they had not missed any ART doses in the 3 days preceding their routine appointment. IHISB was associated with ART adherence independent of other factors, such as educational attainment, age, and race. To address the possibility that IHISB did not directly influence adherence but rather served as a marker of greater patient activation, or greater interest in and enthusiasm for ART, we evaluated measures of self-efficacy and ART-related beliefs as potential confounders. We found that ART-related beliefs were not associated with IHISB, and that medication self-efficacy, although associated with IHISB, did not explain the relationship between IHISB and adherence. These findings suggest that IHISB is not merely serving as a proxy for these other factors but is potentially influencing adherence via other mechanisms.

There are several possible explanations for an association between IHISB and adherence. It may be causal or due to unmeasured confounding factors. Both possibilities are worth consideration. The concept that IHISB could increase patient adherence is supported by qualitative studies that explore how PLWHA use the Internet for social support, information, and to inform treatment decisions.^{10,30,31} The Internet may provide tools and methods to help with complicated medication regimens. For example, the online social networking site Patient-sLikeMe goes well beyond a message board for sharing experiences; it includes a drug database to help patients accurately record the treatments they are taking and a visual display of their treatment history.³² PLWHA who use the site report an impact on the decision to begin ART and better understanding of the consequences of taking a "drug holiday."³³

On the other hand, ours was a cross-sectional study, so there may have been unmeasured or residual confounding of the relationship between IHISB and adherence. The slight reduction in the IHISB-adherence association after adjusting for self-efficacy suggests that this finding may be partly explained by greater self-efficacy among patients reporting IHISB. General motivation and self-efficacy may make people more likely to seek information, from the Internet or otherwise, and also to be adherent to treatment regimens. Alternatively, the reduction in the point estimate could reflect mediation of the IHISB-adherence association by self-efficacy. That is, IHISB may lead to higher medication self-efficacy and, in turn, to greater adherence. Whether the association is causal or not, IHISB appears to be an important marker for greater adherence among PLWHA, even after adjusting for factors like education, clinic site, and medication self-efficacy.

Differences between our findings and those of prior studies that explored similar questions merit further discussion. In one study, Kalichman et al.²² found an association between IHISB and health beliefs, but not between IHISB and adherence. There are a number of possible reasons that our results were different. First, the instrument we used to measure ART-related health beliefs consisted of self-reflective and general questions (e.g., "It is important that I take all doses of my HIV medicine."), while Kalichman and colleagues used factual and specific questions (e.g., "Is AZT a protease inhibitor?"). Second, the patients in our study were slightly older and more racially diverse. Third, participants in the previous study were recruited from a variety of settings including social service agencies, AIDS service organizations, community residences for PLWHA, health care providers, and infectious disease clinics, whereas we recruited only from HIV clinics.

Further research clarifying whether differing associations of IHISB with adherence across studies relates to different patient populations, settings, time frames, or other contextual factors may inform how the Internet might be most effectively used to promote adherence and improve outcomes among PLWHA.

There are several potential limitations of this study. We used a single, self-reported measure to assess ART adherence. Although this measure has been previously validated, additional studies should consider evaluating other measures of adherence, such as pharmacy records, Medication Event Monitoring System caps, and virologic outcomes.²⁸ The cross-sectional design did not allow us to assess how IHISB and ART adherence may change over time. Although our study sample included considerable racial/ethnic diversity and four geographic regions within the United States, it may not be generalizable to PLWHA in rural areas of the United States, those using non-English websites around the world, and those not engaged in medical care. Finally, the question used to measure IHISB may have been interpreted as a question about general Internet use rather than health information seeking behavior. However, the context of the question (asking how much information about HIV diagnosis and treatment was obtained from the respondent's main HIV doctor, AIDS service organizations, and other PLWHA) makes this less likely.

Our findings indicate that IHISB is associated with self-reported ART adherence. This association may reflect an actual benefit of Internet health information, or that IHISB reflects greater personal engagement in managing one's illness, which in turn predicts greater ART adherence. Given the prevalence of IHISB among PLWHA, development of accurate, patient-centered HIV health education websites may prove to be an important tool for improving health outcomes among PLWHA. Future research should aim to empower PLWHA to find relevant and trustworthy information on the Internet and determine whether these efforts can improve ART adherence and other clinical outcomes.

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