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ORIGINAL PAPER

# Blocking the Benefit of Group-Based HIV-Prevention Efforts during Adolescence: The Problem of HIV-Related Stigma

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**Abstract** HIV-related stigma has been shown to impede HIV-antibody testing and safer sexual practices in adults. Less is known about its effects on prevention programs among at-risk youth. This study examined the longitudinal relationships between HIV-stigma and HIV-knowledge following completion of a validated group-based intervention. Data were provided by 1,654 African-American adolescents who participated in a large multi-city prevention trial (Project iMPACCS). Participants were randomly assigned to an empirically-validated skill-based intervention or a general health promotion control group. Both stigma and knowledge were assessed at baseline and post-intervention. Results suggested that adolescents participating in the intervention showed improvements in knowledge and decreases in stigma when compared to controls. Improvements in stigma appeared to be partly driven by improvements in knowledge. Higher baseline stigma was shown to reduce gains in knowledge in both the treatment and control groups. Results suggest that HIV-stigma can interfere with how youth identify with and internalize messages from group-based prevention trials.

**Keywords** HIV · Stigma · Adolescence · Knowledge · Prevention

## Introduction

HIV-related stigma is a prominent and persistent barrier to care and prevention efforts [1–4]. HIV-related stigma refers broadly to unfavorable attitudes and beliefs directed towards individuals who are HIV positive. Recent conceptual frameworks of HIV-related stigma propose mechanisms and processes that operate at the societal, interpersonal, and intrapersonal level of human experience [3, 5, 6]. These frameworks highlight important differences in the way in which stigma may influence the attitudes, behaviors, and experiences of individual living with HIV in comparison to individuals who are not HIV infected.

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For individuals who are unaware of their HIV status, stigma has been shown to interfere with preventative behaviors such as routine HIV screening and safer sexual practices [1, 2, 7, 8]. It is thought that stigma hinders these behaviors because non-infected individuals seek to emotionally, cognitively and behaviorally distance themselves from HIV and people living with HIV, resulting in an underestimation of their personal susceptibility to infection [5, 9].

Stigma may also interfere with the efficacy of group-based educational programs for at-risk youth. Similar to adults, youth who hold more stigmatizing beliefs about HIV may be less likely to identify with infected youth or those whom they perceive as being at risk for infection [10, 11]. Because they do not identify with the risk group, youth with elevated stigma may feel that they will not become infected and may be less likely to internalize and apply the skills and information presented in interventions. If HIV-related stigma does indeed interfere with how youth internalize information from prevention efforts, the effect should be evident in how much youth learn about HIV through participation in a prevention intervention. Those who report more stigmatizing attitudes towards people living with HIV would be expected to show fewer gains in HIV knowledge than those with less stigmatizing attitudes.

Previous research has documented a consistent relationship between HIV-related stigma and HIV-knowledge [12–14]. The relationship, however, is somewhat complex. Results from a number of intervention trials designed to reduce stigma have shown that providing HIV knowledge helps to reduce stigma [3, 13, 15, 16], suggesting increasing knowledge is an important strategy for decreasing stigma. However, improving knowledge may not be sufficient to reduce stigma [15] especially if stigma interferes with how youth internalize information about HIV.

There have been a few reports of HIV prevention trials that have also successfully reduced stigma. These trials included a number of techniques to bolster didactics with non-infected youth including role-plays, debates, visual and performing arts projects, and small-group work [16–19]. Although they did not examine the relationships among knowledge, stigma and treatment condition, these findings suggest that discussing HIV through small-group activities may help to reduce stigma.

In this paper we sought to replicate these previous findings that group activities addressing HIV would reduce HIV-related stigma, and extend the findings by understanding the relationships among knowledge, stigma, and treatment condition. We used data from a multi-city evaluation of the synergistic effects between a culturally sensitive media campaign that targeted beliefs about condom use and a previously validated group-based HIV prevention intervention [focus on youth (FOY)]; [20]. All youth who participated in the trial were African-American and were randomized either to FOY or to a general-health promotion group that included information about HIV [promoting health among teens (PHAT)]. Two of the four cities that participated in the study received the media intervention. Results of the larger trial were reported elsewhere [21]. The primary purpose of this paper was to better understand how stigma might interfere with prevention efforts, by examining the relationships among HIV-related stigma, HIV knowledge, and participation in a previously validated, culturally sensitive, group-based intervention. Although FOY did not directly target stigma, the intervention incorporated content similar to materials used in the previously mentioned prevention studies that showed decreased HIV-stigma; thus, we expected FOY to increase HIV knowledge and reduce HIV-related stigma. Additionally, we expected that changes in knowledge would account for some, but not all, of the intervention's effect on stigma. Because the media campaign of the larger trial targeted safe-sexual practices (e.g., condom-use, postponing intercourse) we did not expect that it would affect HIV knowledge or HIV-related stigma.

