

Content Analysis and User Characteristics of a Smartphone-Based Online Support Group for People Living with HIV

Tabor E. Flickinger, MD, MPH,¹ Claire DeBolt, BA,¹
Erin Wispelwey, MSc,¹ Colleen Laurence, MPH,²
Erin Plews-Ogan, BA,¹ Ava Lena Waldman, MHS, CHES,¹
George Reynolds,³ Wendy F. Cohn, MEd, PhD,¹
Mary Catherine Beach, PhD,⁴ Karen Ingersoll, PhD,¹
and Rebecca Dillingham, MPH, MD¹

¹Department of Medicine, University of Virginia School of Medicine, Charlottesville, Virginia.

²Department of Medicine, Wake Forest School of Medicine, Winston Salem, North Carolina.

³Health Decision Technologies, Oakland, California.

⁴Department of Medicine, Johns Hopkins University School of Medicine, Baltimore, Maryland.

Abstract

Background: Although there is growing interest in mobile applications and online support groups to enhance chronic disease self-management, little is known about their potential impact for people living with HIV (PLWH). **Introduction:** We developed an innovative online support group delivered through a community message board (CMB) within a clinic-affiliated smartphone application Positive Links (PL). We analyzed characteristics of posters and nonposters to the CMB and evaluated content posted to the CMB. **Materials and Methods:** For this study, 38 HIV-infected patients received cell phones with the PL application that included the opportunity to interact with other users on a CMB. Logistic regressions investigated associations between participant characteristics and posting. CMB messages were downloaded and analyzed qualitatively. **Results:** 24 participants posted to the CMB; 14 did not. Participants had lower odds of posting if they were white ($p=0.028$) and had private insurance ($p=0.003$). Participants had higher odds of posting if they had unsuppressed viral loads ($p=0.034$). Of the 840 CMB messages over 8 months, 62% had psychosocial content, followed by community chat (29%), and biomedical content (10%). **Discussion:** Psychosocial content was most prevalent on this CMB, in contrast to other online forums dominated by informational content. Participants who posted expressed support for each other, appreciation for the community, and a perception that the app played a positive role in their HIV self-management.

Conclusions: This CMB on a clinic-affiliated mobile application may reach vulnerable populations, including racial/ethnic minorities and those of lower socioeconomic status, and provide psychosocial support to PLWH.

Keywords: HIV/AIDS, qualitative analysis, online support groups, mobile app, m-health, behavioral medicine

Introduction

People living with HIV (PLWH) face many challenges, including unmet needs for support and information from peers. Online support groups have the potential to overcome barriers to meeting these needs. Prior studies of online support groups for a variety of chronic diseases have shown that the online support group content generally focuses on informational support and illness experience.¹⁻⁵ Online support groups can promote patient empowerment,⁶⁻⁸ but may also present risks.⁸⁻¹¹ Lack of nonverbal cues can lead to misunderstandings, while lack of quality control may allow misinformation to disseminate. Negative postings or inappropriate interactions may undermine users' sense of support. PLWH may be particularly vulnerable to the risks of online support groups, due to the stigma surrounding this illness and the sensitivity of disclosure. At the same time, stigma may make online support groups particularly valuable for PLWH, as a means of accessing support while maintaining anonymity.

Our study examines an online support group delivered through a community message board (CMB) within an innovative smartphone application (Positive Links [PL]) designed to promote linkage and retention in HIV care. The app was developed in-house by the study team and is available only to participants referred by project partners. In addition to the CMB, the PL app includes daily queries of stress and medication adherence, appointment reminders, tailored educational resources, and access to the study team for individualized counseling and assistance. The CMB within the PL app provides a unique data set for content analysis of an online support group for PLWH. In addition to users' posts, our app study includes demographic and clinical data on our participants not available in prior studies in HIV, which used online recruitment

of anonymous support group users or publicly accessible postings.^{2,10,12} Furthermore, the app targets a population not previously studied. Prior work on online support groups in HIV and other chronic diseases has focused on Caucasian highly educated groups.^{10,12-15} Our group may be more representative of the HIV-positive population in the United States, which disproportionately affects disadvantaged persons, including racial/ethnic and sexual minorities and those of lower socioeconomic status.

