



## Utilization of social media and web forums by HIV patients - A cross-sectional study on adherence and reported anxiety level

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### ABSTRACT

Due to the high stigma surrounding the Human Immunodeficiency Virus (HIV), people living with HIV (PLWH) often reach out peers over the Internet for emotional and social support. The purpose of this study was to assess the characteristics of PLWH who use HIV internet forums.

A cross-sectional study was conducted using an online survey investigating demographic characteristics of PLWH, level of satisfaction of the HIV Internet forums, time living with HIV, forum users' anxiety levels, self-reported adherence to antiretroviral treatment (ART), and reasons for missing pills ( $n = 222$ ).

Logistic regression models were constructed to compare the use of general HIV forums with social networking sites, general HIV forums with group emails, and social networking sites with group emails.

Two hundred and twenty-two patients responded to the survey. Social networking sites were used by recently diagnosed PLWH who were on antiretroviral treatment (ART) > 1 year. Young patients ( $\leq 40$  years) and those diagnosed < 1 year before, tended to use social networking sites, while older patients (> 40 years), those diagnosed > 5 years, and from low- and middle-income countries, were more likely to use emailing lists. There was no significant difference between PLWH's adherence to treatment and anxiety levels and the usage of different Internet forums.

PLWH's Internet resource choice varied depending on the availability of Internet and illness duration. Different segments of the population could be reached via social networking sites versus group emails to provide HIV information.

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### 1. Introduction

Globally, over 33 million people are living with the Human Immunodeficiency Virus (HIV) (WHO, 2010). People living with HIV (PLWH) usually seek the emotional support they need through family, friends, and community-based organizations. However, due to the high degree of stigmatization associated with HIV, patients may be switching to Internet resources (Reeves, 2001). Internet resources have proven to be able to inform patients of the latest HIV developments and provide them with emotional support while protecting their anonymity (Reeves, 2001). Additionally, the Internet provides a wide range of up-to-date HIV-related information, which is easy to access and navigate

(Courtenay-Quirk et al., 2010; Desouza and Jyoti Dutta, 2008; Kalichman et al., 2005). Through the Internet, PLWH use emailing lists, social networking sites, and general forums to communicate with other patients (Boards, 2010). In 20% of cases, patients also tend to offer advice and share their own experiences. For periods as long as years, PLWH may communicate with recently diagnosed individuals about their experiences and treatment and provide suggestions for better adherence (Boards, 2010). This comradeship between PLWH assists in building a positive attitude towards HIV (Kalichman et al., 2005) and helps patients to better cope with their psychological health (Griffiths et al., 2009).

There have been a few studies on how Internet technologies influence PLWH (Houston et al., 2002; Mo and Coulson, 2008). However, these studies typically do not include the latest Internet technologies and focuses on only on online support groups' resource (Bar-Lev, 2008; Desouza and Jyoti Dutta, 2008; Houston et al., 2002; Mo and Coulson, 2008).

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Our study analyzes the characteristics of PLWH using three different types of Internet technologies: forums, social networking sites (such as Facebook, Orkut and MySpace), and group emails of Yahoo and Google. These internet technologies have been selected because they allow peer to peer communication and do not limit participants as a result of geographical barriers. Although there is a digital divide, PLWH coming from low- and middle-income countries are catching up to their peers in high-income countries. If a person living with HIV reaches out through the Internet, it suggests they may have a lack of emotional help or need to gather extra information (Kalichman et al., 2005; Ybarra et al., 2006). By analyzing the characteristics of PLWH seeking Internet support, we can compare differences in users' characteristics and explore whether they are associated with particular factors.