Beyond expecting more change in the FOY group for knowledge and stigma, we expected that higher levels of stigma at baseline would interfere with the acquisition of HIV knowledge from baseline to the 3-month follow-up in both FOY and PHAT groups. Further, the format and content of FOY were expected to facilitate increased knowledge by reducing the interference of baseline HIV stigma.

## Methods

### Participants

This study used baseline and 3-month follow-up data collected from 1,654 African American adolescents during Project iMPPACS, a multilevel, multisite HIV prevention-intervention [21]. Participants were recruited using community-based outreach in two midsized cities in the northeastern United States and two midsized cities in the southeastern United States. Eligibility criteria included age 13–18 years at the beginning of the study and being able to speak and read English. Of the 2,146 adolescents invited to participate, 1,654 were consented, assented and were assessed at baseline (77%). Of those who completed the baseline assessment, 1542 completed the 3-month follow-up (93%). All participants completing the baseline assessment were included in this study. Demographics for this sample are listed in Table 1.

## Procedures

Participants were randomly assigned to either FOY ($n = 821$) or a general health promotion control group PHAT ($n = 833$). Attrition rates were similar across both conditions (FOY: 6.3%; PHAT: 7.2%). After obtaining parental consent and participant assent, participants completed psycho-social measures using an audio computer-assisted self-interview (ACASI). The ACASI took approximately 45 min to complete and participants were compensated $30 for their time and effort.

## Intervention

FOY is a knowledge- and skill-based small-group intervention designed in collaboration with community organizations to be delivered in community settings [20]. FOY was designed to help youth identify HIV risk exposure in their communities, anticipate and prepare for risky situations, and reduce risky activities. The intervention has been previously validated in low-income, urban African-American youth. FOY was designed according to protection motivation theory and included various activities (i.e., group discussions, arts and crafts, role plays, didactics, story-telling, and videos) that address extrinsic and intrinsic rewards for HIV-preventative behaviors and emphasize value clarification and goal setting. The intervention also provides skill-based instruction around condom use, decision-making and communication. The multilevel design of Project iMPPACS required that FOY be modified from eight 90-min sessions to be a two-day workshop. PHAT was used as the control condition. It was also administered during a two-day workshop and included similar activities as FOY. The focus, however, was on general health related topics (diet, exercise, drug avoidance, general sexual health). The control condition provided limited didactic information about HIV.

**Table 1** Baseline characteristics of participants

| | PHAT ($n = 833$) | FOY ($n = 821$) |
|---|---|---|
| Site | | |
| Syracuse (%) | 210 (25) | 205 (25) |
| Macon (%) | 208 (25) | 204 (25) |
| Providence (%) | 206 (25) | 205 (25) |
| Columbia (%) | 209 (25) | 207 (25) |
| Age (SD) | 15.08 (1.10) | 15.09 (1.09) |
| Gender (% female) | 496 (60) | 495 (60) |
| Ethnicity (% hispanic) | 31 (4) | 47 (6) |
| Free lunch (% yes) | 618 (74) | 598 (73) |
| Attends religious services | | |
| Never (%) | 89 (11) | 85 (10) |
| Rarely (%) | 257 (31) | 301 (37) |
| Monthly (%) | 150 (18) | 130 (16) |
| Weekly (%) | 337 (41) | 305 (37) |
| Sexually active (% Yes) | 502 (60) | 486 (59) |

*PHAT* promoting health among teens, *FOY* focus on youth, *SD* standard deviation

## Measures

The measures included participants' report of demographic information, sexual activity, HIV-related knowledge, and HIV-related stigma. The reliability of measures used in Project iMPPACS has been reported previously [22]. HIV-knowledge was assessed using an 18-item scale (HIV-KQ-18) with three response options, *mostly true, mostly false,* or *don't know* [23]. Correct answers were summed, with a possible range of 0–18. The internal consistency of the HIV-KQ-18 for this study was $\alpha = .77$ at baseline and $\alpha = .74$ at the 3-month follow-up. HIV stigma was assessed using 7 items that were rated on a 6-point scale (1 = *strongly disagree* to 6 = *strongly agree*; [24]. These items addressed participants' negative attitudes toward persons with HIV (e.g., "People who have HIV should be ashamed" and "I do not want to be friends with someone who has HIV"). The internal consistency for this measure was $\alpha = .84$ at baseline and $\alpha = .86$ at the 3-month follow-up.

