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Symptom profile and technology use of persons living with HIV who access services at a community-based organization in the Deep South

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Abstract

Currently, the Southern United States has the highest rates of new HIV diagnoses, the largest percentage of people living with HIV (PLWH), and the most people dying from the disease in the United States. Given the rise of the HIV epidemic in the Deep South and the availability of evidence-based self-management tools for PLWH, we conducted an in-person survey in Birmingham, Alabama, to understand the symptom profile and the use of technology by PLWH. Muscle aches or joint pain was the most frequently (67%) reported symptom followed by fatigue, sleep difficulties, neuropathy, and depressive symptoms. We also assessed mobile technology use and ownership and found that 83.7% of persons own a smartphone with most of these (79.9%) being Android users. Given these findings, there is strong scientific premise to support the feasibility of a mobile-delivered symptom self-management tool in the Deep South for improving health outcomes for PLWH.

Keywords

Mobile technology; symptom burden; Deep South

INTRODUCTION

The Southern United States has the highest rates of new HIV diagnoses, the largest percentage of people living with HIV (PLWH), and the most people dying from the disease in the United States. In 2016, 44% of new diagnoses in the United States were among people living in the South even though only one-third of the domestic population resides in Southern states (Bureau, 2018; Prevention, 2015). In addition to huge geographic disparities,

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there are also significant racial disparities in HIV/AIDS incidence with Blacks/African Americans accounting for 54% of new HIV diagnoses in the South, despite comprising only 38% of the Southern population (Prevention, 2015).

These rates are exemplified in Alabama, at the heart of the Deep South and the setting of our study. Black/African Americans account for 64% of PLWH in Alabama despite only approximately 26% of the state population identifying as Black (AIDS Vu, 2015). Further, the rate of Black males living with an HIV diagnosis is 5.3 times that of White males (AIDS Vu, 2015). The rate of Black females living with an HIV diagnosis is 10.4 times that of White females in Alabama (AIDS Vu, 2015). These staggeringly high rates of HIV/AIDS in racial minorities in Alabama highlight tremendous health disparities among Blacks and point to the need for targeted prevention interventions to curb the epidemic as well as to manage the disease for those who are the most affected.

Symptom profiles have been well-studied among PLWH, especially in the early years of the epidemic (Cook et al., 2004; Holzemer, 2002; Justice, Chang, Rabeneck, & Zackin, 2001; Kalichman, Rompa, & Cage, 2000). Poor symptom experience in PLWH has been shown to negatively affect combination antiretroviral therapy (cART) adherence, viral suppression, and quality of life (I. B. Wilson & Cleary, 1996). Historically, researchers have demonstrated that quality of life and productivity decrease as the number and severity of HIV-related symptoms increase (Lorenz, Cunningham, Spritzer, & Hays, 2006; Siegel, Schrimshaw, & Dean, 1999). Yet, the current HIV medication regimens are vastly improved both in terms of efficacy and side effect profile, pointing to the need to better understand the symptom profile of PLWH. This may be especially true in the Deep South where the HIV epidemic continues to proliferate and access to care has often been insufficient to meet the needs of PLWH.

For instance, a 2015 study at the 1917 Clinic at the University of Alabama at Birmingham (UAB), which has a clinic volume of more than 5,700 visits per year, showed that 1,885 of 1,945 (96.9%) unique patients reported symptoms in the past year (N. L. Wilson et al., 2016). Muscle aches/joint pain, fatigue, and poor sleep were included in the top five most prevalent and most bothersome symptoms reported (N. L. Wilson et al., 2016). In our national online survey ($N = 1,373$), there was a high symptom burden with fatigue, depression, muscle aches and pain, sleep difficulties, and anxiety being the most prevalent symptoms, and neuropathy being one of the most burdensome symptoms and affecting over 25% of our study participants (Schnall, Siegel, Jia, Olender, & Hirshfield, 2018). In our New York City in-person study ($N = 80$), our participants also reported a high prevalence of symptoms with fatigue being the most frequently reported symptom ($N = 61$, 76.3%), followed by difficulty falling or staying asleep ($N = 59$, 74.7%), neuropathy ($N = 46$, 59.0%), anxiety ($N = 45$, 57.0%), and depression ($N = 43$, 53.8%) (Schnall, Cho, Mangone, Pichon, & Jia, 2018).

