

Stigma Reduction in Adolescents and Young Adults Newly Diagnosed with HIV: Findings from the Project ACCEPT Intervention

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Abstract

This article describes the influence of a group-based behavioral intervention for adolescents and young adults newly diagnosed with HIV (Project ACCEPT) on four dimensions of HIV-related stigma—*personalized stigma*, *disclosure concerns*, *negative self-image*, and *concern with public attitudes about people with HIV*—as measured by the Berger HIV Stigma Scale. Stigma was addressed in a holistic manner during the intervention by providing HIV/AIDS-related information, facilitating the acquisition of coping skills, and providing contact with other youth living with HIV in order to improve social support. Fifty youth (28 male, 22 female; mean age = 19.24 years) newly diagnosed with HIV from four geographically diverse clinics participated in a one-group pretest-posttest design study whereby they received the intervention over a 12-week period, and completed assessments at baseline, post-intervention, and 3-month follow-up. Results from the combined sample (males and females) revealed overall reductions in stigma in three dimensions: *personalized stigma*, *disclosure concerns*, and *negative self-image*, although only the combined-sample effects for *negative self-image* were maintained at 3-month follow-up. Gender-specific analyses revealed that the intervention reduced stigma for males across all four dimensions of stigma, with all effects being maintained to some degree at the 3-month follow-up. Only *personalized stigma* demonstrated a decrease for females, although this effect was not maintained at the 3-month follow-up; while the other three types of stigma increased at post-intervention and 3-month follow-up. Findings are discussed in terms of gender specific outcomes and the need for a different type of intervention to reduce stigma for young women.

Introduction

HIV-RELATED STIGMA HAS BEEN INCREASINGLY recognized as a key factor impeding HIV identification, prevention, and treatment.^{1–3} Stigma and discrimination impact the way communities, family, and partners interact with people living with HIV, and undermine public health efforts to combat the epidemic. This is largely due to the negative impact stigma has on primary and secondary preventive behaviors such as condom use, HIV testing, engagement in HIV care, and quality of care.^{4–6}

Most HIV-related stigma research and theory is based in the original work of Goffman (1963),⁷ who described stigma as a type of “spoiled identity” that occurs when a person or group possesses a particular attribute that is viewed by others in society as an “undesirable difference” resulting in social sanctions against those who possess that attribute. Stigma has

further been conceptualized as a psychosocial stressor that can take two forms—one which is manifested as anticipation of a negative treatment by others (typically a dominant group member), and the other as a self-directed internalization of negative societal attitudes held by others.⁸ Specific to people living with HIV, HIV-related stigma has been defined as socially shared attitudes, beliefs, or actions that promote and perpetuate the devalued status of people living with or affected by HIV.^{3,9,10} It is a multi-faceted construct that can impact the degree to which people living with HIV may choose to disclose their status, given the negative social consequences of such disclosure. HIV-related stigma can be manifested through *external* negative attitudes or acts of discrimination aimed at people perceived to be living with HIV (as well as individuals and groups with whom they are associated), or *internal* negative feelings, beliefs or actions experienced by people living with HIV.^{3,10} Parker and Aggleton¹¹ caution

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against a static individualistic view of HIV-related stigma and encourage a perspective that recognizes HIV-related stigma as a social process of exclusion whereby certain groups that possess power and control dominate those with less power, ultimately resulting in a process of devaluing. While there is some evidence that overt expressions of HIV-related stigma may be declining in the US,³ internalized stigma still persists and can impact long-term adjustment and coping with HIV infection, increase psychological distress, decrease disclosure of HIV status, and deter individuals from seeking medical care.^{9,12,13}

For adolescents and young adults living with HIV, there are unique challenges that may further impact how HIV-related stigma influences their quality of life and adherence to care.^{9,14–16} These challenges may be further exacerbated by stigma, social isolation, and oppression associated with HIV as well as their sexual behavior and/or sexual orientation identity.^{3,17} Because HIV confers a strong social stigma, these youth may not have the depth, breadth, or quality of social support resources that might typically be available to uninfected youth. Thus, the perception and internalization of HIV-related stigma, coupled with the lack of supportive social relationships, can lead to increased substance use, decreased general psychological health, and decreased engagement in healthcare.^{18–21} The negative impact of HIV-related stigma on the self-acceptance, mental health, and overall adjustment of youth living with HIV has not only been demonstrated in the United States, but also in global settings such as Thailand, Zimbabwe, and Zambia.^{22–24}

The stigma associated with HIV also has been shown to be associated with specific psychological challenges for young people living with HIV in the form of increased symptoms of depression and anxiety, as well as decreased self esteem.^{24–28} Such psychological distress, in turn, has been associated with higher rates of participation in sexual and substance use risk behaviors,^{26,27,29} as well as decreased adherence to antiretroviral therapies^{15,30} and medical appointments³¹ among adolescents living with HIV. In addition, youth are often apprehensive about disclosing their HIV status to parents, friends, and sexual partners for fear of a stigmatizing reaction.^{31,32} Given the range of negative psychosocial and medical outcomes that adolescents and young adults living with HIV may experience due to the deleterious effects of HIV-related stigma, it is important to equip young people with the skills needed to combat these negative societal influences. Such interventions should be delivered when adolescents and young adults are newly diagnosed with HIV to prepare them for healthy adjustment and long term positive functioning.³³ This is supported by prior research in the United States and South Africa with populations of youth and adults living with HIV, which has demonstrated the deleterious effects of stigma on individuals who are newly diagnosed with HIV, such as being associated with lower rates of retention in medical care.^{34–36}

