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## ***The Positive Living Program: Development and pilot evaluation of a multimedia behavioral intervention to address HIV-related stigma and depression among African-immigrant PLWH in a large, Northwestern U.S. metropolitan area***

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### **Keywords**

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There are approximately 1.5 million African immigrants living in the United States (an estimated 99% of which are from Sub-Saharan Africa; (Anderson, 2015), and growing evidence suggests they are disproportionately and distinctly affected by HIV (Blanas et al., 2012; Koku et al., 2016). From 2008 to 2014, 11% of HIV diagnoses among Black Americans were among foreign-born Blacks, and 53% of diagnoses among Black foreign-born Americans were among African immigrants (Demeke et al., 2018). Moreover, a 2008 epidemiology study suggested that African immigrants had excessively high HIV incidence rates compared to the general U.S. population and to U.S.-born Black Americans (Kerani et al., 2008). African-immigrant people living with HIV (PLWH) also have unique risk factors, with higher infection rates in women and higher rates of heterosexual transmission when compared to other groups of PLWH in the United States (Demeke et al., 2018; Johnson, Hu, & Dean, 2010; Kerani et al., 2008). Furthermore, evidence has indicated that African-immigrant PLWH may be more likely to delay HIV testing (Ojikutu et al., 2013) and to present for care with advanced disease (Johnson et al., 2010; Page, Goldbaum, Kent, & Buskin, 2009).

For African immigrants, barriers to HIV testing and care include misperceptions of risk and prognosis, language and cultural discordance with health care providers, unfamiliarity with a foreign health care system, lack of employment and insurance, immigration-related issues, concerns about confidentiality, and perceived HIV-related stigma (Bova, Nnaji, Woyah, & Duah, 2016; Foley, 2005; Ojikutu, Nnaji, Sithole-Berk, Bogart, & Gona, 2014; Othieno, 2007; Simbiri, Hausman, Wadenya, & Lidicker, 2010). In addition to hindering testing and care, HIV-related stigma has also been connected to poor psychosocial outcomes (Mitzel et al., 2015). Studies from Europe have demonstrated that African-immigrant PLWH experience fear, anxiety, sadness, loneliness, and other symptoms of depression associated with HIV-related stigma (Chinouya, Hildreth, Goodall, Aspinall, & Hudson, 2017; Ndirangu & Evans, 2009; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012). Moreover, research has suggested that African-immigrant PLWH in the United States have unique and culturally-specific experiences with HIV-related stigma and related psychosocial issues (Koku, 2010; Ojikutu et al., 2013; Othieno, 2007).

Behavioral interventions (i.e., interventions designed to affect health-related behaviors) can benefit PLWH by providing information, skill-building, and coping strategies designed to counteract negative psychosocial consequences of living with HIV and HIV-related stigma (Rao et al., 2012). However, to date, interventions aimed at reducing HIV-related stigma and depression have not been studied among African-immigrant PLWH (Stangl, Lloyd, Brady, Holland, & Baral, 2013). Barrera, Castro, Strycker, and Toobert (2013) emphasized the importance of culturally adapting behavioral health interventions and described the necessary steps as (a) information gathering, (b) preliminary design, (c) preliminary testing, (d) refinement, and (e) final trial. The purpose of our study was to implement the first three steps (information gathering, preliminary design, preliminary testing) in the development of a culturally-adapted multimedia behavioral intervention to reduce HIV-related stigma among African-immigrant PLWH.

## Methods

Our study was conducted in a large, Northwestern U.S. metropolitan area where African immigrants constitute roughly 8% of the foreign-born population (McHugh & Morawski, 2016). The aims of our study were addressed sequentially. In Phase I, we collected qualitative data through individual interviews with key stakeholders (i.e., information gathering). We next used the qualitative data to guide the development of new intervention materials (i.e., a preliminary intervention). Then, in Phase II, we evaluated the preliminary intervention by assessing HIV-related stigma and depressive symptoms pre- and post-intervention in a sample of African-immigrant PLWH (i.e., preliminary testing). Specific methods for each study phase are described below.