In this study we attempt to understand the characteristics of our sample of PLWH in terms of their treatment adherence, anxiety levels, and type of internet support used. We hypothesize that different characteristics may help determine the different choices that PLWH have when using internet technologies. By differentiating PLWH based on their choices of Internet resources, we aim to understand whether specific groups of people tend to seek HIV information through the Internet and if these individuals are isolated from traditional means of support (e.g. family, friends, and community based organization). We also measured anxiety levels and treatment adherence. Self-reported anxiety is an indicator of the patient's psychological health (Pence et al., 2006; Sahay et al., 2007) and self-reported adherence to antiretroviral treatment (ART) has been demonstrated to be an accurate indicator of the patient's clinical/physical health (Simoni et al., 2014).

## 2. Methods

This study was conducted using a 14-item questionnaire hosted on the survey website <http://www.surveymog.com> (Supplementary Appendix 1). A total of 222 participants answered questions about their demographic characteristics, level of satisfaction with the HIV Internet forums, duration of living with HIV, and their anxiety level during the last month. Screening and assessment of generalized anxiety disorder was done using the Anxiety Disorder (GAD-7) questionnaire (Spitzer et al., 2006). Levels of adherence to ART, as well as reasons for missing pills, were measured using the AIDS Clinical Trials Group (ACTG) adherence questionnaire (Chesney et al., 2000).

### 2.1. Ethics

This study was approved by the Regional Ethics Committee in Stockholm, Sweden (protocol number 2010/5:4). An electronic consent was obtained from the participants before proceeding to the survey. No personal information was collected by the research team, including the Internet Protocol (IP) address. Inclusion criteria for participation in the study included being HIV positive, of 18 years age or older, and under ART.

### 2.2. Selection criteria for HIV forums

A complete list of all HIV forums, social networking sites, and emailing lists that were contacted for this study, including the number of registered users, is provided in Supplementary Appendix 2. General HIV forums were identified by inserting the term "HIV forum" in the Google search engine. From 569 million results, 18 were selected. Criteria for inclusion in the study included the forum having > 1000 discussion topics, a minimum of 10 messages per week, and support for patient-based discussion forums.

Emailing lists were identified by researching the term "groups" in the Google search engine, which resulted in 8.5 million results. Criteria for study inclusion included having > 10 million users, 1000 discussion topics, and support for multilingual forums. Within Yahoo and Google search engines, we furthermore researched HIV related discussion forums using the term "HIV AIDS". From these results we selected only

discussion forums that had >500 registered members and at least 10 messages per month. After screening we included five Google groups and 7 Yahoo ones.

Social networking sites were identified by searching for the term "social networking". From the results, three social networking sites Facebook, Orkut, and MySpace were selected. Criteria for inclusion in the study included having > 10 million users, 1000 discussion topics, and support for multilingual forums. Within these three social networking sites we further searched for HIV-related discussion forums by using the keywords 'HIV' or 'AIDS' in their customized search engines. From these results we selected discussion forums that had >500 registered members and included 21 Facebook forums, 16 Orkut forums and five MySpace forums. Most of the social networking sites were administered by HIV care staff or health care organizations (Supplementary Appendix 2).

A flow-chart illustrating the forums selection process can be found in Supplementary Appendix 3. We concluded the search after selecting 72 HIV-related discussion forums, 7 comprising of 18 general forums, five Google groups, 7 Yahoo groups, 21 Facebook groups, 16 Orkut forums, and five MySpace forums. Eight, out of the 72 HIV related internet forums, did not have contact information, so we sent an email message for the administrators of the remaining 64 internet forums, requesting to post an invitation letter and link for the survey. Twenty-eight (44%) websites' administrators accepted the request and seven (11%) refused. For the remaining 29 (45%) HIV forums, we sent them a reminder email message after one week. We did not follow up with the moderators who did not respond to the reminder message. We subsequently posted a message explaining the study aims, contact details of the researchers, ethical considerations and a link to the survey. This invitation was renewed every week over a four-week period to reach intermittent and recent users. Data collection was carried out from April 16th to May 14th. A total of 455 participants opened the survey, out of which 259 (57%) dropped out. Out of the 226 participants who completed the survey, 4 did not fill in the consent page for participation in this study but still completed the survey. The 222 complete responses were used for analysis.

