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# A Randomized Controlled Trial of the Efficacy of a Stigma Reduction Intervention for HIV-Infected Women in the Deep South

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## Abstract

The aim of this study was to compare outcomes (self-esteem, coping self-efficacy, and internalized stigma) across time in HIV-infected women living in the Deep South who received a stigma reduction intervention ($n=51$) with those of a control group ($n=49$) who received the usual care at baseline, and at 30 and 90 days. We recruited 99 women from clinics and an AIDS service organization; they were randomized by recruitment site. A video developed from the results of a qualitative metasynthesis study of women with HIV infection was loaded onto iPod Touch devices. Participants were asked to watch the video weekly for 4 weeks, and to record the number of times they viewed it over a 12-week period. We examined the trajectory model results for efficacy outcomes for the intent-to-treat and the supplemental completers groups. There was a treatment-by-time effect for improved self-esteem (intent-to-treat: $p=0.0308$; completers: $p=0.0284$) and decreases in internalized stigma (intent-to-treat: $p=0.0036$; completers: $p=0.0060$), and a treatment-by-time-by-time effect for improved coping self-efficacy (intent-to-treat: $p=0.0414$; completers: $p=0.0321$). A medium effect of the intervention in terms of improving self-esteem was observed when compared with the control condition in those who completed the study. The magnitude of the intervention effect, however, was large with regard to reducing overall stigma, improving social relationships, and decreasing stereotypes in both groups.

## Introduction

Herek defined HIV-related stigma as ''prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV.''[1] Earnshaw and colleagues defined three different mechanisms of stigma: (1) internalized HIV stigma, which refers to having negative feelings and beliefs associated with HIV and applying them to the self; (2) anticipated HIV stigma, which involves expectations of discrimination, stereotyping, and/or prejudice from others in the future because of one's HIV; and (3) enacted HIV stigma, which involves experiences of discrimination, stereotyping, and/or prejudice from others in the past or present because of one's HIV.[2] Higher levels of HIV-related stigma are related to increased incidence of depression,[3] more post-traumatic stress disorder, and more risky sexual behavior,[4] as well as poorer access to care.[5,6] Stigma is associated with helplessness regarding HIV, increased days in medical care gaps, antiretroviral (ARV) therapy non-adherence, low CD4 count, and chronic illness comorbidity;[2,7] it is also associated with low social support, poor physical and mental health, lower income, and younger age.[8]

According to the Centers for Disease Control and Prevention (CDCP), in the United States, women now account for >25% of all new HIV/AIDS diagnoses.[9] Sandelowski et al.,[10] in their metasynthesis, found that stigma was synonymous with the experience of HIV in women. Living with HIV meant living with the fear and hurtful effects of stigmatization, including social rejection, discrimination, and even violence, in relationships with children, partners, relatives, friends and acquaintances, employers, co-workers, and healthcare providers. Women internalized negative cultural views of HIV infection to such an extent that they perceived stigma even when they did not actually experience it. Just being a woman, with the capacity to bear and infect children, added to their stigmatization.[10] Other researchers have confirmed that women experience greater HIV-related stigma than men.[11,12] The effects of HIV-related stigma appear to be

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worse for women than for men;[13,14] women who experience HIV discrimination have more stress, suicidal ideations, depressive symptoms, and unprotected sexual episodes than infected men.[15] They have poor self-esteem[15–17] and quality of life,[15] and are less likely than men to receive medical care for HIV.[15] Stigma has profoundly adverse effects on HIV prevention and treatment.[18,19] Because of stigma, women who are infected may not insist that a male partner use a condom, fearing that this request may signal HIV-infected status. Further, HIV-infected women may not want to take ARV medications in front of others, fearing questions about the pills and their reasons for taking them.

Stigma and stigmatization function at the intersection of power and culture,[20] areas in which HIV-infected women are often subordinate. Because stigma is culturally bound, we have limited the studies reviewed here to those conducted in the United States. The stigma is compounded for those who are most at risk: poor minority women with children, who are marked by the stigmas of poverty and racism, assumptions of promiscuity and/or illicit drug use as the source of her infection, and condemnation of being an HIV-infected mother who should not have had children because of the infection. African American women living with HIV experience stigma internally as existential despair, socially as shunning and callousness, and institutionally as disregard.[21] In a report from the Southern HIV/AIDS Strategy Initiative (SASI), North Carolina was identified as one of the Deep South states that, according to CDCP surveillance data, has been disproportionately affected by the HIV epidemic in recent years as a result of overall poor health status, high poverty rates, and a cultural conservatism fostering HIV-related stigma.[22] Rural women living with HIV infection in the Southeastern United States report perceived and internalized stigma as having a negative effect on quality of life,[23] and older women in the South found HIV infection to be isolating because of stigma.[24] Turan and Nyblade,[25] in a review of the evidence about HIV-related stigma as a barrier to achievement of global prevention of mother-to-child transmission (PMTCT) and maternal health goals, found that stigma negatively impacted service uptake and adherence at each step of the PMTCT cascade, and that the effects were cumulative. These findings about stigma adversely impacting PMTCT were also found by Hiarlaithe et al.[26]