### Phase I: Individual Interviews with Key Stakeholders

**Participants.**—Two types of key stakeholders were recruited for interviews: (a) African-immigrant PLWH and (b) health care workers (HCW) who provided care to African-immigrant PLWH. Eligible African-immigrant PLWH were at least 18 years old, English-speaking, and currently seeking HIV-related services. These individuals were recruited from a university-affiliated HIV clinic and a local peer-led community-based organization (CBO) for women living with HIV. Recruitment efforts were conducted in private and emphasized the voluntary nature of the study. Eligible HCW included physicians, social workers, mental health workers, and case managers currently working with African-immigrant PLWH.

**Data collection.**—For African-immigrant PLWH participants, we collected sociodemographic information including age, gender, living arrangement, marital status, number of children, highest education level, country of origin, years since immigrating to the United States, and years since HIV diagnosis. For HCW, we documented participant professional position only.

Audio-recorded, semi-structured interviews were conducted to elicit participant perspectives. One participant declined audio-recording, so the interviewer took detailed field notes to document responses. Participants were first asked about personal experiences living with HIV; these data are presented elsewhere (Nevin et al., 2017). Next, participants were asked questions about reducing HIV-related stigma using a behavioral intervention. Questions in this section pertained to intervention content, e.g., *Do you think disclosure is an important issue to include in a program designed to help PLWH?* and intervention delivery, e.g., *Should meetings be separated by language?* All questions were followed with clarifying probes (e.g., *Why? In what way?*). Finally, participants were shown materials from existing HIV-related stigma-reduction interventions and asked for feedback. The interventions included *Living Positively with HIV: A Follow-up Counseling Toolkit* (Strengthen Abilities to Manage and Respond Effectively to HIV/AIDS in India, 2006), developed for PLWH in India; *The Unity Workshop* (Rao et al., 2012), developed for African American women living with HIV in the United States; and *Turning to Sunshine* (unpublished), developed for PLWH in China. Materials demonstrated different media options including paper booklets, video vignettes, and multimedia tablet-based programs that incorporated images, audio, videos, and interactive exercises.

**Analysis.**—Audio-recorded responses were transcribed verbatim and uploaded into ATLAS.ti v.7 for coding and analysis. Two coders created a start list of thematic codes based on interview guides and initial reads of the transcripts. They then independently, deductively coded from this start list, while also inductively coding new themes that emerged from the data (Miles, Huberman, & Saldana, 2014). The coders met on multiple occasions to refine codes, address discrepancies, and reach consensus on themes.

## Phase II: Pre- and Post-Intervention Assessment

**Participants.**—For Phase II, we recruited African-immigrant PLWH only. Phase II participants included some Phase I participants ( $n = 17$ ) as well as participants recruited from the HIV clinics and a local peer-led CBO for women living with HIV. Recruitment was done privately, emphasized the voluntary nature of the study, and reminded potential participants that they could discontinue participation at any time.

**Data collection.**—After providing verbal consent, study participants used a tablet computer to self-report sociodemographic and HIV-related information and to complete a pre-intervention assessment. One week after the intervention, a research assistant contacted study participants and completed a post-intervention assessment. The post-intervention assessment was completed by phone to reduce participant burden and minimize loss to follow-up. All interactions were conducted in English.

**Measures.**—For Phase II, in addition to socio-demographic information collected in Phase I, we also collected information regarding where the participant was living when diagnosed with HIV (United States vs. country of origin), last CD4+ T-cell count, and medication adherence. The primary outcomes of interest were HIV-related stigma and depressive symptoms. To evaluate HIV-related stigma, we used the 14-item Stigma Scale for Chronic Illness (SSCI), validated for use with African Americans living with HIV (Rao et al., 2009; Rao et al., 2012). The scale included statements such as, *Because of my illness, people were unkind to me*. Participants responded on a 5-point Likert-type scale (from 1 = *Never* to 5 = *Always*) resulting in scores between 14 and 70. Depressive symptoms were assessed with the standardized and validated 8-item Patient Health Questionnaire (PHQ-8) scale (Kroenke et al., 2009). Regarding the preceding 2 weeks, participants responded to questions such as, *Have you been feeling down, depressed or hopeless?* and ranked answers on a 4-point Likert-type scale (from 0 = *Not at all* to 3 = *Nearly every day*) resulting in scores between 0 and 24.