### 2.3. Data analysis

We analyzed gender, age, education, country of residence, time being HIV positive, duration of using HIV forums, level of satisfaction using HIV forums, source of social support, duration of ART, self-reported history of missing pills, self-rated anxiety levels, and use of different types of internet forums. Self-rated anxiety levels were categorized from the GAD-7 questionnaire into low (score 0–14) or high (score 15–21). We compared the use of general HIV forums to social networking sites, general HIV forums to email groups, and social networking sites to email groups.

In the analysis, these variables were first examined for any differences among the three different HIV forums using Chi-square tests with unadjusted odds ratios (ORs) and 95% confidence intervals (CI). For variables with less than five observations, Fisher's exact test was conducted. Subsequently, several logistic regression models were used to remove confounding factors and analyze associations between the different variables. Only the variables with a p-value < 0.10 were included in the multivariate logistic regression models, adjusted for gender and age. Saturated models were developed using stepwise regression and included only the variables which were statistically significant (p < 0.05) in the final step. All data analysis was carried out with the statistical software, PASW Statistics 18 (SPSS Inc.).

## 3. Results

### 3.1. Participant characteristics (Table 1)

Of the 222 participants, the majority (72%) were men. Half of the participants were between the ages 18 and 40 and only 2% were

above 61 years of age. Most participants had a college education (79%) and used social networking sites (42%) or group emails (37%). Study participants were from 50 different countries of which 60% were low- and middle-income countries.

About half (49%) of our study participants had been diagnosed as HIV positive for >5 years and half of them preferred to use group emails, compared to general HIV forums and social networking sites. However, recently diagnosed subjects preferred to use social networking sites (42%) compared to group emails and general HIV forums. Ninety percent of study participants were on ART. Generally, PLWH using all types of HIV forums had a high adherence to ART: 35% did not miss any pills and 42% missed only 1–3 pills during the last month. Overall, 78% of the participants had low anxiety levels.

### 3.2. Participant's usage of all HIV forums (Table 1)

Most PLWH (84%) had used one of the HIV forums for more than a month. Patients using any HIV forums for less than a month tended to use social networking sites while patients using any HIV forums for more than a year tended to use emailing lists. Sixty percent of participants were highly satisfied with usage of the HIV forums. PLWH felt more

comfortable talking about their HIV status with their peers from online forums (93%) or to their doctors (87%) compared to family, friends, or colleagues. Sixty-five percent of participants declared that they missed their ART medication in the last month. Reasons for missing pills included fearing being noticed taking ART pills (N = 169, 83%), wanting to avoid side effects (N = 172, 83%), feeling like the drug was toxic/harmful (N = 173, 85%), being away from home (N = 150, 74%), being distracted by other chores (N = 152, 75%), having a change in their daily lives (N = 159, 78%), or simply forgetting them (N = 160, 79%).

### 3.3. HIV forums and social networking sites (Table 2)

We found an association between country of origin and type of Internet recourses used by HIV patients to obtain the emotional support needed. Compared to general HIV forums, social networking sites were more likely to be used by PLWH from low-income countries (unadjusted OR = 3.5, 95% CI = 1.5–8.3), and by PLWH from countries with low Internet penetrance (The World Bank, 2010) (unadjusted OR = 2.0, 95% CI = 1.2–3.4). PLWH who were on ART for less than a year preferred to use general forums, compared to social networking sites, whereas PLWH who were on ART for 1–5 years, preferred to use social

**Table 1**

Participant characteristics and usage of HIV forums (n = 222).