Better symptom management has the potential to improve cART adherence, viral suppression, and quality of life among PLWH. Patients' symptom experiences and symptom management successes are strongly related to HIV disease progression and adverse clinical profiles (Leserman et al., 1999; Spirig, Moody, Battegay, & De Geest, 2005) making the management of symptoms increasingly important. One approach is through self-care, a

process whereby an individual undertakes activities to promote his/her own health, limit illness, and restore health (Levin & Idler, 1983). Further, there is evidence to support the use of self-care strategies to manage adverse symptoms of HIV illness. To detail, scientists at the University of California-San Francisco (UCSF) School of Nursing demonstrated the efficacy of 21 common HIV/AIDS self-management strategies presented in a paper-based manual in a randomized controlled trial ($N = 775$) over 3 months at 12 sites, including Puerto Rico and South Africa (Wantland et al., 2008). To facilitate dissemination of the evidence-based strategies for symptom self-management, we developed a mobile application (app), Video Information Provider (mVIP), to deliver these self-care strategies to PLWH based on their symptom reporting and tested it in a rigorous feasibility trial with English-speaking, low-income, racial and ethnic minority New York City residents. mVIP was efficacious for (a) reducing anxiety ($p < .001$), (b) reducing depression ($p = .001$), (c) reducing neuropathy ($p = .003$), (d) reducing fever/chills/sweat ($p = .036$), (e) reducing weight loss/wasting ($p = .019$), and (f) improving adherence to antiretroviral medications ($p < .05$) in mVIP users in comparison to control group participants (Schnall, Cho, et al., 2018).

Given the rise of the HIV epidemic in the Deep South and the availability of evidence-based self-management tools for PLWH, we conducted a study to better understand the symptom profile and the use of technology by PLWH in Birmingham, AL. The goal of this study was to determine the symptom burden of PLWH who receive services at a local community-based organization (CBO). The secondary goal of this study was to evaluate mobile technology ownership as a means to understand the feasibility of PLWH using mobile tools for self-management of their disease.

METHODS

SETTING AND SAMPLE

The setting was Birmingham AIDS Outreach (BAO), in Birmingham, AL, a CBO that provides services to 550 unduplicated PLWH each month. Of these persons, 92 unduplicated PLWH receive counseling and/or participate in support groups. BAO provides legal services to 40 new individuals each month and has 105 open cases monthly. The range of services for PLWH at BAO are vast (e.g., food bank, clothing closet, GED classes, personal hygiene supplies, women's sewing and support groups, and education programs). Participants comprised a convenience sample of PLWH who were recruited from the BAO waiting area.

INSTRUMENTS

HIV Symptom Index.—The HIV Symptom Index is a 20-item, self-report instrument that takes less than 5 minutes to complete (Justice et al., 2001). It is considered to be comprehensive and comprehensible and has demonstrated construct validity and strong associations with physical and mental health summary scores and with disease severity (Justice et al., 2001). The symptom index asks PLWH if they have had any of 20 symptoms in the past 4 weeks. If the person has had the symptom then s/he is asked to indicate how much the symptom bothers him/her (0 = *I do not have the symptom*; 1 = *I have the symptom and it doesn't bother me*; 2 = *I have the symptom and it bothers me a little*; 3 = *I have the symptom and it bothers me*; 4 = *I have the symptom and it bothers me a lot*).