To our knowledge, there are no HIV medical apps that offer an anonymous online CMB. To address this gap, we developed the PL app and are conducting a pilot study on its impact. In the current analysis of the CMB, our objectives were to (1) compare characteristics of posters and nonposters to the CMB and (2) evaluate content posted to the CMB. We hypothesized that posters would be more likely to be female, younger, and with a longer time period since diagnosis, based on the literature about posting behaviors in other chronic diseases.¹³⁻¹⁵ In the content analysis, we anticipated a predominance of biomedical content, similar to the patterns found in other online support groups. Ultimately, an online CMB (provided within an app) may be an opportunity to reach vulnerable PLWH, connect them with information and support from peers, and help them link to and remain in medical care, fostering better health outcomes.

Materials and Methods

COMMUNITY MESSAGE BOARD

The PL app was developed using an iterative formative phase, in which we gathered input from our patient population to identify features that would be relevant, useful, and appealing.¹⁶ Formative phase participants welcomed the idea of a CMB and emphasized the importance of anonymity and access to support.

For the current phase of the study, enrollment began in September 2013. Eligibility criteria were as follows: a score of 40 on the Wide Range Achievement Test (WRAT-4) or passing a subsequent reading test *and* HIV diagnosis since January 2012 OR at risk of falling out of care, as determined by their care provider. Participants were adults, age 18 years and older. There were no additional explicit exclusion criteria. We recruited participants through provider referrals at our local university-based Ryan White Clinic and from area AIDS service organizations and HIV testing sites. During enrollment, individuals consented to participate in the study, completed the WRAT-4 literacy test, answered baseline questions, and learned how to use the phone and PL app. Samsung Galaxy 2 or Galaxy 3 phones were provided and included a voice/data plan with unlimited minutes, texting, and data for the study

duration. Phones were encrypted and password protected and had a remote locate and wipe functionality. The app was also password secured. After enrollment, each participant will be included in the study for 18 months. Due to staggered enrollment, the total duration of the study is projected to require 2 years for all participants to complete study procedures and follow-up. The current analysis has been performed after 8 months of study duration, to evaluate preliminary findings in app usage to inform further iterative development of the app and, in particular, the CMB.

Participants had the opportunity to interact on the CMB through user names that they selected for themselves, to protect anonymity. Participants could start new conversations on the board or respond to older conversations. The PL team also introduced new conversation topics on HIV or general well-being and posted weekly funny videos, as had been suggested by formative phase participants. The team monitored the board for incorrect information or inflammatory comments and could also communicate with participants privately, as needed. This study was approved by the Institutional Review Board.

QUANTITATIVE ANALYSIS

Participants' characteristics were collected at enrollment by self-report. Demographic characteristics included age, gender, race, transmission risk behavior, time since diagnosis, and religious belief. Participants were categorized as "newly diagnosed" if they were enrolled in the study less than 3 months after their HIV diagnosis. Socioeconomic variables included education, insurance status, food security, employment status, and self-reported income. Participants also completed the WRAT-4 to assess literacy,¹⁷ the Perceived Stress Scale,¹⁸ and the Berger Stigma Scale.¹⁹ Clinical data were extracted from the electronic medical record. Characteristics were compared between posters and nonposters to the CMB with Fisher's exact tests for categorical variables and *T*-tests for continuous variables. We performed logistic regressions to investigate associations between participant characteristics and posting on the CMB. All analyses were done using STATA 11 (StataCorp, College Station, TX).

QUALITATIVE ANALYSIS

After the PL study had been ongoing for 8 months, the CMB messages were downloaded and imported into NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012). Using a Grounded Theory approach,²⁰ two independent coders assigned codes to every post to categorize themes expressed by participants. Individual codes were grouped into

three broad types of content: biomedical, psychosocial, and community chat. The codebook was refined until intercoder agreement reached a kappa statistic of 0.93. After thematic saturation was achieved with no additional topics identified by either coder, the codebook was applied to the entire data set of posts, so that the frequency of each topic category could be evaluated.