Variables	Overall N (%) Total N = 222	General forums N (%) Total N = 50	Social networking sites N (%) Total N = 71	Group emails N (%) Total N = 101
Gender				
Men	160 (72)	35 (70)	43 (61)	82 (81)
Women	62 (28)	15 (30)	28 (39)	19 (19)
Age				
18–30	36 (16)	7 (14)	18 (25)	11 (11)
31–40	53 (24)	11 (22)	27 (38)	15 (15)
41–50	40 (18)	5 (10)	17 (24)	18 (18)
51–60	14 (6)	5 (10)	4 (6)	5 (5)
61–70	3 (1)	1 (2)	0 (0)	2 (2)
Education				
Elementary school	3 (1)	2 (4)	1 (1)	0 (0)
Secondary school	27 (12)	4 (8)	14 (20)	9 (9)
College	117 (53)	24 (48)	50 (70)	43 (43)
Region				
High income countries	118 (53)	35 (70)	32 (45)	54 (53)
Middle and low income countries	104 (47)	12 (24)	36 (51)	55 (54)
Time since diagnosis				
<1 year	20 (9)	6 (12)	8 (11)	6 (6)
1–5 years	93 (42)	14 (28)	38 (54)	41 (41)
>5 years	108 (49)	30 (60)	24 (34)	54 (53)
Duration of using forums				
<1 month	37 (17)	6 (12)	17 (24)	14 (14)
1–12 months	95 (43)	19 (38)	39 (55)	37 (37)
>12 months	82 (37)	25 (50)	11 (15)	46 (46)
Frequency of using forums				
Everyday	103 (46)	33 (66)	27 (38)	38 (38)
Once a week	94 (42)	14 (28)	37 (52)	42 (42)
Once a month	27 (12)	3 (6)	5 (7)	19 (19)
Time on ART				
Not on ART	21 (10)	2 (4)	9 (13)	10 (10)
<1 year	53 (24)	16 (32)	17 (24)	20 (20)
1–5 years	79 (36)	14 (28)	33 (46)	32 (32)
>5 years	66 (30)	17 (34)	11 (15)	38 (38)
Disclosure of HIV status				
No one	11 (5)	5 (10)	2 (3)	4 (4)
Online forums	188 (85)	46 (92)	58 (82)	84 (83)
Family	132 (59)	32 (64)	40 (56)	60 (59)
Friends	144 (65)	38 (76)	46 (65)	60 (59)
Doctors	177 (80)	39 (78)	57 (80)	81 (80)
Partner/spouse	78 (35)	22 (44)	17 (24)	24 (24)
Workmate	43 (19)	12 (24)	7 (10)	24 (24)
Missed pills in the last month				
Did not miss any pills	71 (32)	18 (36)	10 (14)	37 (37)
1–3 times	86 (39)	21 (42)	31 (44)	36 (36)
4–9 times	41 (18)	6 (12)	17 (24)	18 (18)
>10 times	5 (2)	2 (4)	0 (0)	3 (3)