Clearly, reducing HIV-related stigma is essential to improving health outcomes for HIV-infected women. Brown et al.[27] reviewed 22 studies that tested a variety of interventions to decrease HIV-related stigma; however, they were directed primarily at the general population (people without HIV), and healthcare workers. In their reviews, Mahajan et al.[28] and Sengupta et al.[29] also found that interventions were conducted primarily with the general population; only a few were directed toward developing coping skills among people living with HIV. A more recent systematic review reported only two interventions to reduce HIV-related stigma and discrimination conducted with people living with HIV in the United States; one of those is reported later in this article, and the other was for HIV-infected youth, who have different concerns from those of adults with regard to stigma.[30] Recently, several intervention studies conducted with HIV-infected people in the United States have included content on dealing with stigma and disclosure, such as disclosure from parent to child.[31] A self-care symptom management program administered by nurses over six visits was found to reduce feelings of stigma,[32] and women who received an emotional writing disclosure intervention designed to alleviate perceived HIV-related stigma had greater cognitive reorganization and improvements in perceived HIV-related stigma scores than did a control group.[33] Another intervention to target those being stigmatized was a workshop across two afternoons, focused on internalized stigma experiences for African American women living with HIV infection.[34] Participants watched videos, learned coping mechanisms, and practiced them by role-playing with one another. Stigma decreased from the start of the workshop to the end and 1 week after.[34] Project ROADMAP, a targeted secondary prevention program for older HIV-infected women, led to decreases in stigma and risky sexual behaviors.[35] Farber et al.[36] reported that participating in an HIV mental health services program reduced perceived stigma. However, stigma reduction interventions conducted with HIV-infected persons thus far have been face-to-face interventions, which are not only expensive but are difficult to implement when participants have a stigmatizing illness and may not want to participate in a group. Therefore, examining alternatives to face-to-face interventions is critical to mitigate stigma. For women in rural locations, or for those without reliable transportation, technologically driven interventions may be an effective way to reach women who would otherwise be excluded.[37] In the rural Deep South, isolation and poverty compound the stigma of HIV infection.[38] We need new ways to mitigate the negative effects of stigma on women with HIV infection, improve their self-esteem and coping self-efficacy, and enable them to safely disclose their status, which may help them to better practice prevention behaviors and adhere to their medication regimens.

This study builds on research done by Sandelowski et al. from 2000 to 2005[10,39] on a National Institute of Nursing Research (NINR)-funded study (R01 NR04907, Sandelowski PI) that developed a protocol for the systematic integration of findings of qualitative studies conducted with HIV-infected women in the United States. The sample consisted of 1780 women, mostly pregnant women and mothers; 71% were minorities. The stigmatization inherent in HIV compelled women to engage in the ''unending work and care''[40] of stigma management. Although most of the women had contracted HIV in heterosexual and monogamous relationships, other people often assumed that these women had become infected through intravenous drug use, promiscuity, or prostitution. These assumptions, and the minority social position of most of the women, resulted in others viewing the women as being especially blameworthy. Stigma management included normalization of HIV infection, education and advocacy, participation in supportive communities, and information control.[10,41] This metasynthesis inspired Sandelowski and Barroso to find a novel way to disseminate information on HIV-related stigma to clinicians, researchers, and women with HIV infection. One of these vehicles is a video based on the metasynthesis, which explores the stigma borne by HIV-infected women.[10,39] The 45-min video presents vignettes of five seropositive women and the ways in which stigma has affected their lives, and is meant to empower HIV-infected women by reducing internalized stigma, enhancing self-esteem, and improving coping self-efficacy. The video is designed to work via narrative transportation, a

mental process that melds attention, imagery, and feelings, allowing the viewer to become absorbed and transported into the worlds of the women featured.[42] The video was converted to an MP4 file so that it could be viewed on an iPodTouch, a portable media player approximately the size of a cell phone, to allow women safety and privacy when viewing the video. This mixed-methods, longitudinal, pilot study allowed us to compare outcomes across 90 days in women who received the stigma intervention with a control group receiving the usual care (standard medical care for HIV infection, without any particular attention to stigma).

The primary aim of the study reported here was to assess the feasibility, acceptability, and utility of implementing a low-cost, technologically delivered intervention to mitigate the negative effects of HIV-related stigma on women. The second aim was to compare outcomes (self-esteem, coping self-efficacy, and internalized stigma) across time in women who received the stigma intervention with those of a control group who received the usual care at baseline and at 30 and 90 days. We report the findings related to the second aim in this report.

## Methods

### *Participants, sites, and recruitment*

Women living with HIV or AIDS, $\geq 18$ years of age, who were able to communicate in English and were mentally competent to provide informed consent, were included in the study. We included only women who scored $\geq 40^5$ on the Internalized HIV Stigma Scale[43] to ensure that we were capturing women who felt stigmatized. The video is in English only. Participants were recruited from six sites in a Southeastern state, ranging from health departments to infectious disease clinics, from which HIV-infected people receive healthcare or social services. Most HIV-infected people in the Raleigh/Durham/Chapel Hill area use one of these sites.

Power analyses indicated that a sample size of 100 would be required to achieve at least 80% power to detect significant between-group changes in the primary outcomes (self-esteem, coping self-efficacy, and stigma) using mixed-effects models for repeated measures with the significance set at 0.05 for each nondirectional statistical test. The sample size determination was based on the following assumptions: (1) 70% within-person correlation across time; (2) a medium effect size (Cohen $f = 0.35$) would represent the smallest clinically meaningfully effect for the group trajectories; and (3) a medium effect size (Cohen $d = 0.55$) would yield clinical significance when comparing group means at day 90.[44] The sample size estimate was not adjusted for attrition, because mixed-effects models allow data missing at random.

A stratified, permuted block randomization was applied in which recruitment site was the stratification variable and the block size was four. Using a 1:1 treatment allocation, the 100 enrolled women were randomly assigned to either the stigma reduction intervention ($n = 51$) or the control condition ($n = 49$). Those randomized to the intervention arm received an iPod Touch with the video loaded on it as an MP4 file, whereas the 49 women in the control group received an iPod Touch with nothing loaded on it. We collected data at baseline and at 30 and 90 days post-randomization; the time intervals selected allowed enough time for women to assimilate the messages in the video (30 days) and to test the durability of the intervention (90 days). Before implementing the intervention, we distributed flyers at a tertiary care infectious diseases clinic to recruit 10–15 HIV-infected women (who met the inclusion criteria for the primary study) to participate in a pre-intervention focus group, to obtain data for refining study instruments and procedures. The group viewed the video, and we asked them about the logistics of viewing it as an MP4 file on an iPod Touch, with a focus on safety and privacy. We also asked for a critique of the viewing log and suggestions for its improvement, and if there was anything that would interfere with or facilitate watching the video and completing the study requirements. Each woman received a $25 gift card for focus group participation. These women were not eligible to participate in the intervention portion of the study.