## Analytical Approach

Covariance modeling was used to examine the study hypotheses. Covariance modeling allowed multiple outcomes to be simultaneously estimated, allowed for tests of indirect effects (e.g., treatment affecting stigma by way of increasing knowledge), and allowed us to account for the reciprocal influences between knowledge and stigma. A single model was used to test the hypotheses of this study (Fig. 1). The model simultaneously regressed HIV knowledge and stigma measured at the 3 month follow-up on a treatment indicator (0 = PHAT, 1 = FOY), as well as on baseline measures of knowledge and stigma. The moderating effect of FOY on the relationship between baseline stigma and knowledge at follow-up was tested by including an interaction term consisting of baseline stigma and the treatment indicator. Maximum likelihood was used to derive the parameter estimates. Bias-corrected bootstrapped confidence intervals (2,000 draws) were used to provide robust inference for parameters in the model, especially for the indirect effects hypothesized in the model [25]. Separate analyses were run to examine group differences for the individual items on the HIV-knowledge and HIV-stigma scales. To maintain consistency throughout the paper, covariance modeling was used for these analyses with all the items of a scale simultaneously regressed on

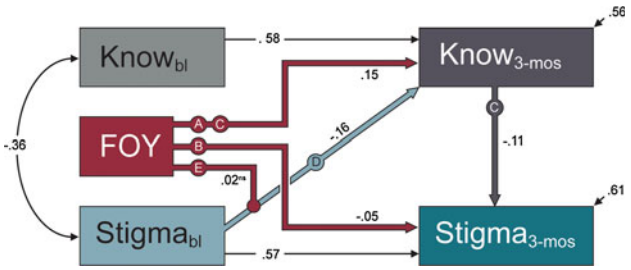


**Fig. 1** Standardized model of HIV knowledge and HIV stigma. Although estimated, non-significant parameters were not presented in the figure. *Letters* were used to label paths discussed in text: (*A*) the direct effect of treatment on HIV-knowledge, (*B*) the direct effect of treatment on HIV-stigma, (*C*) the indirect effect of treatment on HIV-stigma via HIV-knowledge, (*D*) the effect of baseline HIV-stigma on change in HIV-knowledge, and (*E*) the moderating effect of treatment on path D. *ns* not significant, *FOY* focus on youth, *Know* HIV-knowledge, *Stigma* HIV-stigma

the treatment indicator. This approach accounted for the intercorrelations between items. All analyses were performed using Mplus 5.0 [26].

## Results

### Treatment Effects

The effects of FOY versus PHAT were tested by examining the direct effect of treatment on change in HIV knowledge (Fig. 1, Path A) and the total effect of treatment on HIV stigma (Fig. 1, Path B + Path C). As expected, FOY versus PHAT showed increased knowledge (unstandardized ($b$) = 1.16 (95% CI = .85 to 1.46); standardized ($\beta$) = .15) and decreased stigma ($b = -.90$ ($-1.49$ to $-.37$); $\beta = -.06$). The effect sizes for these differences were Cohen's $d = .30$ and $d = .09$, respectively. Means for the HIV knowledge and HIV stigma scales are presented in Table 2 and item means are presented in Tables 3 and 4.

### Direct and Indirect effects for HIV stigma

The effect of treatment on HIV stigma was separated into the indirect effect through change in knowledge (Fig. 1, Path C) and the direct effect of treatment on stigma (Fig. 1, Path B). Both the indirect effect ($b = -.25$ ($-.40$ to $-.12$); $\beta = -.02$) and direct effect of FOY ($b = -.65$ ($-1.26$ to $-.12$); $\beta = -.05$) were significant.

### Longitudinal Relationships HIV Knowledge and Stigma

As hypothesized, HIV knowledge and HIV stigma were related at baseline ($r = -.36$). Controlling for baseline relationships, higher Stigma at baseline was related to fewer gains in HIV knowledge (Fig. 1, Path D; $b = -.08$ ($-.11$ to $-.05$); $\beta = -.16$). Contrary to hypotheses, treatment condition did not moderate the relationship between baseline stigma and gains in HIV-knowledge (Fig. 1, Path E; $b = .02$ ($-.03$ to .06); $\beta = .02$).