**Table 2**  
Use of different internet resources compared to each other.

	Model 1 <sup>a</sup>		Model 2 <sup>a</sup>		Model 3 <sup>a</sup>	
	Unadj. OR (95% CI)	Adj. <sup>b</sup> OR (95% CI)	Unadj. OR (95% CI)	Adj. <sup>b</sup> OR (95% CI)	Unadj. OR (95% CI)	Adj. <sup>b</sup> OR (95% CI)
Gender						
Women	1		1		1	
Men	0.7 (0.4–1.2)		1.4 (0.9–2.3)		1.7 (1.2–2.4)	
Age						
20–30	1		1		1	
31–40	0.9 (0.4–2.1)		0.9 (0.4–1.9)		0.1 (0.1–0.4)	
41–50	1.2 (0.4–3.3)		1.7 (0.6–4.7)		1.2 (0.8–1.9)	
51–60	0.5 (0.2–1.1)		0.7 (0.3–1.8)		1.3 (0.6–3.0)	
61–70	0.2 (0.1–0.5)		1.1 (0.2–6.3)		0.3 (0.2–0.6)	
Education						
Elementary school	1		1		1	
Secondary school	3.0 (0.9–9.7)		3.2 (1.4–7.3)		1.6 (1.1–2.2)	
College	2.0 (0.8–4.8)		2.7 (2.0–3.8)		1.8 (1.5–2.2)	
Region						
High Income countries	1		1		1	
Middle and low income countries	3.5 (1.5–8.3)		1.8 (1.1–3.1)		0.8 (0.5–1.1)	
Internet users in the region						
>22%	1		1		1	
≤22%	2.0 (1.2–3.4)		2.0 (1.1–3.4)		0.8 (0.6–1.2)	
Time since diagnosis						
<1 year	1		1		1	
1–5 years	1.5 (0.8–3.3)		1.9 (1.0–4.0)		1.1 (0.7–1.9)	
>5 years	0.7 (0.4–1.4)		1.4 (0.7–2.6)		1.8 (1.0–3.2)	
Duration of using forum						
<1 month	1		1		1	
1–12 months	0.5 (0.2–1.1)		0.7 (0.3–1.6)		1.4 (1.0–2.0)	
>12 months	0.3 (0.1–0.7)		0.7 (0.3–1.3)		2.5 (1.4–4.5)	3.8 (1.3–11.8)
Frequency of forum use						
Frequent user	1		1		1	
Non frequent user	3.0 (1.4–6.5)		3.2 (1.5–6.6)	3.8 (1.6–8.9)	1.0 (0.6–1.9)	
Time on ART						
Not on ART	2.6 (0.7–9.8)		2.6 (0.7–9.9)		0.9 (0.5–1.7)	
<1 year	1		1		1	
1–5 years	2.3 (1.0–5.3)	2.6 (1.0–6.5)	1.5 (1.0–2.7)		0.9 (0.6–1.3)	
>5 years	0.8 (0.5–1.3)		1.4 (0.8–2.4)		2.0 (1.1–3.5)	
Disclosure of HIV status						
None	1		1		1	
Online forums	0.5 (0.2–1.2)		0.5 (0.2–1.3)		1.0 (0.6–1.6)	
Family	0.8 (0.5–1.2)		0.8 (0.5–1.4)		1.0 (0.7–1.5)	
Friends	0.7 (0.4–1.2)		0.5 (0.3–1.0)		0.8 (0.5–1.2)	
Doctor	1.0 (0.6–1.7)		1.0 (0.6–1.8)		1.0 (0.6–1.5)	
Partner/spouse	0.6 (0.4–0.9)		0.8 (0.5–1.3)		1.5 (0.9–2.3)	
Workmate	0.6 (0.3–0.9)		0.9 (0.5–1.6)		2.0 (1.0–3.9)	

<sup>a</sup> Model 1: Use of social networking sites compared to HIV forums; Model 2: Use of group email compared to HIV forums; Model 3: Use of group emails compared to social networking sites.

<sup>b</sup> Model adjusted for gender and age.

networking sites, compared to general forums (unadjusted OR = 2.3, 95%CI 1.0–5.3). Participants who disclosed their HIV status to their partner/spouse were less likely to use social networking forums than general HIV forums.

#### 3.4. General HIV forums and group emails (Table 2)

When comparing general HIV forums and group emails chi-square tests also showed a difference between countries. Compared to general HIV forums, group emails tended to be used more by PLWH from low- and middle-income countries (unadjusted OR = 1.8, 95%CI 1.1–3.1) and by PLWH from countries with poor Internet penetrance (unadjusted OR = 2.0, 95%CI 1.1–3.4). Group emails were less likely to be used than general HIV forums by PLWH who disclosed their HIV status (unadjusted OR = 2.0, 95%CI 1.2–3.4). Frequent users tended to use HIV forums, compared to group emails, whereas irregular users were more likely to use group emails compared to general HIV forums (unadjusted OR = 3.2, 95%CI 1.5–6.6).