**Analysis.**—Mean HIV-related stigma and depressive symptom scores were calculated at pre-intervention and 1-week post-intervention. Missing items on scales were mean imputed. Individuals missing entire scale responses were dropped from analysis. We utilized two sets of paired  $t$  tests to examine the null hypothesis that there was no change in HIV-related stigma or depressive symptoms from pre-intervention to 1-week post-intervention. We also calculated Cohen's  $d$  to estimate effect sizes for each outcome. Analyses were completed using Stata Statistical Software v.13.

All procedures were reviewed and approved by the University of Washington Institutional Review Board.

## Results

### Phase I: Individual Interviews With Key Stakeholders

During 2013 and 2014, interviews were completed with 20 African-immigrant PLWH: 8 recruited from HIV clinics and 12 recruited from the local CBO. Sociodemographic information for African-immigrant PLWH participants is provided in Table I. The majority (65%) were female and the median age was 43 years (range = 25–58 years). African-immigrant PLWH participants represented nine countries of origin with a majority (90%) from East Africa. Median time living in the United States was 12 years (range < 1–28 years) and median time since HIV diagnosis was 11 years (range = 1–19 years). We conducted 10 HCW interviews, which included 2 physicians, 2 social workers, 5 case managers, and 1 clinical psychologist/researcher.

**Necessity for Intervention**—Most participants reported that stigma was a challenge for African-immigrant PLWH, and stressed the importance of stigma-reduction interventions. One African-immigrant PLWH noted, “Information is power. If I got more knowledge about what to expect and how to deal with it, I’m better off.” Another African-immigrant PLWH emphasized the utility of targeting interventions to PLWH, “I think the only way we can help stigma is empower the person who is HIV positive because the other things you cannot change.”

### Intervention Content

**HIV-related stigma**.—Several participants requested general information about HIV-related stigma. One HCW explained why a module about stigma would be beneficial: “Just to give a name to what people are feeling, that alone. Because I think people don’t necessarily think about [their experiences] as stigma.” An African-immigrant PLWH expressed that it would be helpful to include content specifically on self-stigma, stating, “Knowing it happens to everyone and that they deal with it lets me know that I have to deal with it and can deal with it. This is useful.”

**Emotional distress and depression**.—Many participants also advocated for the inclusion of content on emotional distress and depression. One African-immigrant PLWH noted, “The more you talk with people, the more you get healed up from depression.” Often, the importance of these topics was discussed in the context of the additional stigma related to mental health. Some participants indicated that mental health stigma was especially problematic for African immigrants, potentially because of, “lack of information in our community.”

**Coping strategies**.—African-immigrant PLWH and HCWs both highlighted the importance of providing information about different coping mechanisms, including how to manage disclosure. A HCW remarked that, “You have to give them some tools [on] how to stay positive and cope with the stress [of living with HIV].” An African-immigrant PLWH

responded positively to the materials that demonstrated disclosure scenarios, stating, “It helps you know how to tell. No one has told me how to do disclosure and what questions I should consider. So, it would be nice to go through a process like this.”

### Intervention Delivery

**One-on-one versus group format.**—Responses were mixed regarding whether the program should be conducted in a one-on-one or group format. One African-immigrant PLWH expressed that she would prefer one-on-one, both because she was “self-conscious” and because listening to other people’s stories can be “emotionally exhausting.” Many participants suggested starting with one-on-one before transitioning to a group format. An African-immigrant PLWH thought this was particularly suitable for African immigrants, stating, “I know African culture. It would be appropriate to talk one-on-one with them first, like you’re talking to me, and ask them if they are comfortable to do a group.” A HCW agreed with the approach, but stressed the significance of ultimately transitioning to a group setting “because then they actually have to talk to people about it in front of people, and that exercise alone would be empowering and to also know that other people are in their same shoes.”