Results

CHARACTERISTICS OF POSTERS AND NONPOSTERS

Among the 38 participants in this analysis, mean age was 34.1 years (SD 11.5). Twenty-eight participants were male (74%), 9 were female (24%), and 1 transgender male to female (3%). Seventeen participants identified as black, non-Hispanic (45%), 13 as white, non-Hispanic (34%), 3 as Hispanic (8%), 3 as multiple races (8%), 1 as African American/Caucasian (3%), and 1 refused to answer (3%). *Table 1* shows differences in participant characteristics between the 24 who posted to the CMB (posters) and 14 who never posted (nonposters). Posters were more likely to be nonwhite, with 76% of nonwhite participants posting and only 38% of white participants ($p=0.035$). The majority of nonwhite participants (68%) self-identified as “Black, non-Hispanic”. Participants with public insurance or uninsured were more likely to post than those with private insurance (79% vs. 20%, $p=0.002$). Participants with unsuppressed viral loads were also more likely to post than those who were suppressed (82% vs. 48%, $p=0.043$). Several other trends were suggested by the data, such as posters being younger and more likely to be newly diagnosed with HIV than nonposters, but these findings were not statistically significant. There were no differences in gender, literacy scores, perceived stress, or stigma scores.

Table 2 shows the results of unadjusted logistic regression analyses investigating associations between participant characteristics and posting on the CMB. Participants had lower odds of posting if they were white [OR 0.20 (0.05–0.84), $p=0.028$] and had private insurance [OR 0.07 (0.01–0.41), $p=0.003$]. Participants had higher odds of posting if they had unsuppressed viral loads [OR 5.13 (1.13–23.30), $p=0.034$]. When race, insurance status, and viral load were included in one multivariable model, race was no longer significant, but insurance status and viral load remained significant ($p=0.020$ and 0.047 , respectively). The association between viral suppression and posting was attenuated when adjusted for newly diagnosed status, but a trend remained [OR 4.44 (0.87–22.56), $p=0.073$]. When race, insurance status, viral load, and newly diagnosed status were all included in multivariate analysis, only insurance status remained statistically significant [OR 0.09 (0.01–0.71), $p=0.023$].

CONTENT AND THEMES POSTED ON THE CMB

In total, 840 messages from participants posting on the CMB were analyzed. Posts on the CMB were most commonly psychosocial content (62% of posts), followed by community chat (29%) and biomedical content (10%). *Table 3* shows each category from the codebook with frequency of occurrence and examples. Posts could be assigned more than one code if several different topics were expressed.

PSYCHOSOCIAL CONTENT

Of psychosocial content, posts frequently described stressors, offered support for and affirmations of other users, described users' state of mind, and discussed coping strategies. Posts describing stressors represented 9.3% of total posts ($N=840$) and 15.2% of posts with psychosocial content ($n=515$). Participants reported many sources of stress, including from relationships outside the CMB and HIV-related concerns, including disclosure, stigma, and both geographic and social isolation. Many posts expressed more than one stressor and, either explicitly or implicitly, asked the CMB community for advice. It should be noted that posters frequently used abbreviations common in text messages, such as “u” for “you,” and additionally used nonstandard grammar, punctuation, and spelling, perhaps consistent with the skew toward lower educational attainment in this sample.

Among coping strategies identified, participants most frequently used the CMB for coping, in 31.6% of total posts and 51.5% of posts with psychosocial content. Participants reached out to the community for help with statements such as “Im so mad and not sure what to do ... Need someone to talk to.” Participants also discussed coping methods that had helped them and could help others, which included prayer, music or dance, maintaining positive thinking, and maintaining positive relationships outside the CMB. Non-CMB coping methods were shared in 9.8% of total posts and 16.0% of posts with psychosocial content.

Posts expressing the user's state of mind represented 10.6% of total posts and 17.3% of posts with psychosocial content. Positive posts endorsed optimism, contentment, perseverance, and gratitude. Negative emotions were also shared, including anger, frustration, depression, grief, embarrassment, worry, or anxiety. These negative posts were generally met with encouragement and empathy, such as “I know how u feel ... but one thing I can say there is light at the end of the tunnel.” However, some negative posts appeared to be disturbing or disruptive to the community. In particular, posts expressing suicidal thoughts caused tension on the CMB. The PL team reached out privately to participants expressing mental health concerns, including suicidal thoughts, to provide assistance.