After incorporating the feedback from the women in the focus group and refining the intervention, flyers were distributed at the recruitment sites instructing women to call the principal investigator (PI), who screened them over the phone using the inclusion criteria, and explained what the study would require. If they were interested, the PI obtained participants' contact information. A meeting was arranged with the participant at a location of her choice, to obtain written informed consent, give her the iPod Touch and show her how to use it, and collect the baseline data. The iPod Touch was password protected for the woman's safety, and women were instructed how to enter the password. The research assistant (RA) also reviewed the viewing log with the woman and showed her how to complete it, if she was randomized to the intervention arm. The RA emphasized that the video discusses HIV infection, and discussed with the participant how, when, and where she could safely and privately watch it.

### *Intervention*

The stigma intervention is a 45-min video titled, ''Maybe Someday: Voices of HIV-Positive Women.'' It portrays five composite representations of the women from the studies in the metasynthesis, with each relating a narrative based on one or two themes derived from the synthesized studies. Characters in the video are designed to connect with viewers on multiple levels and acknowledge the interplay, connections, and potential disconnections between their HIV status and other aspects of their lives. Each character shares difficult personal details with an off-camera listener and affords viewers the privilege of witnessing her reflections and, in some cases, decision making. Main points in the video include the experience of being an HIV-infected women; the fear of the negative social effects that come with telling other people about one's HIV status; women's tremendous struggle about whether or not to tell their children; the importance of communicating with nurses, doctors, and those family members and friends whom they trust; the positive effects of disclosure; the extra stigma and discrimination connected with being a woman, being a minority woman, and being a mother; and ambivalence about disclosing one's HIV status to potential and actual sex partners.[39] Two characters are African American, two are Hispanic/Latina, and one is white. A female narrator speaking directly to the camera (and viewer) offers an orientation to the program, introduces each character, debriefs each monologue, and provides a conclusion. The narrator informs the viewer that performers are not actual patients but are actors presenting information generated from studies in which research interviews were conducted with HIV-positive

women.[39] Our research staff told women that the video dealt directly with issues surrounding HIV-infected women, with vignettes based on interviews conducted with ~1700 HIV-infected women in 93 different studies.[10] To ensure adequate exposure to the content, women were asked to watch the entire video at least once a week during the first 4 weeks; however, they could watch more often if desired, and were asked to note in the viewing log when and how long they watched.

### Procedures

When the participants met with the RA to receive the iPod Touch device, the participant completed the baseline study surveys, including an investigator-developed demographic form, the Rosenberg Self-Esteem Scale (RSES),[45] and the Coping Self-Efficacy Scale (CSES).[46] The Internalized HIV-Related Stigma Scale (IHSS)[43] completed during the screening phone call was also included in the baseline study data. Women who were randomized to the intervention were given an MP4 player with the ''Maybe Someday'' video loaded on it, a wall charger, and a guided tutorial to operating the player. Before leaving the visit, the participant was asked to demonstrate accessing and playing the video. If confidentiality was a concern, the RA helped generate ideas about the best time and place to watch the video, and where to safely store the device. Participants were instructed to watch the video at least once per week for the first 4 weeks of the study, then as much or as little as desired for weeks 5–12. The women were given a log book to record their time spent viewing the video, and were encouraged to journal any thoughts that were prompted by the video. A study team member called the women in the intervention group within 2 weeks of the baseline visit to see if they were having any issues with the MP4 player, and to remind them about watching the video weekly.

The RSES, CSES, and IHSS surveys were mailed out at 30 days with self-addressed, stamped envelopes. Study team members made reminder calls if the surveys were not returned after 2 weeks, and re-mailed them if necessary. Upon return of the surveys, participants were given a $10 gift card to thank them for their time. At 90 days, the same surveys were mailed out to participants in both the control and intervention groups. Women in the intervention were also asked to return their viewing logs along with their surveys at 90 days. Women in both groups kept the iPod Touch to thank them for participating in the study. At the conclusion of data collection, we randomly selected participants from the intervention arm to participate in a focus group, to get their perceptions of the intervention and to identify what was most helpful to them. We offered the video to the women in the control group at the conclusion of data collection and several (fewer than five) requested it; we fulfilled these requests. These data helped us determine the feasibility, acceptability, and utility of the intervention. Women who participated in the focus group received a $25 gift card.

### Measures

Most of the instruments have been used in other studies of HIV-infected participants. All require less than an eighth grade reading level. The IHSS, the primary outcome, was developed after the advent of protease inhibitors, so the items represent stigma in the era of highly active ART (HAART). We used a demographic data collection instrument that we developed and that has been used in our other studies with HIV-infected participants [age, race, educational level, type of employment, current living arrangements, number of children, caregiving responsibilities, adequacy of income, history of injection drug use, history of other substance abuse (including alcohol), beliefs about how the participant acquired HIV, number of years with HIV diagnosis, antiretroviral history, current medications, knowledge of most recent CD4 count and HIV viral load, and history of HIV-related illnesses].

Self-esteem was measured using the RSES, which is a 10-item measure of global self-esteem using a four-point Likert scale ranging from ''strongly agree'' to ''strongly disagree.''[45] The overall scale scores range from 0 to 30; some items are reversed. Higher scores indicate greater self-esteem. The RSES has been widely used in psychological, sociological, nursing, and biobehavioral research. There is evidence of high internal consistency (Cronbach's $\alpha$ ranging from 0.72 to 0.87) and test–retest reliability;[45] it has been used extensively in research with HIV-infected participants.