PROMIS-29.—PROMIS-29 is a multi-item measure for assessing generic profile health-related quality of life (Cella et al., 2010). Patient-Reported Outcomes Measurement Information System® (PROMIS) is an NIH Roadmap initiative to develop instruments to measure patient-reported outcomes in respondents with a wide range of chronic illnesses and demographic characteristics. The PROMIS-29 is an especially useful instrument for measuring health-related quality of life among PLWH since it has been validated in a large U.S. sample of persons living with the disease (Schnall et al., 2017). Raw scores are transformed using the T-score metric based on the item response theory calibrations, in which scores have a mean of 50 and standard deviation (*SD*) of 10 for the general population in the United States. A higher PROMIS T-score represents more of the concept being measured. For negatively-worded concepts (e.g., sleep disturbance), a T-score of 60 is one *SD* below average. By comparison, an anger T-score of 40 is one *SD* above average (DeWalt, Rothrock, Yount, Stone, & Group, 2007; Revicki & Cella, 1997).

eHealth Literacy Scale.—The eHealth Literacy Scale (eHEALS) is an 8-item measure of eHealth literacy and was designed to measure consumers' knowledge, perceived skills, and comfort at using health information technology (Norman, & Skinner, 2006). The eHEALS uses a 5-point Likert scale (1-strongly disagree, 5-strongly agree). The eHEALS has been found to be internally consistent ($\alpha = .94$) and the exploratory factor analysis yielded a single factor structure explaining 67.3% of the variance (Chung & Nahm, 2015). The sum across the eight items on the scale are equally weighted and the score ranges from 8 to 40, with a higher score indicating higher eHealth literacy. There is no fixed cut-off to delineate high from low eHealth literacy (Cameron, Norman, & Skinner, 2006).

PROCEDURES

All study activities were approved by the Columbia University Medical Center Institutional Review Board (IRB). Participants provided written informed consent prior to the start of the survey, and no unique patient identifiers were collected as part of the survey. Using Qualtrics survey software, licensed social workers at BAO distributed a self-report survey to 150 unduplicated HIV-infected patients via an iPad in August 2018. The survey consisted of the three study instruments, as well as investigator-developed self-report questionnaires that measured demographic characteristics, technology access and use, and most recent viral load.

DATA ANALYSIS

We conducted a descriptive analysis of our survey results using STATA version 15. We also used Chi-square analysis to assess differences in smartphone ownership based on demographic characteristics. Level of significance was set at $\alpha = .05$. Symptom frequency was calculated as the percentage of participants who reported the symptom in the last 30 days. Symptom bother was calculated as the mean score of those who reported the symptom. Finally, we calculated the internal consistency reliability of the eHEALS and the PROMIS-29 subscales and reported the Cronbach's alpha.

RESULTS

One hundred and fifty four PLWH completed the survey (Table 1). Participants' ages ranged from 24–79 years with a mean age of 52 years ($SD = \pm 11.44$). The majority of participants were male (69%) and self-identified as Black non-Hispanic (81%). Almost 75% of participants reported their most recent viral load as undetectable (<200 copies/mL). We found no significant differences ($p > .05$) in smartphone ownership based on any of the demographic characteristics, including sex at birth and race/ ethnicity.

Muscle aches or joint pain was the most frequently reported and most bothersome symptom followed by fatigue, sleep difficulties, neuropathy, and depressive symptoms. Nausea/ vomiting was reported the least in the symptom profile. A full listing of patients' symptom profiles is described in Table 2.

PROMIS-29 scores are reported in Table 3. Participants had mean scores on each of the subscales ranging from 46–55.2. Physical functioning and pain interference in our sample were worse than the average person. In contrast, anxiety, fatigue, sleep disturbance and satisfaction with social role were slightly better than the average person. Internal consistency reliability was very high ($\alpha > .90$) for all measures except for sleep disturbance, suggesting that the PROMIS measure is reliable. Given the very low Cronbach's alpha for the sleep disturbance scale, the sleep disturbance score is unlikely to be reliable and should be interpreted with caution. Overall, most of the scores hovered around 50, suggesting that this study sample was similar to the national average. Yet these scores come with considerable standard deviation, suggesting a range of t-score means across our study sample.