Table 1. Characteristics of All Participants, and Comparing Posters Versus Nonposters to the Community Message Board

CHARACTERISTIC	ALL PARTICIPANTS (N= 38)	POSTERS (N= 24)	NONPOSTERS (N= 14)	p
Age in years: mean (SD)	34 (11.5)	33.5 (11.8)	35.1 (11.3)	0.680
Gender, n (%)				0.715
Male	28 (74)	17 (61)	11 (39)	
Female	10 (26)	7 (70)	3 (30)	
Race, n (%)				0.035
White, non-Hispanic	13 (34)	5 (38)	8 (62)	
Not white (all other categories)	25 (66)	19 (76)	6 (24)	
Transmission risk, n (%)				0.740
Men who have sex with men (MSM)	21 (55)	14 (67)	7 (33)	
Not MSM	17 (45)	10 (59)	7 (41)	
Religious practices, n (%)				0.611
Religious	16 (42)	9 (56)	7 (44)	
Spiritual	15 (39)	11 (73)	4 (27)	
Neither	7 (18)	9 (57)	3 (43)	
Education, n (%)				1.000
Did not complete 12th grade	7 (18)	5 (71)	2 (29)	
Completed high school	31 (82)	19 (62)	12 (39)	
Insurance, n (%)				0.002
Private	10 (26)	2 (20)	8 (80)	
Does not have private insurance	28 (74)	22 (79)	6 (21)	
Employment status, n (%)				0.168
Employed	15 (39)	7 (47)	8 (53)	
Unemployed	23 (61)	17 (74)	6 (26)	
Poverty, n (%)				1.000
Income below 100% federal poverty level	17 (45)	11 (65)	6 (35)	
Income above 100% federal poverty level	21 (55)	13 (62)	8 (38)	
Food security, n (%)				0.329
High	23 (61)	13 (57)	10 (43)	
Less than high	15 (39)	11 (73)	4 (27)	
Owns a cell phone, n (%)				0.383
Owns a cell phone	32 (84)	19 (59)	13 (41)	
Does not own a cell phone	6 (16)	5 (83)	1 (7)	
Literacy level (WRAT score): mean (SD)	55.8 (8.7)	54.6 (8.1)	57.3 (9.8)	0.462
Perceived stress score: mean (SD)	25.8 (8.9)	25.3 (8.8)	26.9 (9.4)	0.608
Stigma score: mean (SD)	100 (19.8)	99 (20.7)	101 (18.7)	0.7415

continued →

Table 1. Characteristics of All Participants, and Comparing Posters Versus Nonposters to the Community Message Board *continued*

CHARACTERISTIC	ALL PARTICIPANTS (N= 38)	POSTERS (N= 24)	NONPOSTERS (N= 14)	p
Enrollment type, n (%)				0.198
Newly diagnosed	10 (26)	8 (80)	2 (20)	
Not newly diagnosed	28 (74)	16 (57)	12 (43)	
CD4 count, n(%)				0.268
Participants with CD4 < 200	10 (26)	8 (80)	2 (20)	
Participants with CD4 > 200	28 (74)	16 (57)	12 (43)	
Viral load, n (%)				0.043
Suppressed VL (VL <50)	21 (55)	10 (48)	11 (52)	
Unsuppressed VL (VL >50)	17 (45)	14 (82)	3 (18)	

SD, standard deviation; VL, viral load.

COMMUNITY CHAT CONTENT

Community chat was defined as content that was not related to psychosocial or medical information or concerns. This category was initially termed “chit-chat” because it contained seemingly superficial content such as comments on the

weather and holidays. However, these interactions appeared to serve a more significant function, as a means of community building, and were renamed “community chat”.

In this category, greetings were most common, found in 8.3% of total posts (N= 840) and 29.1% of posts with community chat content (n= 240). Greetings included messages welcoming new members, greetings to individual users, and greetings to the entire group. Participants discussed events in their lives unrelated to HIV in 7.8% of total posts and 27.3% of posts with community chat content. Community chat also included religious or spiritual posts not related to a particular problem or coping strategy, such as “its all good don’t forget God loves YOU,” in 1.8% of total posts and 6.3% of posts with community chat content. Participants appeared to regard the CMB as a community, with group-related messages in 6.8% of total posts and 23.8% of posts with community chat content. These messages included such posts as “I don’t know if many of you realize it, but each and every one of us who uses this app is making a difference in someone else’s life battling every day of this new journey.” One participant suggested a name for the community as the Positive Links Posse (PLP). This was adopted by other members as well, with such as expressions as “PLP 4 LIFE” or “PL Family.”