Coping self-efficacy was measured using the CSES;[46] this 26-item scale measures perceived efficacy for coping with challenges and threats. Respondents are asked to rate on an 11-point scale the extent to which they believe they could perform behaviors important to adaptive coping when faced with life challenges. An overall CSES score is created by summing item ratings. It was developed for people with HIV infection. The range of scores is from 0 to 286, with higher scores indicating greater coping self-efficacy.[46] Exploratory and confirmatory factor analyses revealed three factors composing the scale; internal consistency and test–retest reliability were strong for all three. Researchers have also found strong evidence of concurrent and predictive validity.[46]

HIV-related stigma was assessed using the IHSS, a 28-item, multidimensional measure of internalized HIV stigma.[43] Respondents are asked to rate on a five-point categorical response scale the extent to which they experience stigma (none of the time, a little bit of the time, some of the time, most of the time, all of the time). The range of scores is 0–100, with lower scores reflecting fewer perceptions and experiences of internalized HIV stigma, and higher scores reflecting greater levels of stigma.[43] The median score on this instrument has been documented to be 40; as stated previously, all women in the study scored $\geq 40$, as this was used to screen participants. Sayles[43] reports strong internal consistency (Cronbach's $\alpha = 0.93$). The instrument examines four factors associated with internalized stigma: stereotypes, disclosure concerns, social relationships, and self-acceptance. Psychometric analysis by Sayles included exploratory and confirmatory factor analysis, which revealed the four factors and demonstrated concurrent and predictive validity.[5,43]

### Statistical analyses

Descriptive statistics were used to summarize the sociodemographic characteristics at enrollment and the efficacy measures collected at baseline (enrollment), day 30, and day 90 for the entire sample and the intervention condition (intervention vs. control). The two treatment conditions were compared at baseline using Wilcoxon two-sample tests for quantitative, continuous measures caused by issues of non-normality of some measures, and Fisher's exact tests for categorical measures caused by low frequency counts observed for some measures to

identify potential covariates to be included in the efficacy analysis. The evaluation of the change in the efficacy outcomes over the 90 days in the two conditions included an intent-to-treat (defined as all randomized women) as a primary analysis and a completer's analysis as a supplemental analysis. Two tailed statistical tests were performed using SAS 9.3 (Statistical Analysis Software, Cary, NC), with the level of significance set at 0.05. Because of the exploratory nature of the study, the significance level for each test was not adjusted for multiple testing.

Random coefficients regression models (a type of hierarchical mixed-effects model for measures) were used to examine between-condition differences in the trajectories of change in the efficacy outcomes across time (baseline, 30 days, and 90 days). Fixed effects were treatment condition, time, and treatment-by-time, whereas random effects were participant and participant-by-time. The models were fitted for a nonlinear pattern of change in outcome over time, as needed. Racial/ethnicity category (black or non-black) and other potential covariates were included as fixed-effect terms in the initial regression models, but only those potential covariates that were significant at the 0.05 level were retained in the final model. *A posteriori* contrasts were performed based on the individual trajectories results to test for between-treatment differences and to estimate effect sizes for each outcome at 90 days.

## Results

Of the 129 women screened, 114 were eligible to participate and 100 signed consent forms to participate and were randomized. Among the 51 women randomized to the stigma intervention, 48 (94.1%) remained in the study at 30 days, and 43 (84.3%) remained at 90 days. Of 49 women assigned to the control condition, 47 (97.9%) remained in the study at 30 days and 45 (93.8%) remained at 90 days. Therefore, 88 (88.9%) of the 99 women completed the day 90 assessment [see Fig. 1 – Consolidated Standards of Reporting Trials (CONSORT) Diagram]. There was no statistical difference in attrition rates between the intervention and control conditions, or among the recruitment sites (all $p > 0.05$). Demographic and HIV illness characteristics are included in Table 1: 82% of the women were African American, 37% were single/never married, the median monthly income was $700, the mean number of years since diagnosis was 13.7 years, and the mean age was 46 years. Among the 99 women, 52% of the participants were taking an antidepressant medication; most (90%) had some other chronic health condition, with the largest number reporting hypertension (40%); 66% reported some form of lifetime substance abuse, with marijuana use reported by 51%; and 92% were on ART.

With regard to Aim 1, these data are still being compiled. However, evidence suggests that utilizing technology to deliver a stigma reduction intervention to women infected with HIV is feasible. Among the women in the intervention arm, there were no breaches in privacy, no breaches in confidentiality, and no unplanned disclosures of HIV status to another person. Further, there was no evidence that women could not successfully utilize the technology independently. During the course of the study, only two women (3.9% of the women in the intervention arm) had to have the iPod replaced. Data