## Discussion

This study examined the longitudinal relationships between HIV-related knowledge and stigma using data from a large, multisite trial of a validated skills-based youth intervention, FOY. Overall, we found support for our hypotheses that participation in the FOY intervention would lead to improved HIV knowledge and reduced stigma. Change in knowledge, although not sufficient to reduce risk behavior, is likely necessary for risk reduction [27]; if true, then improving knowledge in at-risk youth is important, especially given the low levels of initial HIV-related knowledge among these youth (i.e., 50% correct [28]). Improvements in knowledge were demonstrated by the FOY group; youth participating in this group showed a moderate increase in knowledge compared to youth in the control intervention (Cohen's $d = .30$). This effect size observed is similar to other efficacious interventions [29].

A smaller effect was seen for HIV-related stigma ($d = .09$). Consistent with previous literature, the effect on HIV stigma was composed of an indirect relationship through change in HIV knowledge, and a direct relationship from FOY, suggesting that group-based activities like those used in FOY help to reduce stigma by increasing knowledge and through other processes not assessed in this study. Understanding these processes will help inform future interventions. Previous research has suggested a number of additional processes that may contribute to reduced stigma including providing skills on how to interact with people living with HIV, interaction with infected individuals, live testimonials, and visualizing living with HIV [15]. Although the pattern of relationships with HIV-knowledge is consistent with previous literature, the overall effect of the intervention was small. It is not known why the effect was smaller than expected and comparisons with the few previous studies on reducing stigma in the context of prevention trials was hindered by the use of different measurement instruments across studies and insufficient information about the previous studies to calculate effect sizes [16].

Our second set of hypotheses addressed the longitudinal relationships between HIV-related stigma and knowledge. Because adolescents with higher levels of stigma were expected to be less likely to identify with youth whom they perceived as being risky, they were thought to be less likely to internalize the intervention. Stigma, therefore, was

**Table 2** HIV knowledge and HIV stigma at baseline and 3-month follow-up

| | PHAT ($n = 833$) Mean (std error) | FOY ($n = 821$) Mean (std error) |
|---|---|---|
| HIV knowledge: BL | | |
| Number of correct responses out of 18 | 9.02 (.13) | 9.07 (.14) |
| HIV knowledge: 3-mos | | |
| Number of correct responses out of 18 | 9.99 (.14) | 11.13 (.14) |
| HIV stigma: BL | | |
| Range: 7–42 | 16.31 (.26) | 16.81 (.27) |
| HIV stigma: 3-mos | | |
| Range: 7–42 | 14.88 (.26) | 14.26 (.26) |

*PHAT* promoting health among teens, *FOY* focus on youth, *BL* baseline assessment, *3-mos* 3 month follow-up assessment

**Table 3** HIV knowledge item scores at the 3-month follow-up assessment

| Abbreviated item stems | Proportion of correct responses | |
|---|---|---|
| | PHAT ($n = 833$) Mean (std error) | FOY ($n = 821$) Mean (std error) |
| Coughing and sneezing spread HIV | .50 (.02) | .57 (.02)* |
| Sharing a glass of water spreads HIV | .62 (.02) | .71 (.02)* |
| Pulling out before climax prevents HIV | .64 (.02) | .64 (.02) |
| A woman can get HIV through anal sex | .64 (.02) | .71 (.02)* |
| Washing genitals prevents HIV | .65 (.02) | .64 (.02) |
| HIV+ women will have babies born with AIDS | .15 (.01) | .23 (.02)* |
| HIV+ people quickly show serious signs of being infected | .65 (.02) | .72 (.02)* |
| There is a vaccine that can prevent HIV | .49 (.02) | .55 (.02)* |
| Deep kissing spreads HIV | .51 (.02) | .61 (.02)* |
| Having sex during a women's period prevents HIV | .67 (.02) | .66 (.02) |
| Female condoms exist and help prevent HIV | .66 (.02) | .76 (.02)* |
| Natural skin vs. latex condom works better against HIV | .34 (.02) | .47 (.02)* |
| Antibiotic protect against HIV | .53 (.02) | .54 (.02) |
| Having multiple sex partners increases risk of HIV | .86 (.01) | .84 (.01) |
| HIV testing after one week after having sex tells if HIV+ | .23 (.02) | .35 (.02)* |
| Hot tubs and swimming pools spread HIV | .71 (.02) | .80 (.02)* |
| A person can get HIV from oral sex | .66 (.02) | .66 (.02) |
| Using Vaseline or baby oil with condoms prevents HIV | .50 (.02) | .70 (.02)* |