BIOMEDICAL CONTENT

Of biomedical content, most posts discussed medications, 4.1% of total posts (N= 840) and 40.5% of posts with biomedical content (n= 85). Other frequent topics were seeing a healthcare provider (2.2% of total posts, 21.7% of posts with biomedical content) and laboratory results (1.5% of total posts, 14.8% of posts with biomedical content). Posts on medications were centered on the importance of adherence and support for

Table 2. Odds of Being a Poster (Versus Nonposter) by Participant Characteristics

CHARACTERISTIC	ODDS RATIO (95% CI)	p
Age	0.99 (0.93–1.05)	0.673
Male gender	0.66 (0.14–3.12)	0.603
White, non-Hispanic	0.20 (0.05–0.84)	0.028
Men who have sex with men (MSM)	1.40 (0.37–5.27)	0.619
Did not complete 12th grade	1.58 (0.26–9.48)	0.617
Private insurance	0.07 (0.01–0.41)	0.003
Employed	0.31 (0.08–1.22)	0.094
Income below 100% federal poverty level	1.13 (0.30–4.26)	0.859
High food security	0.47 (0.12–0.94)	0.298
Literacy level (WRAT score)	0.97 (0.89–1.05)	0.428
Perceived stress score	0.98 (0.91–1.06)	0.590
Stigma score	0.99 (0.96–1.03)	0.740
Newly diagnosed	2.63 (0.54–16.77)	0.211
CD4 Count >200	0.33 (0.06–1.86)	0.211
Unsuppressed VL (VL >50)	5.13 (1.13–23.30)	0.034

WRAT, wide range achievement test.

Table 3. Community Message Board Content with Categorized Themes, Examples, and Frequencies

CATEGORY AND DEFINITION	EXAMPLE	FREQUENCY (% OF TOTAL POSTS)
Biomedical Content		10.1
Alternative medicines: describes options of alternative medical treatments or experiences with them.	"...All they can do is treat me with acupuncture and injections and medication to help with the pain..."	0.1
Laboratories: describes different laboratories or results; can include an individual's initial laboratory results, changes, or current values.	In response to another user's concern about their cd4 count: "(I've) been fine but when I got emitted to the hosp my cd4 was 8 and my viral was in the mill. Kinda scary but I'm good now."	1.5
Comorbidities: describes a different health problem (outside of HIV) that a user has; it can also describe treatments or visits to a provider regarding the problem. Can include comorbidities related to HIV, such as opportunistic infections or neuralgias.	"... they said that my skull is actually smaller than my brain so they are sending my to a neurologist. I'm still in pain, my neck and back still sore hopefully I will get better soon..."	1.0
Drug use: discusses how drug(s) might affect user or HIV medication efficacy.	"Is it good to smoke weed on HIV meds or even at all?"	0.4
HIV symptoms: discusses how user experienced initial symptoms of HIV; does not include descriptions of how laboratory results have changed.	Describing time before diagnosis: "My last six months began to make sence. I have lost 120lbs in two months and found myself getting sicker more than I have ever in my life."	0.4
Medications for HIV/AIDS: includes details of and coherence to treatment plan, initiation of medications, and side effects of medications.	In response to another user asking about side effects of ATRIPLA: "I asked the doctor about the zside effects to my med and got her to print out all of the info on them. U should do so as well. One needs to know exactly what is possible so they can adjust accordingly."	4.1
Seeing a healthcare provider: discusses appointment (planned or upcoming meeting with care provider) or emergency appointment (going or possible going to emergency department or hospital).	In response to another user discussing headache: "... hate 2 hear ur not feeling well with a headache ... not good! If this headache continues, go back 2 hospital!!!! This is important!!! Keep me posted!!!!"	2.2
Sex and protection: discusses sex practices and concerns about transmitting HIV to partners; also includes suggestions and concerns about sex practices.	In response to another user's fear about infecting their partner: "I feel ya [X] I still have sex bt I use condoms and as long as u and ur partner are comfortable it will get better. My wife and I are very active so talk to ur partner and see how he feels."	0.5
Community chat		28.6
Group-related content: expresses appreciation for the board and community support, as well as interest in meeting other members of the group.	"I don't know if many of you realize it, but each and every one of us who uses this app is making a difference in someone else's life battling every day of this new journey ... We all are making a difference together 1 day, one app, and one click at a time."	6.8
Greetings: participant-to-participant or participant-to-group greetings; also includes personal introductions to group and "welcome" messages to group.	"I just want to say hello n I hope everyone has a good weekend n week. I love y'all"	8.3
Miscellaneous: chitchat that is nonspecific, such as jokes and riddles.	"Did u checkout the riddle I threw out there"	4.0
Outside events and activities: includes posts about current events, participant hobbies, personal activities, seasons and weather, and holidays.	"Happy Halloween everyone!!!!"	7.8
Religious: has religious content that is written in a nonspecific manner or noncoping manner.	"its all good don't forget God loves YOU"	1.8