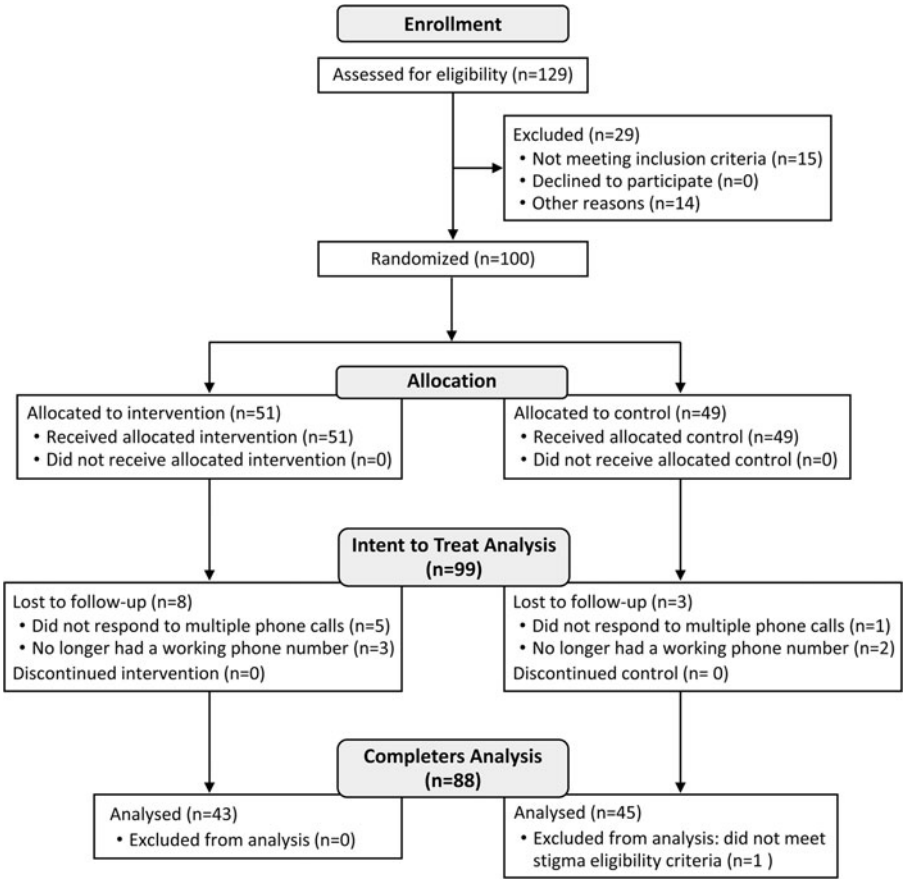


**FIG. 1.** CONSORT diagram.

Table 1. Sociodemographic and HIV Illness Characteristics of Sample

| *Characteristic* | *Total* (n = *99*) | *Control* (n = *48*) | *Intervention* (n = *51*) | p *Value* |
|---|---|---|---|---|
| Age, in years | 45.9 ± 9.7 | 45.5 ± 9.4 | 46.3 ± 10.1 | ns |
| Racial group | | | | ns |
| Black or African American | 82 (82.8%) | 40 (83.3%) | 42 (82.4%) | |
| White or Caucasian | 11 (11.1%) | 5 (10.4%) | 6 (11.8%) | |
| Other | 6 (6.1%) | 3 (6.3%) | 3 (5.9%) | |
| Hispanic/Latino ethnicity | 6 (6.1%) | 3 (6.3%) | 3 (5.9%) | ns |
| Marital status-1 | | | | ns |
| Married–monogamous relationship | 22 (22.7%) | 16 (34.0%) | 6 (12.0%) | |
| Not currently married–widowed | 16 (16.5%) | 7 (14.9%) | 9 (18.0%) | |
| Not currently married–divorced | 19 (19.6%) | 2 (4.3%) | 17 (34.0%) | |
| Cohabitating with long-term partner | 4 (4.1%) | 3 (6.4%) | 1 (2.0%) | |
| Single/never married | 36 (37.1%) | 19 (40.4%) | 17 (34.0%) | |
| Marital status-2 | | | | 0.0054 |
| Married or cohabitating with long-term partner | 26 (26.8) | 19 (40.4%) | 7 (14.0%) | |
| Years of education | 12.5 ± 2.2 | 12.7 ± 2.1 | 12.4 ± 2.3 | ns |
| Currently employed | 18 (18.4%) | 11 (23.4%) | 7 (13.7%) | ns |
| Number residing in household (including self) | 2.6 ± 1.8 | 2.7 ± 1.6 | 2.5 ± 2.1 | ns |
| 1 resident | 35 (36.1%) | 11 (23.9%) | 24 (47.1%) | |
| 2 residents | 23 (23.7%) | 15 (32.6%) | 8 (15.7%) | |
| 3 residents | 16 (16.5%) | 9 (19.6%) | 7 (13.7%) | |
| 4 residents | 10 (10.3%) | 5 (10.9%) | 5 (9.8%) | |
| 5 residents | 5 (5.2%) | 2 (4.4%) | 3 (5.9%) | |
| > 5 residents | 8 (8.2%) | 4 (8.7%) | 4 (7.8%) | |
| Primary caregiver for someone in your household | 32 (33.7%) | 18 (38.3%) | 14 (29.2%) | ns |
| Total monthly income, in dollars (mean ± SD) | 1111 ± 1445 | 1308 ± 1905 | 919 ± 737 | ns |
| Total monthly income, in dollars (min, median, max) | 0, 700, 12500 | 0, 699, 12500 | 0, 700, 4000 | ns |
| How contracted HIV | | | | ns |
| Sex with a man | 76 (76.8%) | 39 (81.3%) | 37 (72.6%) | |
| Injection drug use | 8 (8.1%) | 2 (4.2%) | 6 (11.8%) | |
| Blood transfusion | 4 (4.0%) | 2 (4.2%) | 2 (3.9%) | |
| Occupation exposure | 1 (1.0%) | 1 (2.1%) | 0 (0.0%) | |
| Other | 10 (10.1%) | 4 (8.3%) | 6 (11.8%) | |
| Ever injected street drugs | 22 (22.2%) | 7 (14.6%) | 15 (29.4%) | ns |
| Sexual orientation | | | | ns |
| Heterosexual | 84 (86.6%) | 41 (87.2%) | 43 (86.0%) | |
| Lesbian | 4 (4.1%) | 2 (4.3%) | 2 (4.0%) | |
| Bisexual | 7 (7.2%) | 3 (6.4%) | 4 (8.0%) | |
| Other | 2 (2.1%) | 1 (2.1%) | 1 (2.0%) | |
| Years since contracted HIV | 13.7 ± 7.1 | 14.1 ± 7.0 | 13.4 ± 7.3 | ns |
| Most recent CD4 count (mean ± SD) | 629 ± 348 | 656 ± 337 | 602 ± 362 | ns |
| Most recent CD4 count (min, median, max) | 25, 567, 1693 | 50, 635, 1500 | 25, 550, 1693 | ns |