Finally we assessed participants' access to mobile technology as measured through ownership and use. Eighty-two percent of participants used a mobile device at least once/ day. Eight-four percent owned a smartphone with most of these (79.9%) being Android users. Eight-five percent of participants used their phone to send/ receive text messages; 75.8% used their smartphones to access the Internet; 75.2% sent/ received emails on their smartphones; and 65.4% used their smartphones to participate in video calls. eHealth literacy was measured through the eHEALS instrument. The eHEALS had a Cronbach's alpha score = 0.970 in our study sample, demonstrating high internal consistency reliability, and an eHEAL mean score of 27.5 ($SD \pm 11.15$). Further details on our participants' technology access and use is detailed in Table 4.

DISCUSSION

The high rates of HIV/AIDS in rural Southern States stems from a confluence of social factors, including poverty, racism, persistent anti-gay attitudes, unstable housing, a lack of transportation in rural areas and a lack of access to medical care (Frumkin, Hess, Lubet, Malilay, & McGeehin, 2008). HIV rates continue to rise in the Deep South and symptom burden continues to be a current and relevant problem for PLWH, demonstrating the need for testing a symptom self-management intervention in this region.

Symptoms continue to burden PLWH. Our current study in Birmingham, AL, demonstrated that nearly 67% of PLWH who sought services at a local CBO experienced symptoms and

reported being burdened by their symptoms within the past 7 days. Pain and fatigue were reported as the most frequently reported bothersome symptoms. Our past work had similar findings in post-menopausal women who suffered a greater impact from fatigue and muscle aches, regardless of their age, duration of their HIV infection, and the existence of other health conditions (Schnall, Jia, Olender, Gradilla, & Reame, 2018).

Despite the symptoms that continue to burden PLWH in the United States, symptom self-care for PLWH is available. The goal of symptom management is to avert or delay symptom(s) that compromise functioning through biomedical or professional intervention ("A model for symptom management. The University of California, San Francisco School of Nursing Symptom Management Faculty Group," 1994). It is imperative that PLWH learn to cope with the wide spectrum of HIV-related symptoms they may experience. As a result, there is a need to help PLWH self-manage their symptoms in order to optimize their quality of life and other health outcomes (Greene, Justice, Lampiris, & Valcour, 2013). Self-management involves helping patients set achievable goals and learn problem-solving techniques relevant to their conditions (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Symptom self-management in PLWH has been shown to decrease symptom severity (Corless et al., 2002; Eller et al., 2005; Heaven CM, 1998; Kemppainen et al., 2006; Nicholas et al., 2007; Nicholas, Kirksey, Corless, & Kemppainen, 2005), improve quality of life (Indyk D, 1993), reduce disability, increase medication adherence, and promote health (Burgoyne et al., 2005; Buseh, Kelber, Stevens, & Park, 2008; Corless et al., 2002; Gustafson et al., 1999). To facilitate dissemination of evidence-based strategies for symptom self-management, we developed a mobile app, mobile Video Information Provider (mVIP), which delivers self-care strategies in English to PLWH based on their symptom reporting (Schnall, Cho, et al., 2018). Given the findings from the survey data and the availability of innovative strategies to improve quality of life for PLWH, there is a unique opportunity to implement this intervention in the Deep South, a key geographic area for improving the U.S. HIV/AIDS epidemic.

There are a number of limitations to our study. First, there may be selection bias given that the survey was delivered using an iPad, thus participants' comfort with the technology may have resulted in a sample that was more likely to own a smartphone. Second, the generalizability of our findings is limited to those who accessed social services at a CBO. Despite these limitations, our survey participants are representative of most of the people who were accessing HIV care services in the Birmingham, AL, area since the clients at BAO were the same patients who accessed HIV care at the University of Alabama 1917 clinic, which was the only clinic in the area that provided HIV care.