continued →

Table 3. Community Message Board Content with Categorized Themes, Examples, and Frequencies *continued*

CATEGORY AND DEFINITION	EXAMPLE	FREQUENCY (% OF TOTAL POSTS)
Psychosocial content		61.3
Coping strategies		9.8
Activity-based coping: participant describes their own coping strategy. Includes spirituality; also includes maladaptive behavior, such as violent thinking.	"I went out today and did some african drumming ... Then went on a walk and listened to nothing but some uplifting music. And not one thought crossed my mind."	
Relationships outside of the board: describes how participant uses partners, family, or friends outside of the board for coping.	"I was blessed! I have [X]. He excepted it from the beginning ... but sometimes I question why. Never-the-less, he stands by my side! I do thank God!"	
Strategies suggested by the Positive Links Team: suggestions from the Positive Links Team that receive participant endorsement.	"Just tried the auditory resource when I actually needed it ... It seemed to have an even better effect than normal. Please remember them. They do help."	
Coping by using the board		31.6
Coping by using the board: user describes a problem or stressor; can ask for help with the problem.	"Im so mad and not sure what to do ... Need someone to talk to."	
Support for another user: community or another user's suggestions on activities for coping or on using outside resources. Can also include compliments or affirmations for the original user.	"CONGRATS [X]!!!) I am happy 4 u! I have faith that you will move mountains ... u go girl!"	
Describing participant's state of mind		10.6
Negative state of mind: describes feelings such as anger, frustration, depression, grief, embarrassment, worry, or anxiety.	"Hi community its [x] ... Not really feeling in the best mood right now inside I want to cry times are not easy doing it on my own..."	
Positive state of mind: describes feelings such as contentment, optimism, perseverance, gratefulness, or otherwise improved state of being	"I appreciate the welcome ... I have full assurance that one day this will be eradicated and people will say I never knew you were hiv positive and my response will be I was because I know for me HIV means Heavens in View."	
Stressors		9.3
Drug use: describes relapses, wanting to come off drugs and not feeling able to, or previous drug use that user finds disappointing.	"... I told my sycho doc that I would fall deep ... and now im falling im relapsing in so my diff way and I can't stop I would do things for fun now it's a habit I can't break and I don't know what to do it sucks"	
Financial and work stress: conveys stress about working, making enough money to pay for expenses, and information about financial expenses.	"... thank u [X] trying to stay on my meds but its hard with no food to eat"	
Geographic isolation: describes living away from others or family.	"... when I think about my family in jersey city I get a lil down ... im just a lil homesick u know"	
HIV-related psychosocial stress: describes a user's appointments, how they contracted HIV, disclosure of their status to others or a partner's status to others, feelings about their health status or insurance, and social isolation and stigma.	"How can I feel good to talk about my HIV status with my roommate who is also a best friend to me"	
Relationship stress: includes stress resulting from family, friends and roommates, and partners.	"Why do I have a husband that don't do anything but play on his phone he don't clean cook nothing im tired of doing it by myself"	

others who might be having difficulty: “Keep your head high, everything will be okay. Just remember your lifeline Your Meds!!!!” One participant who was newly diagnosed reached out to the CMB community with concerns about starting medications. Others responded with encouragement, advice about how to find more information on treatment, and personal stories of success.

In addition to seeking biomedical information from healthcare providers, participants asked their questions to the CMB community. Many questions addressed issues of substance use (4.0% of biomedical content) and sexual behavior (4.9% of biomedical content). One participant asked: “Is it good to smoke weed on HIV meds or even at all?” Another inquired about risks of transmission and received advice, such as “I still have sex but I use condoms and as long as you and your partner are comfortable it will get better.” The PL study team also provided posts addressing biomedical questions, if an incomplete or incorrect answer was offered by the community or conflicting opinions were posted.