**Intervention facilitator.**—Participants had varying perspectives regarding who should lead the intervention. One African-immigrant PLWH thought a peer facilitator would be best, “somebody going through the same thing as you are going through.” Another African-immigrant PLWH thought a professional would be better, “someone who understands the aspects of the mental situation, maybe a counselor or psychologist.” Several participants reported that co-leaders (a peer and a professional) would be ideal. Interestingly, despite the support for a peer leader, many African-immigrant PLWH expressed that it was only acceptable, “as long as you’re not from my country.” Reluctance to have a peer facilitator from the same country seemed to stem from concerns about confidentiality. A HCW echoed this sentiment, but also noted that in her experience, some African-immigrant PLWH preferred providers from the same country of origin because, “they feel like, okay, she gets it, she gets the culture, she speaks the language.”

**Accommodating differences in culture and language.**—Multiple participants noted that differences in culture and language could present a challenge. “You cannot overcome the same issue with one approach,” one African-immigrant PLWH stated. A few participants suggested using translators or having language-specific groups, while another commented that many African-immigrant PLWH (in this large Northwest U.S. metropolitan area) speak English.

### Beta Testing and Final Adaptation

Based on findings from Phase I, a preliminary version of the behavioral intervention was developed and beta-tested with four African immigrants (not living with HIV) and two HCW with HIV expertise. The final version, entitled, *The Positive Living Program*, consisted of five modules covering four topics (a) self and social stigma, (b) understanding emotional distress and its effects on daily life, (c) coping strategies, and (d) disclosure. Coping strategies included mood monitoring, behavioral activation and problem-solving.



Coping strategies were chosen based on evidence-based effectiveness and simplicity of use, especially for non-native English speakers (Cuijpers, van Straten, & Warmerdam, 2007).

The intervention was delivered individually using a tablet-interfaced multimedia (visual, audio, and video) program, which was narrated by an African-immigrant physician. Character scenarios and storylines were played by African-immigrant actors, and were customized to reflect composites of actual experiences of African-immigrant PLWH (Nevin et al., 2017). Four research assistants (2 White American females, 1 Ethiopian-American female, and 1 Sudanese male) were trained to facilitate the tablet intervention, lead discussions and exercises, answer questions, and complete study measures with participants. The intervention was offered exclusively in English and took 90 to 120 minutes to complete.

## Results

### Phase II: Pre- and Post-Intervention Assessment

From December 2014 to June 2015, 25 African-immigrant PLWH participated in *The Positive Living Program* pilot: 9 recruited from HIV clinics, 9 recruited from the local CBO, and 7 referred by study participants or other university researchers working with African immigrants. One participant was lost to follow-up before completing the 1-week post-intervention assessment. No adverse events or unintended effects of the intervention were reported.

As seen in Table II, participants were mostly female (60%), and the median age was 45 years (range = 25–59 years). Most (80%) had at least some college-level education. The majority (84%) of participants were from East Africa. The median time since immigrating to the United States was 13 years (range <1–35 years), and the median time living with HIV was 11 years (range = 2–21 years). The majority (60%) were first diagnosed in the United States. All participants were currently taking antiretroviral therapy, and close to half (48%) reported perfect adherence in the previous month.

**HIV-related stigma (SSCI).**—Pre-intervention, the mean SSCI score was 38.5 ( $SD = 11.5$ ) with all participants reporting at least some level of stigma ( $SSCI > 14$ ). At 1-week post-intervention, all study participants again reported at least some form of stigma. However, the mean SSCI score was lower (mean = 35.6,  $SD = 12.5$ ,  $t = 1.31$ ,  $p = 0.20$ , Cohen's  $d = 0.27$ ). Post-hoc analyses showed that, on average, items corresponding to internalized stigma decreased more than items corresponding to enacted stigma. The mean for internalized stigma items decreased from 16.3 ( $SD = 1.2$ ) to 14.6 ( $SD = 1.4$ ,  $t = 1.39$ ,  $p = 0.18$ , Cohen's  $d = 0.28$ ) and the mean for enacted stigma items decreased from 13.6 ( $SD = 1.1$ ) to 12.7 ( $SD = 1.2$ ,  $t = 0.76$ ,  $p = 0.46$ , Cohen's  $d = 0.15$ ).