Further logistic regression analysis confirmed that the irregular users were also more likely to use group emails compared to general HIV forums (adjusted OR = 3.8, 95%CI 1.6–8.9).

#### 3.5. Social networking sites and group emails (Table 2)

PLWH were more likely to use group emails than social networking sites if they were on ART therapy for >5 years (unadjusted OR = 2.0, 95%CI 1.1–3.5) or if they were using Internet forums for more than a year (unadjusted OR = 2.5, 95%CI 1.4–4.5).

Group emails were more likely to be used than social networking sites by PLWH who disclosed their HIV status (unadjusted OR = 1.5, 95%CI 0.9–2.3). Analyses also showed that PLWH who used group emails were more likely to use them for >12 months, compared to social networking sites (adjusted OR = 3.8, 95%CI 1.3–11.8).

#### 3.6. Anxiety and adherence levels (Table 3)

Individuals who had high anxiety levels were less likely than patients with low anxiety levels to have disclosed their HIV status to anyone, and in particular to family members, friends, or workmates (unadjusted OR = 0.9, 95%CI 0.9–1.0).

Patients who had high adherence to ART therapy were more likely than patients with lower ART adherence to have a college education

**Table 3**  
Self-related anxiety levels and adherence to ART therapy, high vs. low.

	Anxiety level			ART adherence		
	High N (%)	Low N (%)	Unadj. OR (95% CI)	High N (%)	Low N (%)	Unadj. OR (95% CI)
Gender						
Women	1 (2)	57 (98)	1	44 (76)	14 (24)	1
Men	7 (5)	138 (95)	2.8 (0.3–22.3)	113 (78)	32 (22)	0.9 (0.5–1.6)
Age						
20–30	0	26 (100)	1	18 (69)	8 (31)	1
31–40	1 (2)	50 (98)	1.0 (0.9–1.0)	36 (71)	15 (29)	0.9 (0.7–1.3)
41–50	1 (3)	36 (97)	1.0 (1.0–1.1)	25 (67)	12 (33)	1.0 (0.7–1.4)
51–60	3 (30)	12 (80)	1.3 (1.0–1.6)	10 (67)	5 (33)	1.0 (0.7–1.6)
61–70	3(10)	26(90)	1.0 (0.9–1.0)	2 (67)	1 (33)	1.0 (0.4–2.4)
Education						
Elementary	0	1 (100)	1	0	1 (100)	1
Secondary school	1 (4)	25 (96)	1.0 (0.9–1.1)	16 (62)	10 (38)	2.6 (1.5–4.2)
College	4 (4)	100 (96)	1.0 (1.0–1.1)	74 (71)	30 (29)	3.4 (2.5–4.6)
Region						
High income countries	3 (4)	86 (96)	1	96 (84)	18 (16)	1
Middle and low income countries	5 (5)	109 (95)	1.0 (0.9–1.0)	61 (69)	28 (31)	1.9 (1.2–3.4)
Time since diagnosis						
<1 year	0	13 (100)	1	8 (62)	5 (38)	1
1–5 years	3 (3)	89 (97)	1.0 (0.9–1.0)	62 (67)	30 (33)	0.9 (0.5–1.4)
>5 years	5 (5)	92 (95)	1.0 (1.0–1.1)	86 (89)	11 (11)	0.6 (0.4–1.0)
Duration of using forum						
<1 month	1 (3)	29 (97)	1	21 (70)	9 (30)	1
1–12 months	7 (4)	166 (96)	1.0 (0.9–1.0)	136 (79)	37 (21)	0.8 (0.6–1.1)
>12 months	6 (7)	75 (93)	1.0 (0.9–1.1)	69 (85)	12 (15)	0.8 (0.1–1.0)
Frequency of forum use						
Everyday	5 (5)	87 (95)	1	74 (80)	18 (20)	1
Once in a week	2 (2)	87 (97)	0.9 (0.9–1.0)	67 (75)	22 (25)	1.0 (0.9–1.2)
Once in a month	1 (5)	21 (95)	0.9 (0.8–1.0)	16 (73)	6 (27)	1.1 (0.8–1.4)
Time on ART						
<1 year	1 (2)	54 (98)	1	46 (84)	9 (16)	1
1 to 5 years ago	5 (6)	77 (94)	1.0 (0.9–1.1)	57 (70)	25 (30)	1.2 (1.0–1.4)
>5 years ago	2 (3)	64 (97)	1.0 (0.9–1.0)	54 (82)	12 (18)	1.0 (0.8–1.2)
Not on treatment						
Disclosure of HIV status						
Online forums	8 (4)	171 (96)	1.0 (1.0–1.1)	138 (77)	41 (23)	1.0 (0.8–1.2)
Family	4 (3)	123 (97)	0.9 (0.9–1.0)	92 (73)	35 (27)	1.1 (1.0–1.3)
Friends	4 (3)	135 (97)	0.9 (0.9–1.0)	105 (76)	34 (24)	1.0 (0.9–1.2)
Doctor	7 (4)	158 (96)	1.0 (0.9–1.0)	130 (79)	35 (21)	0.9 (0.7–1.1)
Partner/spouse	5 (7)	68 (93)	1.0 (0.9–1.1)	60 (82)	13 (18)	0.9 (0.7–1.0)
Workmate	1 (3)	40 (97)	0.9 (0.9–1.0)	34 (83)	7 (17)	0.9 (0.7–1.0)
None	0	7 (100)	0.9 (0.9–1.0)	6 (86)	1 (14)	0.8 (0.6–1.2)