Discussion

This study of a CMB within a smartphone app for PLWH revealed several unexpected findings. First, we found that posting behaviors did not vary with gender or age, and posters did not have more illness experience, in contrast to studies of online support groups in other chronic diseases.^{8,13,14} In fact, there was a trend toward those newly diagnosed with HIV being more likely to post on the CMB, although this did not reach statistical significance. Participants in this sample who were white, had private insurance, and had suppressed viral loads were significantly less likely to post to the CMB. Second, we found that the CMB contained more psychosocial than biomedical content. Again, this contrasts with published data on other online support groups, in which biomedical content is predominant.

The population targeted in this study has been underrepresented in prior work on online support groups, which have generally focused on well-educated Caucasian groups. This is an ongoing pilot project with a small number of participants, therefore, firm conclusions cannot be drawn. However, our findings suggest that our CMB is being used by participants from racial/ethnic minority groups and lower socioeconomic status, who tend to be disproportionately affected by HIV and are at risk for health disparities. The lower rate of viral suppression among the CMB posters (compared to nonposters) also suggests that the intervention may target those who need it most, that is, those who are at risk for poor clinical outcomes. Furthermore, the app may reach a population with relatively low literacy. Nonstandard spelling and grammar were more

prominent on our CMB than other qualitative studies of online support groups. This may be a function of the mobile medium, in which autocorrect and shorthand tend to be more accepted than other settings. However, an informal style of exchange could encourage participation from those with lower literacy and this will be investigated with participant interviews.

There was much more psychosocial content and community chat than biomedical content on this CMB. Most other studies have identified informational support as the primary content on online forums for chronic illness.¹⁻⁵ Possible explanations for this difference might be that participants in our study have other sources of biomedical information (such as their healthcare providers), users are less readily able to look up or share biomedical content on their cell phones, or that an important usage of the app is social interaction with peers. Participants who posted on the CMB expressed support for each other, appreciation for the community, and a perception that the app was playing a positive role in their daily struggles with HIV. Even the community chat content, which did not relate to a specific problem or concern, appeared to serve an important function of support and community building.

Despite the generally positive nature of interactions on the CMB, there are potential dangers. Negative posts could be disruptive to other CMB users or result in the poster not seeking adequate help. Posts with personal identifiers (which were specifically prohibited during the enrollment and app training process, but did rarely occur) might pressure users who wish to remain anonymous. Last, while no misinformation was observed on this CMB, the potential for misinformation must be considered in online forums.^{21,22}

This study has several limitations to consider. As there was a small sample size and potential for truncated age ranges or limited variance in other characteristics, we may have been unable to detect some true differences between posters and nonposters. Second, the value of the CMB to “lurkers” (those who read others’ posts, but do not contribute their own) was not assessed, although we are conducting interviews with participants that may address this question. Third, the app functions in close coordination with the PL study team and with connections to the participants’ HIV care setting. Some potential dangers, such as negative interactions or misinformation, may have been mitigated by the study team, which included licensed clinicians. Monitoring the CMB and reaching out to participants who appeared to need additional help were accomplished by the PL study team and in coordination with the participants’ care providers. The functioning of the app and particularly of the CMB would likely be different if delivered through a publicly available app marketplace and without the link to a care setting.

Next steps will include further evaluation of the CMB, such as investigation of support mechanisms and community dynamics, and longitudinal assessment of users and evaluation of outcomes of the PL app and CMB participation. Investigation of barriers to CMB participation may also help adapt the CMB to reach nonposters. The app will be refined, using participant input and additional formative work, and integrated further with the users' clinical care. After this next demonstration project is complete, plans for offering the app to other users or care settings will be pursued.

To our knowledge, this is the first study to examine an online support group delivered through a CMB as part of a smartphone app for PLWH. Results indicate that the CMB may be able to reach a previously understudied vulnerable population. Exploratory analysis reveals a predominance of psychosocial content, possibly indicating that the CMB is meeting a previously unmet need for information and support from peers. Online support groups have the potential to address challenges faced by PLWH, including social isolation, while protecting anonymity. Further development of this smartphone application and its CMB will include investigation of possible benefits in improving social support, linkage and retention in HIV care, and health outcomes for PLWH.