**Depressive symptoms (PHQ-8).**—Pre-intervention, the mean PHQ-8 score was 7.8 ( $SD = 5.3$ ). At 1-week post-intervention, the mean PHQ-8 score had decreased to 5.4 ( $SD = 5.3$ ,  $t = 2.76$ ,  $p = 0.01$ , Cohen's  $d = 0.56$ ). Post-hoc analyses examined the distribution of symptomatic groups based on PHQ-8 clinical cut-points (Kroenke et al., 2009). Pre-intervention, 7 (28%) study participants reported minimal depressive symptoms, 9 (36%) reported mild depressive symptoms, and 9 (36%) reported moderate to moderately severe

depressive symptoms. At 1-week post-intervention, 13 (54%) study participants reported minimal depressive symptoms, 6 (25%) reported mild depressive symptoms, and 5 (21%) reported moderate to moderately severe depressive symptoms. A Stuart-Maxwell test of marginal homogeneity did not show a statistically significant difference ( $\chi^2 = 6.85$ ,  $p = 0.08$ ) in these clinical categories pre- and post-intervention.

## Discussion

The purpose of this mixed-methods study was to develop and pilot a culturally-adapted multimedia behavioral intervention to address HIV-related stigma and depression among African-immigrant PLWH. In Phase I, African-immigrant PLWH and HCW provided rich qualitative data about adapting existing HIV-related stigma intervention materials for an African-immigrant audience. Participants generally concurred regarding intervention content and the importance of considering confidentiality and cultural factors; however, there were differing opinions about intervention delivery. In Phase II, the adapted intervention, *The Positive Living Program*, was piloted in a small sample of African-immigrant PLWH. At 1-week post-intervention, participants reported reduced depressive symptoms.

In our study, key stakeholders indicated that an effective intervention for this population should include content on HIV-related stigma, emotional distress and depression, coping strategies, and disclosure. These topics were consistent with stigma-related challenges reported by African-immigrant PLWH in the United States (Foley, 2005; Nevin et al., 2017), Europe (Chinouya et al., 2017; Sumari-de Boer et al., 2012), and Canada (Gardezi et al., 2008; Logie, James, Tharao, & Loutfy, 2013). Furthermore, this combination of content highlighted three of the four most common types of HIV-related stigma-reduction strategies: (a) information, (b) skill-building, and (c) counseling approaches; the fourth strategy, contact with affected groups, is discussed below (Brown, Macintyre, & Trujillo, 2003).

Delivering the intervention individually with a tablet-interfaced multimedia program featuring African-immigrant characters was a compromise between a one-on-one format and group setting. Several participants in Phase I expressed the desire for a group format. Contact with affected people is a key component of stigma reduction (Brown et al., 2003; Corrigan, 2011), and there is evidence that peer interventions can improve HIV knowledge and attitudes (Simoni, Nelson, Franks, Yard, & Lehavot, 2011). However, intense concerns about inadvertent disclosure made group contact impractical for a pilot program in this population. Instead, *The Positive Living Program* used African-immigrant actors and customized storylines based on experiences of local African-immigrant PLWH to provide a peer-like environment without evoking fears about confidentiality.

Phase II of this study explored the effectiveness of *The Positive Living Program*. At 1-week post-intervention, participants had a statistically significant reduction in depressive symptoms. The effect size, while small, may also be considered clinically significant (Norman, Sloan, & Wyrwich, 2003). These results suggest that a behavioral intervention like *The Positive Living Program* may be effective in relieving poor psychosocial outcomes experienced by African-immigrant PLWH. Participant HIV-related stigma scores also decreased, although this change was not statistically significant. Clinically significant



changes in HIV-related stigma are not defined; however, the fact that there was some decrease in stigma scores, especially in internalized stigma, may suggest that part of the psychosocial relief was a result of changes in stigma.