In summary, our findings support the use of technology for the delivery of health interventions in a low income, poorly educated, and racial minority population. Our sample had high smartphone ownership and use, and medium to high eHealth literacy. Given the scores on the eHEALS instrument, there is evidence to support the use of consumer eHealth tools, such as the mVIP app, to inform clinical decision making and health promotion. In summary, given these findings in Birmingham, AL, and other recent studies on symptom burden in the United States (Schnall, Cho, et al., 2018; Schnall, Siegel, et al., 2018; N. L. Wilson et al., 2016), there is strong scientific premise to support the feasibility of a mobile-

delivered symptom self-management tool in the Deep South and other U.S. communities for improving health outcomes for PLWH in the United States.

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Key Considerations

- Muscles aches or joint pain was the most frequently reported and most bothersome symptom reported by persons living with HIV in our study sample.
- 83.7% of our study sample owned a smartphone and most participants use Android devices.
- There is strong scientific premise to support the feasibility of a mobile delivered symptom self-management tool in the Deep South.

Table 1.Study Sample Demographic Characteristics (*N* = 154) *N*(%)

	Total <i>N</i> (%)	Smartphon e Owner	Not a Smartphon e Owner	<i>p</i> -value*
Education – highest level of education				<i>p</i> = 0.139
High school diploma or equivalent	51 (33.1)	39	12	
Some high school, no diploma	30 (19.5)	24	6	
Some college	30 (19.5)	28	2	
Associate degree or technical degree	16 (10.4)	14	2	
Bachelor/college degree	16 (10.4)	16	0	
Professional or graduate degree	9 (5.8)	6	3	
Elementary school	1 (0.7)	1	0	
Unknown	1 (0.7)			
Work				<i>p</i> = 0.122
Disabled	76 (49.3)	58	18	
Retired	18 (11.7)	13	5	
Unemployed, looking for work	17 (11.0)	16	1	
Working, full time	16 (10.4)	16	0	
Working, part time	11 (7.1)	11	0	
Unemployed, not looking for work	9 (5.8)	8	1	
Unemployed, not looking for work & Disabled	2 (1.3)	2	0	
Student	2 (1.3)	2	0	
Working off the books	2 (1.3)	2	0	
Unknown	1 (0.6)			
Income				<i>p</i> = 0.256
Less than \$10,000	90 (58.4)	70	20	
\$10,000-\$19,999	44 (28.6)	39	5	
\$20,000-\$39,999	8 (5.2)	8	0	
\$40,000-\$59,999	7 (4.5)	7	0	
\$60,000-\$79,999	1 (0.7)	1	0	
Don't know	2 (1.3)	2	0	
Unknown	2 (1.3)			
Relationship Status				<i>p</i> = 0.401
Single	100 (65.0)	87	13	
In a relationship	26 (16.9)	21	5	
Married	14 (9.1)	10	4	
Divorced/Separated/Widowed	13 (8.4)	10	3	
Unknown	1 (0.6)			
Smoking				<i>p</i> = 0.330
Regular smoker/e-cigarette user	60 (39.0)	54	6	

	Total N (%)	Smartphone Owner	Not a Smartphone Owner	<i>p</i>-value*
Occasional smoker/e-cigarette user	20 (13.0)	16	4	
Non-smoker/e-cigarette user	70 (45.5)	57	13	
Unknown	4 (2.6)			
Results of most recent viral load Test				<i>p</i> = 0.992
Undetectable OR < 200 copies/ ml	110 (71.4)	92	18	
Detectable OR => 200 copies/ ml	13 (8.4)	11	2	
I don't know – but I think I was detectable	8 (5.2)	7	1	
I don't know – but I think I was undetectable	20 (13.0)	17	3	
Unknown	3 (2.0)			

* Analyses for all variables did not include unknown/missing entries.