Acknowledgments

This project was supported by the M.A.C.AIDS Fund and AIDS United. These sponsors had no role in study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

Author Disclosure Statement

No competing financial interests exist.

REFERENCES

- van Uden-Kraan CF, Drossaert CH, Taal E, Smit WM, Moens HJ, Siesling S, et al. Health-related internet use by patients with somatic diseases: Frequency of use and characteristics of users. *Inform Health Soc Care* 2009;34:18–29.
- Mo PK, Coulson NS. Exploring the communication of social support within virtual communities: A content analysis of messages posted to an online HIV/AIDS support group. *Cyberpsychol Behav* 2008;11:371–374.
- Gill PS, Whisnant B. A qualitative assessment of an online support community for ovarian cancer patients. *Patient Relat Outcome Meas* 2012;3:51–58.
- Wesemann D, Grunwald M. Online discussion groups for bulimia nervosa: An inductive approach to internet-based communication between patients. *Int J Eat Disord* 2008;41:527–534.
- Hadert A, Rodham K. The invisible reality of arthritis: A qualitative analysis of an online message board. *Musculoskeletal Care* 2008;6:181–196.
- van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. *Qual Health Res* 2008;18:405–417.
- Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, et al. Sharing health data for better outcomes on PatientsLikeMe. *J Med Internet Res* 2010;12:e19.
- Holbrey S, Coulson NS. A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. *BMC Womens Health* 2013;13:51.
- Mo PK, Coulson NS. Living with HIV/AIDS and use of online support groups. *J Health Psychol* 2010;15:339–350.
- Mo PK, Coulson NS. Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Educ Couns* 2013;93:426–432.
- Horvath KJ, Danilenko GP, Williams ML, Simoni J, Amico KR, Oakes JM, et al. Technology use and reasons to participate in social networking health websites among people living with HIV in the US. *AIDS Behav* 2012;16:900–910.
- Mo PK, Coulson NS. Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of "lurkers" and "posters". *Comput Hum Behav* 2010;26:1183–1193.
- Kalichman SC, Cherry C, Cain D, Weinhardt LS, Benotsch E, Pope H, et al. Health information on the internet and people living with HIV/AIDS: Information evaluation and coping styles. *Health Psychol* 2006;25:205–210.
- Lasker JN, Sogolow ED, Sharim RR. The role of an online community for people with a rare disease: Content analysis of messages posted on a primary biliary cirrhosis mailinglist. *J Med Internet Res* 2005;7:e10.
- Mo PK, Malik SH, Coulson NS. Gender differences in computer-mediated communication: A systematic literature review of online health-related support groups. *Patient Educ Couns* 2009;75:16–24.
- Laurence C, Wispelwey E, Flickinger TE, Plews-Ogan E, DeBolt C, Reynolds G, Cohn W, Ingersoll K, Dillingham R. Development, feasibility and acceptability of a smartphone application to promote linkage to HIV care among nonurban newly diagnosed people. 9th International Conference on HIV Adherence and Engagement, Miami, FL, 2014. Oral Abstract #413.
- Casaletto KB, Cattie J, Franklin DR, Moore DJ, Woods SP, Grant I, et al. The wide range achievement test-4 reading subtest "holds" in HIV-infected individuals. *J Clin Exp Neuropsychol* 2014;36:992–1001.
- Koopman C, Gore-Felton C, Marouf F, Butler LD, Field N, Gill M, et al. Relationships of perceived stress to coping, attachment and social support among HIV-positive persons. *AIDS Care* 2000;12:663–672.
- Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Res Nurs Health* 2001;24:518–529.
- Hennink M, Hutter I, Bailey A. *Qualitative research methods*. Sage: London, 2011.
- Malik S, Coulson NS. "They all supported me but I felt like I suddenly didn't belong anymore": An exploration of perceived disadvantages to online support seeking. *J Psychosom Obstet Gynaecol* 2010;31:140–149.
- Mo PK, Coulson NS. Are online support groups always beneficial? A qualitative exploration of the empowering and disempowering processes of participation within HIV/AIDS-related online support groups. *Int J Nurs Stud* 2014;51:983–993.

Address correspondence to:
Rebecca Dillingham, MD, MPH
UVA Center for Global Health
P.O. Box 801379
Charlottesville, VA 22908

E-mail: rd8v@virginia.edu

Received: August 26, 2015

Revised: January 5, 2016

Accepted: January 7, 2016