Data presented as mean ± standard deviation (SD) for continuous measures and number of *n* (%) for categorical data; Wilcoxon two sample tests for continuous measures and Fisher's exact tests for binary measures; ns = $p > 0.05$.

indicate that the women participating in the intervention arm of this study found the video vignettes to be meaningful and reflective of their experiences related to HIV-related stigma and being a woman infected with HIV. Data revealed that the women could easily imagine the stories taking place, could picture themselves in the stories described in the video, wanted to learn what happened to the women after each story ended, thought about how the women's lives might have turned out, and believed the stories were relevant to everyday life. Further, the women identified the stories in the video as realistic and believable; felt that these stories represented people whom they might actually know, dealt with the kind of very difficult choices people in real life have to make, and showed that women living with HIV or AIDS experience many challenges; and believed that the events depicted could have actually happened. Items suggest that the women were engaged in the stories being portrayed. Qualitative data from the viewing log substantiated the quantitative data.

Table 2 provides the adjusted means for each efficacy outcome of interest for the 99 women in the intent-to-treat analysis at baseline and at 30 and 90 days. Adjusted means were calculated from the predicted scores at each of the three assessments derived from the estimated trajectory for each individual generated by the random coefficients regression method. Figure 2A–C graphically presents the mean adjusted scores for the two conditions across time for the three efficacy

Table 2. Adjusted Means for the Efficacy Measures for the Intent-to-Treat Cases

| *Outcome* | *Intervention* (n = *51*) | *Control* (n = *48*) | *Effect size* (*Cohen* d) |
|---|---|---|---|
| RSES Total Score | | | |
| Baseline | 19.2 ± 4.7 | 19.1 ± 5.1 | |
| Day 30 | 19.8 ± 4.7 | 18.9 ± 5.1 | |
| Day 90 | 21.0 ± 4.7 | 18.7 ± 5.1 | 0.47 |
| CSES Scales | | | |
| Total Score-Baseline | 162.4 ± 45.5 | 165.4 ± 49.0 | |
| Total Score-Day 30 | 174.8 ± 46.0 | 162.3 ± 49.5 | |
| Total Score-Day 90 | 178.1 ± 48.1 | 167.1 ± 51.4 | 0.22 |
| CSES Problem Focused Coping | | | |
| Baseline | 37.0 ± 10.8 | 35.9 ± 11.3 | |
| Day 30 | 41.2 ± 10.8 | 37.3 ± 11.4 | |
| Day 90 | 41.4 ± 11.1 | 37.6 ± 11.6 | 0.33 |
| CSES Stop Unpleasant Emotions & Thoughts | | | |
| Baseline | 23.7 ± 8.3 | 23.8 ± 8.6 | |
| Day 30 | 25.3 ± 8.2 | 23.3 ± 8.3 | |
| Day 90 | 26.2 ± 8.0 | 24.4 ± 8.1 | 0.22 |
| CSES Support from Family & Friends | | | |
| Baseline | 17.4 ± 6.5 | 18.9 ± 6.7 | |
| Day 30 | 18.8 ± 6.6 | 19.1 ± 6.6 | |
| Day 90 | 18.4 ± 6.9 | 18.4 ± 6.8 | 0.00 |
| IHSS Weighted Scales | | | |
| Overall Score-Baseline | 63.6 ± 9.4 | 63.5 ± 8.6 | |
| Overall Score-Day 30 | 58.1 ± 10.8 | 61.6 ± 9.8 | |
| Overall Score-Day 90 | 47.3 ± 13.5 | 57.7 ± 12.2 | 0.81[a] |
| IHSS Disclosure | | | |
| Baseline | 71.5 ± 16.8 | 72.8 ± 17.3 | |
| Day 30 | 57.0 ± 16.8 | 60.3 ± 17.3 | |
| Day 90 | 55.6 ± 16.8 | 61.9 ± 17.3 | 0.37 |
| IHSS Acceptance | | | |
| Baseline | 77.8 ± 12.0 | 70.8 ± 13.3 | |
| Day 30 | 73.4 ± 13.3 | 71.2 ± 14.8 | |
| Day 90 | 64.6 ± 16.0 | 72.0 ± 17.8 | 0.44 |
| IHSS Social Relationships | | | |
| Baseline | 46.5 ± 13.4 | 46.3 ± 14.9 | |
| Day 30 | 28.7 ± 13.4 | 38.8 ± 14.9 | |
| Day 90 | 26.8 ± 13.4 | 38.0 ± 14.9 | 0.79[b] |
| IHSS Stereotypes | | | |
| Baseline | 66.9 ± 11.8 | 69.9 ± 10.1 | |
| Day 30 | 62.4 ± 13.4 | 68.4 ± 11.2 | |
| Day 90 | 53.3 ± 16.9 | 65.4 ± 13.8 | 0.78[b] |

Mean ± standard deviation and effect sizes for the adjusted means at 90 day also provided.

[a] $p \leq .01$; [b] $p \leq 0.05$ for contrasts evaluating the adjusted mean differences between conditions at Day 90. Adjusted means are for the estimated mean trajectory scores at each time point derived from the random coefficients regression model incorporating the fixed main and interaction effects of treatment, time, and any covariates, and the random effects of patients and patient-by-time in the model.

RSES, Rosenberg Self-Esteem Scale; CSES, Coping Self-Efficacy Scale; IHSS, Internalized HIV-Related Stigma Scale.