Table 2.Patient Symptom Profile Prevalence ($N = 154$)

Symptoms, Ranked by Prevalence	Prevalence of Persons Reporting Symptom	Bothersome Score [*]
	<i>N</i> (%)	<i>M</i> (<i>SD</i>)
Muscle aches or joint pain	67 (45)	2.82 (0.97)
Fatigue or loss of energy	60 (40)	2.50 (1.08)
Difficulty falling or staying asleep	52 (35)	2.75 (1.01)
Neuropathy (Pain, numbness, or tingling in the hands or feet)	48 (32)	2.54 (0.97)
Felt sad, down, or depressed	47 (31)	2.57 (0.99)
Headache	43 (29)	2.53 (1.03)
Felt nervous or anxious	40 (27)	2.58 (0.96)
Trouble remembering	38 (25)	2.37 (0.82)
Cough or trouble catching your breath	31 (21)	2.26 (1.00)
Skin problems, such as rash, dryness, or itching	30 (20)	2.60 (1.00)
Bloating, pain, or gas in your stomach	28 (19)	2.29 (0.90)
Problems with having sexual intercourse	28 (19)	2.82 (1.16)
Lipodystrophy or weight gain	28 (19)	2.07 (0.98)
Feeling dizzy or lightheaded	27 (18)	2.26 (0.76)
Loss of appetite or a change in the taste of food	26 (17)	2.27 (1.00)
Diarrhea or loose bowel movements	24 (16)	2.21 (1.02)
Fevers, chills, or sweats	21 (14)	1.81 (0.75)
Problems with weight loss or wasting	18 (12)	2.22 (0.94)
Hair loss or changes in the way your hair looks	17 (11)	2.59 (1.06)
Nausea or vomiting	13 (9)	2.15 (0.90)

* Bothersome Score was reported as the mean score of those who reported "I have this symptom and...1-*does not bother me*, 2-*it bothers me a little*, 3-*it bothers me*, 4-*it bothers me a lot*.

Table 3.Health-Related Quality of Life/ PROMIS T-scores* ($n = 154$)

	Cronbach's Alpha	MMean (S.D.)ean (SD)
Physical Function	0.912	47.9 (9.94)
Anxiety	0.926	47.5 (14.88)
Depression	0.952	50.3 (12.82)
Fatigue	0.953	46.0 (13.48)
Sleep Disturbance	0.151	48.6 (11.44)
Satisfaction with Social Role	0.953	55.2 (11.20)
Pain Interference	0.985	52.5 (12.44)

* T-score of 50 represents the mean score of the general population. A higher PROMIS T-score represents more of the concept being measured. For positively-worded concepts like physical function, a T-score of 60 is one *SD* better than average. By comparison, a physical function T-score of 40 is one *SD* worse than average (DeWalt et al., 2007; Revicki & Cella, 1997)

Table 4.Technology Use ($N = 154$)

	<i>N</i> (%)
Do you own a smartphone (a phone where you can access the Internet)?	128 (83.7)
Which type of mobile device do you use most frequently?	
Android Phone	115 (74.7)
iPhone	20 (13.0)
Tablet	2 (1.3)
Other	7 (4.6)
Unknown	10 (6.5)
How often do you use the mobile device (e.g., smartphone, tablet, cellphone)?	
Several times every day	126 (81.8)
Once a day	6 (3.9)
Several times per week	10 (6.5)
Several times per month	1 (0.7)
Once a month or less often	1 (0.7)
Never	9 (5.8)
Unknown	1 (0.7)
When did you start using a mobile device (e.g., smartphone, tablet, cellphone)?	
Past 6 months	7 (4.6)
Past year	7 (4.6)
Past 2 years	9 (5.9)
More than 2 years ago	129 (83.8)
Unknown	2 (1.3)
About how many text messages do you send per day?	
0	25 (16.2)
1–10	57 (37.0)
11–50	55 (35.7)
51–100	10 (6.5)
101+	5 (3.3)

Unknown	2 (1.3)
How many hours per day, on average, do you use your mobile device (e.g., smartphone, tablet, cellphone)?	
1 hour/day or less	20 (13.0)
2–3 hours/day	36 (23.4)
4–6 hours/day	55 (35.7)
7–11 hours/day	12 (7.8)
12 or more hours/day	23 (15.0)
Unknown	8 (5.2)

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