*PHAT* promoting health among teens, *FOY* focus on youth

* $P \leq .05$

expected to reduce the acquisition of HIV-related knowledge. It was further hypothesized that if the intervention effectively reduced stigma, the antagonistic relationship between stigma and knowledge would be lower in FOY versus PHAT. The first hypothesis was supported, the second was not. The model showed that baseline stigma interfered with knowledge acquisition. After adjusting for the baseline relationship between HIV knowledge and stigma, those who reported more HIV stigma at baseline showed less improvement in knowledge. This relationship, however, was the same for both FOY and PHAT, which although contrary to what we expected, was consistent with the previously discussed weak treatment effect for HIV stigma.

Results from this study suggest that HIV-related stigma likely interferes with the acquisition of HIV-related knowledge, and suggests that current approaches employed in validated interventions may not be sufficient to adequately reduce stigma. Although FOY did not directly target stigma, it included a number of activities that were similar to those included in previous trials of HIV prevention interventions that assessed stigma, and it was surprising that it did not have a stronger impact on HIV-stigma. It is not clear why the effect was not stronger, but the small effect suggests that more work is needed to determine how to reduce stigma in the context of prevention programs.

Reducing stigma has been a persistent challenge throughout the HIV-epidemic and recent reviews have suggested that reducing stigma likely requires interventions that focus on intrapersonal, interpersonal, and societal level processes [3, 5, 6]. When considering how to mitigate the impact of stigma on youth prevention trials, there may be a

**Table 4** HIV stigma item scores at the 3-month follow-up assessment

| *Scale: 1-Strongly Disagree to 6-Strongly Agree* | PHAT ($n = 833$) Mean (std error) | FOY ($n = 821$) Mean (std error) |
|---|---|---|
| People who have HIV are dirty | 2.26 (.05) | 2.11 (.05)* |
| People who have HIV are cursed | 1.78 (.04) | 1.73 (.04) |
| People who have HIV should be ashamed | 2.30 (.06) | 2.25 (.06) |
| It is not safe for children to be around somebody who is infected with HIV | 2.59 (.06) | 2.36 (.06)* |
| A person with HIV must have done something wrong and deserves to be punished | 1.90 (.05) | 1.88 (.05) |
| People who have HIV should be isolated | 1.84 (.05) | 1.79 (.04) |
| I do not want to be friends with someone who has HIV | 2.14 (.05) | 2.12 (.05) |

*PHAT* promoting health among teens, *FOY* focus on youth

* $P \leq .05$

few approaches that could prove beneficial. One approach would be to couple prevention interventions such as FOY with larger community based initiatives aimed at reducing HIV-related stigma. This approach would not require changes to existing, validated interventions, but would require coordination between agencies providing the group-based intervention and those seeking to reduce HIV-related stigma through community-based efforts. Alternatively, prevention programs could include additional modules that explicitly target HIV-related stigma. It will be important to design modules that are effective, but do not significantly add to the time or burden experienced by participants. For example, interventions have been developed that have directly targeted HIV-related stigma [16], but many of them are as long as interventions focusing on increasing HIV preventative behaviors. Regardless of the approach it will be important to identify effective strategies that target stigma. Again, recent reviews have highlighted the weaknesses in the current literature, including few interventions targeting stigma, lack of internally valid studies, inconsistent use of validated measures, and limited information about the public health significance of existing interventions [16]. More work is needed to have a clear picture of strategies that effectively reduce stigma in the context of prevention trials.

There are a number of limitations that should be considered when interpreting findings from this study. First, the modeling tested directional causal relationships between HIV knowledge and HIV stigma; these causal assumptions, however, cannot be confirmed using the current study, as it was not designed to test the causal relationships between these two variables. Second, all of the measures used in the study were self-report and any relationships due to common assessment modality cannot be assessed using these data. Finally, the sample consisted of African-American youth that were recruited using community based outreach and not randomly selected. Caution should be used when generalizing to other populations and other geographical regions.

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