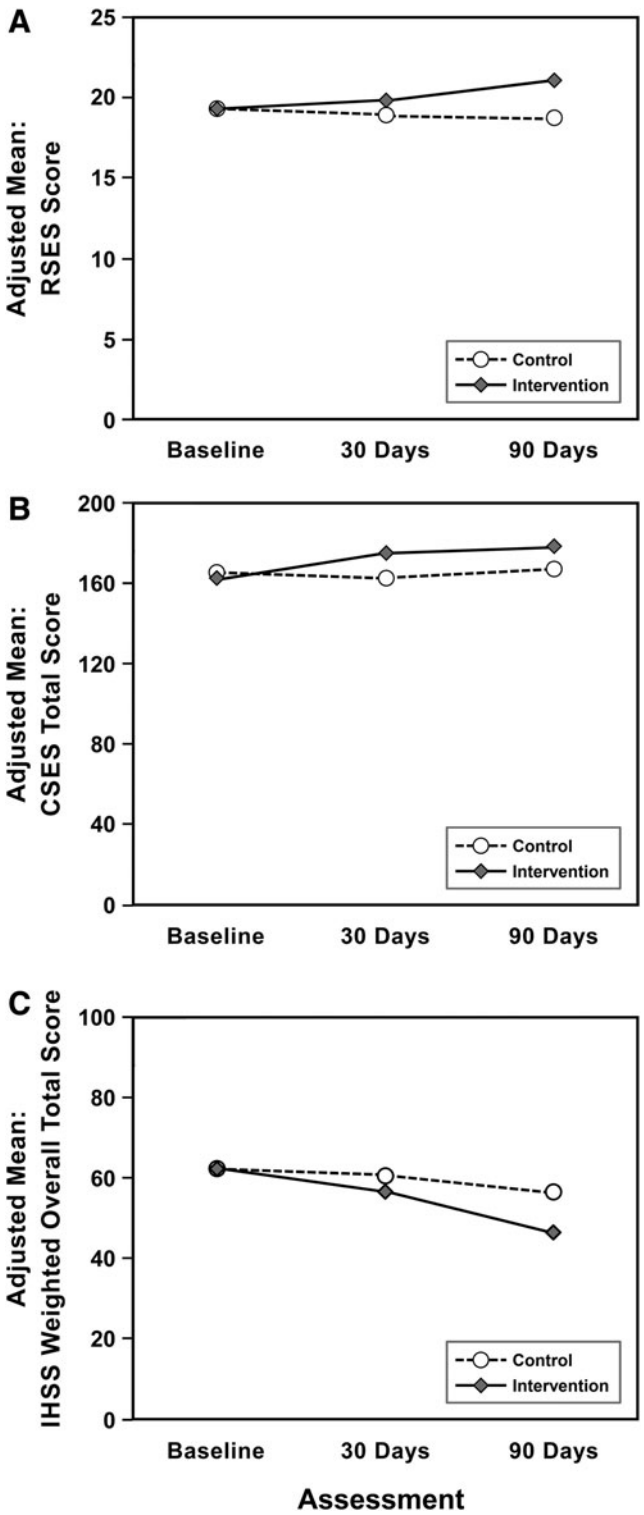


**FIG. 2.** Mean adjusted scores for the efficacy outcomes.

outcome: RSES self-esteem total scores, CSES coping self-efficacy total scores, and IHSS overall stigma scores. Higher scores on the self-esteem and self-efficacy scales indicate better self-esteem and coping self-efficacy, whereas lower scores on the stigma scale indicate less stigma.

With regard to how long women watched the video, according to the viewing logs, the mean number of minutes spent viewing the video for weeks 1–4 was 265 (SD = 160), or an average of 66.25 min/week (the video was 45 min long, and it was possible to watch individual segments). For weeks 1–12, the mean number of minutes spent viewing the video was 487 (SD = 292), or 40.58 min/week. When women were asked how many times they watched the entire video during the first 4 weeks, the mean number of times was 5.3 (SD = 3.4), and over weeks 1–12, the mean number of times was 9.7 (SD = 7.3). We examined dose data in many different ways, but dose as collected did not predict change in scores over time; the dose had minimal impact on reduction of stigma.

The following describes the results from the trajectory analysis models for the efficacy outcomes for the intent-to-treat and supplemental completers groups. The treatment-by-time for each outcome was of particular interest because this indicates whether the rate and pattern of change over time in the intervention condition was significantly different that that observed in the control condition. For those models requiring a time-by-time term to best fit the quadratic nature of the data over time, the treatment-by-time-by-time interaction was used to evaluate differential changes in the outcome in the two conditions. The trajectory analyses for the both the intent-to-treat and supplemental completer groups yielded a similar pattern of results.

There was a treatment-by-time effect for self-esteem (intent-to-treat: $p = 0.0308$; completers: $p = 0.0284$), with the intervention showing a significant linear increase in self-esteem over the 90 days. Race/ethnicity was a significant covariate, with black women in both conditions reporting higher mean self-esteem scores when compared with women representing other racial/ethnic groups (intent-to-treat: $p = 0.0332$; completers: $p = 0.0525$). With regard to coping self-efficacy, a significant treatment-by-time-by-time interaction effect was demonstrated (intent-to-treat: $p = 0.0414$; completers: $p = 0.0321$). As shown in Fig. 2, the relation between the CSES total scores and time was a slight quadratic (time-by-time) function within each condition. However, the direction of treatment effect over time was different in the two conditions. Women in the intervention condition showed a nonlinear increase in their CSES total scores, whereas the women in the control condition showed a nonlinear decrease in scores. In both conditions, the change in scores occurred primarily in the initial 30 days before leveling off. With regard to overall stigma scores, there was also a treatment-by-time effect for stigma scores (intent-to-treat: $p = 0.0036$; completers: $p = 0.0060$), with both of the intervention arms showing a significantly greater linear decrease in scores over time relative to the control arm.