(unadjusted OR = 3.4, 95%CI 2.5–4.6), to be from low- or middle-income countries (unadjusted OR = 1.9, 95%CI 1.2–3.4), and to have disclosed their status to family members (unadjusted OR = 1.1, 95%CI 1.0–1.3). Patients who had been living with HIV for >5 years and had been using HIV forums for more than a year were less adherent to therapy, when compared to patients who had been living with HIV for 5 years or less, and were more adherent to therapy, respectively. Logistic regression analysis, however, showed no strong correlation between these factors and adherence levels.

## 4. Discussion

### 4.1. Usage of different HIV forums

In this study we defined characteristics of PLWH using different types of HIV forums.

Study participants used different Internet resources according to their personal and clinical characteristics, including the frequency of using Internet forums and duration of HIV illness. This diversity may be due to PLWH's personal choice or to the different technological format of these forums.

Our study showed no strong correlation between age, gender, education, and the choice of Internet forums used. However, previous research suggests that these variables are associated with the use of any

HIV forums (Courtenay-Quirk et al., 2010; Kalichman et al., 2005; Mo and Coulson, 2010; Reeves, 2001). Even though no strong correlation between age and choice of forum was observed, we noticed that older PLWH tended to use group emails, while the younger participants seemed to be more prone to using social networking sites when compared to users of email groups or general HIV forums. This might be due to the fact that social networking sites are the latest technology and group emails are the oldest among the Internet resources investigated.

PLWH from low- and middle- income countries were more likely to use group emails and social networking sites compared to general forums. This could be explained by the low Internet penetration and limited access to Internet that might favor the use of group emails where HIV information is sent to the user.

Our results showed that PLWH who use group emails and social networking sites mostly come from low- and middle-income countries, reported low satisfaction level with the usage of these two methods, and choice to use the general internet forums. This may be due to the fact that general Internet forums have higher level of anonymity compared to group emails and social networking sites, which still require from participants to register personal information. Hence, many PLWH because they belong to a highly stigmatized community, may not trust social networking sites. PLWH who used group emails tended to use them once a month and for more than a year. Limited use of group emails

might be due to limited access to Internet in low-resource settings. However, users that developed social relations with their online peers tend to cultivate them for longer periods and consider it difficult to build the same kind of relations with the newer technologies (Bar-Lev, 2008; Desouza and Jyoti Dutta, 2008; Kalichman et al., 2005).