Our study had several limitations. First, likely due to high levels of HIV-related stigma in this community (Nevin et al., 2017), recruitment was challenging. Consequently, the Phase II sample was relatively small (reducing our power to detect associations of interest) and did not include a control group. Furthermore, we included participants from Phase I in Phase II, potentially introducing bias. Second, while we believe that the study samples were representative of local African immigrants in terms of country of origin, the samples were limited to English speakers, likely excluding key members of the African-immigrant community (e.g., recent immigrants). Similarly, we believe that the African-immigrant PLWH who participated in our study had, on average, been living with HIV longer than the population from which they were sampled. As such, our findings may not be generalizable to African-immigrant PLWH who are newly immigrated and/or diagnosed. Moreover, HIV-related stigma is a known barrier to HIV study participation by ethnic minority communities (Newman et al., 2006). Participants in our study may represent a specific subset of African-immigrant PLWH who have lower levels of stigma or who have better learned to cope with their stigma. Finally, although our measure of HIV-related stigma was validated by African-American PLWH (Rao, Molina, Lambert, & Cohn, 2016), it has not been validated among African-immigrant PLWH. The unique stigma experiences of African-immigrant PLWH may necessitate specialized measurement considerations.

## Conclusion

Input from key stakeholders and observed decreases in depressive symptoms post-intervention indicated that a multimedia behavioral intervention such as *The Positive Living Program* could be an effective way to address poor psychosocial outcomes associated with HIV-related stigma among African-immigrant PLWH. To complete the cultural-adaptation process, our intervention requires further refinement (with the assistance of African-immigrant PLWH) and final testing. Replication of these procedures should be pursued with an updated intervention, in a larger sample, with random assignment to intervention and control arms. Reliability and validity of the final intervention should also be evaluated. Future studies should also investigate (a) generalizability of findings to African-immigrant PLWH who do not speak English or are newly diagnosed, and (b) psychometric evaluation of HIV-related stigma measures for African-immigrant PLWH.

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All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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**Table I.**

Phase I African Immigrant PLWH Participant Characteristics (n = 20)

	Median/n	Range/%
Age (years)	43 years	25–58 years
Sex		
Male	7	35%
Female	13	65%
Living arrangement		
Alone	2	10%
With other adults, no dependents	9	45%
With other adults and dependents	5	25%
With dependents only	4	20%
Marital status		
Never been married	3	15%
Married or living with partner	9	45%
Separated, divorced, or widowed	8	40%
Number of children		
None	3	15%
1–3	16	80%
4+	1	5%
Education		
Less than high school	2	10%
High school or equivalent	2	10%
Some college/associate degree/technical degree	7	35%
College degree or more	9	45%
Area of origin		
Eastern Africa	18	90%
Western Africa	1	5%
Northern Africa	1	5%
Central Africa	0	0%
Southern Africa	0	0%
Years since immigrating to United States	12 years	< 1–28 years
Years living with HIV	11 years	1–19 years

**Table II**

Phase II African Immigrant PLWH Participant Characteristics at Baseline (n = 25)

	Median/n	Range/%
Age (years)	45 years	25–59 years
Sex		
Male	10	40%
Female	15	60%
Living arrangement		
Alone	4	16%
With other adults, no dependents	7	28%
With other adults and dependents	9	36%
With dependents only	5	20%
Marital status <sup>a</sup>		
Never been married	4	17%
Married or living with partner	11	46%
Separated, divorced, or widowed	9	37%
Number of children		
None	6	24%
1–3	14	56%
4+	5	20%
Education		
Less than high school	1	4%
High school or equivalent	4	16%
Some college/associate degree/technical degree	14	56%
College degree or above	6	24%
Area of origin		
Eastern Africa	21	84%
Western Africa	2	8%
Northern Africa	1	4%
Central Africa	1	4%
Southern Africa	0	0%
Years since immigrating to United States	13 years	< 1–35 years
Years living with HIV	11 years	2–21 years
Location of HIV diagnosis		
United States	15	60%
Area of origin	10	40%
Most recent CD4+ T-cell count (cells/ $\mu$ L) <sup>a</sup>	450 cells/ $\mu$ L	10–1,358 cells/ $\mu$ L
In the last 30 days, number of HIV meds missed		
0	12	48%
1–2	10	40%
3+	3	12%



<sup>a</sup>.missing data.

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