The trajectory analyses of the CSES and IHSS subscales indicated the following significant changes over time. The mean problem-focused coping score of the coping self-efficacy scale improved over time in both conditions, and the pattern of change was quadratic with the greatest amount of improvement occurring during the initial 30 days (intent-to-treat: $p = 0.0196$; completers: $p = 0.0153$). The mean IHSS disclosure score decreased in a quadratic fashion in both conditions (intent-to-treat: $p = 0.0003$; completers: $p = 0.0007$), with the greatest improvement occurring at day 30. A significant linear decrease in mean IHSS self-acceptance was demonstrated in the intervention condition relative to the control arm (intent-to-treat: $p = 0.0017$; completers: $p = 0.0017$). The mean IHSS social relationships score showed a quadratic decline over time in both conditions (intent-to-treat: $p = 0.0002$; completers: $p = 0.0006$), with the greatest rate of change at day 30 and then leveling off. The quadratic pattern of change, however, was not significantly different in the two conditions (intent-to-treat: $p = 0.1230$; completers: $p = 0.2577$). Furthermore, the linear decrease in the mean IHSS stereotype score in the intervention arm was significantly greater than that observed in the control group (intent-to-treat: $p = 0.0111$; completers: $p = 0.0117$).

Table 2 also provides the effect sizes for each outcome at 90 days for the intent-to-treat group. A medium effect of the intervention in terms of improving self-esteem was observed when compared with the control condition in those who completed the study. The magnitude of the intervention effect, however, was large with regard to reducing overall stigma, improving social relationships, and decreasing stereotypes in both groups. A similar pattern of results was observed in the completers group, with the exception that the effect size for the self-esteem was slightly larger for the completers (Cohen $d = 0.50$, $p \leq 0.05$).

## Discussion

The Deep South continues to be disproportionately affected by HIV; health disparities such as poverty and unemployment worsen the effects of the epidemic. Because of the modes of transmission of the virus, continued misunderstanding about how it is spread, and the cultural conservatism in this region, the general public in the Deep South is not likely to be receptive to stigma reduction interventions aimed at them. Therefore, we decided to intervene with those most affected by HIV-related stigma: seropositive women.

Our stigma reduction intervention delivered via an iPod Touch device was effective in reducing stigma and enhancing self-esteem and coping self-efficacy in a group of stigmatized HIV-infected women in the Deep South. The success of the intervention in the geographical and cultural context of the Deep South adds to our enthusiasm that we may have found a way to impact one of the most persistent negative outcomes of the epidemic. There were unexpected findings as well; although voluntary disclosure was not one of the outcomes of the study, qualitative data indicated that several of the women in the intervention arm disclosed their diagnoses for the first time since they learned they were HIV-infected.

The mode of delivery of the intervention was an important contributor to the success of the study. For the women in our study, the iPod Touch allowed them to participate in an intervention without having to expose their serostatus to others, as may have happened in a group intervention. This was a particular concern given where our study was conducted, with HIV-related stigma remaining deeply embedded in social mores. For those women living with HIV in rural areas, this worry is heightened by the possibility that the personnel working in the clinic may be their neighbors. Our results are similar to those of Jones et al.,[47] who used smart phones to stream soap opera videos to young urban African American women, to reduce risk of sexually transmitted HIV; text messages were sent to the control group. The soap opera and this mode of delivery were well accepted and effective, with a reduction in unprotected sex with high-risk men. In this study, the smart phones were provided to the participants, just as we supplied the iPod Touch devices to our participants. Our study and that of Jones et al.[47] indicate that technologically delivered interventions may be a way to connect with women who are HIV-infected or at risk for becoming infected.

There are several limitations to the study. First, we do not have a Spanish language version of the DVD, which prevented us from recruiting monolingual Spanish-speaking women. As there were no studies of such women in our metasynthesis, we need to gather more data about these women to confirm that their experiences are similar to those of the two English-speaking Hispanic/Latina women in the video. If they are, we will need to reshoot the video in Spanish. Another limitation was the $200 price for each of the iPod Touch devices. We

believe, however, that this was money well spent in terms of increases in self-esteem, improvements in coping self-efficacy, and decreases in internalized HIV-related stigma. The low cost and ability of the women to control when and how they watch the video contribute to its sustainability; the women can continue to watch it in the future if they need a booster.

However, there is a recent analysis of the economic cost of stigma.[48] An examination of the trade-off between changes in measured stigma and changes in income, allowing for the fact that stigma would reduce the income that a person earned, produced a final valuation of ~$1,000 per unit of stigma. If an intervention could be devised that would completely eliminate maximum stigma (the stigma score would fall from 160 to 1 in the example used by Brent), this would be valued at nearly $160,000. In reality, an intervention would likely affect stigma by a few points, probably 5–10. In this case, we might use a value of $5,000–10,000 for the benefits of a stigma-reduction intervention.[48] Evidence that there is an economic cost to stigma reinforces the need to help patients with psychosocial problems that have an adverse impact on the quality of their lives.

Most of the current research on HIV-related stigma is being conducted outside of the United States. But because the concepts and experiences of HIV-related stigma are culturally embedded, we must continue to develop interventions here in the United States, as those developed in other countries may not be appropriate here. Misir[49] points out that most interventions do not take into account the resistant and active capacity of people living with HIV infection to produce active responses to stigma; they are usually seen as passive and unable to transform their situations. Becoming empowered, as the women in our study were, can provide the wherewithal to resist stigma.[49] Earnshaw et al.[50] also advocate for moving toward resilience against the effects of HIV-related stigma; in particular they advocate for increasing social support, which can be gained with disclosure, and improving adaptive coping, which was one of the results of the study reported here. In the long term, if we are able to positively impact stigma, we believe that this intervention has the potential to improve medication adherence, safer sex practices, and physical and psychosocial outcomes for HIV-infected women who are affected by stigma.

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## Author Disclosure Statement

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