#### 4.2. HIV and ART status

Similar to other studies about PLWH and Internet, our results indicate that PLWH's use of forums is associated with their HIV status and ART treatment (Courtenay-Quirk et al., 2010; Kalichman et al., 2005). This study shows that people who use the general HIV forums and social networking sites were more likely to be recently diagnosed than people who use group emails. Recently diagnosed people tend to be more active in searching the Internet for informational and emotional support (Courtenay-Quirk et al., 2010; Mo and Coulson, 2010). This may be due to the fact that some social networking sites are administered by HIV care staff or health care organizations (Boards, 2010). Administrators of the social networking sites are usually long term HIV survivors (Facebook, 2010) while its members are recently diagnosed individuals.

PLWH who used social networking sites or group emails had disclosed their status to their friends, partners, or workmates. However, we could not find any strong associations between these factors, although more participants felt comfortable talking about their HIV status over online forums than with their doctors.

#### 4.3. Anxiety and adherence

There was no statistically significant correlation between the different types of Internet recourses used and patient anxiety or adherence levels. However, our results suggested that PLWH who disclosed their HIV status had low anxiety levels. High adherence to ART was observed in PLWH who were on ART for more than a year.

Our results are consistent with previous research highlighting medication side effects are among the reasons for low adherence in a multi-center study of PLWH (Ammassari et al., 2001).

#### 4.4. Strengths and limitations

Our study presents a unique methodology. Unlike previous research that was focused on one specific forum (Desouza and Jyoti Dutta, 2008; Kalichman et al., 2005), this study compared three different types of internet forums.

Additionally, the survey was conducted using an online questionnaire hosted on a website. Using the Internet to conduct epidemiological surveys ensures a high level of anonymity to the participants, which is fundamental when exploring characteristics of PLWH. Anonymity provided by an online survey might minimize the chance of social desirability bias, a risk to validity induced by the presence of a surveyor.

Selection bias might, however, have occurred. Fifty-seven percent of websites users who were invited dropped out during the survey or did not provide consent. Hence, it is unclear whether our study population provides a representative picture of all the PLWH using Internet forums. Additionally, we cannot rule out that participants used different types of internet forums simultaneously; however concerns of such bias are reduced under the assumption that study participants are more likely to answer the survey posted on the platform most used, or preferred, and that such misclassification, if existing, would most likely be non-differential.

Even though we posted an invitation to the survey on multilingual forums in group emails and social networking sites in two major global languages, English and French, non-English/French speaking communities were under-represented. Our results also are unlikely to represent the most economically disadvantaged segments of the global population with HIV, if they do not have regular access to internet sites. Finally,

given the cross-sectional nature of the study considerations about causality cannot be made. Therefore, whether anxiety levels are influenced by the usage of Internet forums or are simply characteristics of the users needs to be further studied.

## 5. Conclusions

The use of emailing lists, social networking sites, and general internet forums by PLWH to obtain emotional and psychological support was associated with internet accessibility and duration of illness. Each of the different internet technologies analyzed in this study are used by users with different characteristics. Different segments of the population could be reached via social networking sites versus group emails to provide HIV information. Further studies are needed to improve our understanding of how patients benefit from any of these internet forums and which additional features would be useful to increase support for these patients. Interventions to reach PLWH using the internet should take into account the needs of target populations reached in order to determine the type of information and kind of support to provide these patients.

### Transparency document

The [Transparency document](#) associated with this article can be found, in the online version.

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E.L. took lead in writing the first manuscript draft, V.M. conducted data collection and analysis, H.A. contributed to manuscript writing and review, P.S. co-supervised the study and contributed to manuscript writing and review, Z.E.K. was main supervisor of the study and contributed to manuscript writing and review. All authors declare no conflict of interest.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.pmedr.2017.02.009>.

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