This article describes a group-based intervention for adolescents and young adults newly diagnosed with HIV (within the past year), and its impact over time on four dimensions of HIV-related stigma—*personalized stigma*, *disclosure concerns*, *negative self-image*, and *concern with public attitudes about people with HIV*. The intervention, Project ACCEPT (Adolescents Coping, Connecting, Empowering and Protecting Together), was developed based on qualitative data

gathered within the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN).^{37,38} The current article represents a secondary analysis of data from the feasibility and acceptability trial of Project ACCEPT,³⁸ with a detailed focus on stigma-related elements in the intervention and stigma-specific outcomes.

Methods

This study was a small pilot trial of a behavioral secondary prevention intervention for youth newly diagnosed with HIV (Project ACCEPT) in order to assess its acceptability and feasibility prior to a randomized controlled trial, utilizing a one-group pretest–posttest design with a 3-month follow-up period. The general focus of the intervention is to promote healthy psychosocial adjustment for adolescents who have recently been diagnosed with HIV while also improving engagement in medical care. Intervention development work was completed through the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN). In the initial study, information was elicited from individual interviews with medical and mental health providers, as well as case managers, regarding the intervention needs of youth (ages 16–24 years) newly diagnosed with HIV. “Newly diagnosed” was defined as the first year of the HIV diagnosis, based on feedback from these various care providers. Focus groups and individual interviews with youth living with HIV were then conducted at three clinical sites within the ATN (i.e., Chicago, New York, and Puerto Rico) to identify the challenges, strengths, and needed areas of support/assistance associated with receiving an HIV diagnosis. These interviews/groups were conducted with youth who had been diagnosed within the past 2 years to allow for inclusion of those youth who have had some time to reflect on their experiences during the first year of their diagnosis. Qualitative data from these interviews and focus groups were analyzed and used to guide the development of an intervention manual. Data for the current study come from a pilot test of the Project ACCEPT intervention which was conducted at four ATN sites (i.e., Chicago, New York, Miami, and Memphis) using a single-group pretest–posttest design.

Intervention description

The Project ACCEPT intervention is based on the Disability-Stress-Coping model^{39,40} and incorporates skills-building activities guided by Social Cognitive Theory.⁴¹ The Disability-Stress-Coping model proposes that risk and resistance factors interact to impact an adolescent’s adaptation to his/her chronic illness and/or disability. In this model, risk factors include disease/disability parameters, functional independence, and psychosocial stress. Resistance factors fall into three categories: (1) intra-personal (e.g., competence), (2) socio-ecological (e.g., peers, family, health care providers), and (3) stress-processing (e.g., coping strategies).

In the Project ACCEPT intervention, youth first participated in two individual sessions, followed by nine gender-specific weekly group sessions, and ended with one additional individual session. This combination allowed for more intensive individualized attention as well as supportive group sessions. The individual modules were designed to build rapport, prepare the participants for the groups, and address any salient psychological needs of the participants. The group

modules were designed to be highly interactive and delivered across nine 2-h sessions. Each session was co-facilitated by an interventionist with a mental health background (master's degree in counseling or clinical social work, or a PhD in clinical psychology) and a peer facilitator (age ranges 18–26 years) living with HIV. Each intervention group consisted of 5–7 participants and all groups were gender matched for both the interventionist and peer facilitator with the participants. A detailed description of the full intervention, including more information on specific content and implementation procedures has been published elsewhere.³⁸

Intervention delivery training and fidelity. All intervention delivery staff members participated in a centralized 3-day training (approximately 24 h) consisting of an overview of group-based facilitation skills; a thorough review and discussion of all Project ACCEPT intervention modules and activities; and practice delivering the Project ACCEPT intervention in small mock sessions with corrective feedback by the research team who developed the intervention, as well as by other interventionists and facilitators participating in the training. After the centralized intervention training, all intervention delivery staff members completed audio-recorded mock sessions of all intervention modules (approximately 20 h) at their individual sites and received feedback by the research team prior to the implementation of the Project ACCEPT intervention.

During the delivery of the intervention, all sessions were digitally audio-recorded. A structured coding system was developed in which the coder listened to the audiotapes to assure fidelity to the intervention manual and to record the amount of time taken by each activity in the intervention. The tapes were also reviewed to provide ongoing feedback to the interventionists and the peer facilitators. Discussions with the interventionists and peer facilitators across all sites were held during bi-weekly group supervision conference calls. Implementation logs were also completed by the interventionists and peer facilitators after each session, and these were reviewed by research team members prior to the bi-weekly supervision calls in order to discuss potential barriers to intervention fidelity. The group conference calls between the research team and intervention delivery staff members allowed for: (1) on-going supervision with consistent feedback across sites; (2) continued bonding between intervention delivery staff members across sites; and (3) group problem solving related to intervention implementation issues.

Stigma-specific content. HIV-related stigma was addressed in a holistic manner by providing HIV/AIDS-related information, facilitating the acquisition of coping skills, and providing contact with other youth who are living with HIV in order to improve social support. Throughout the individual and group sessions, four aspects of stigma reduction were specifically targeted, including: (1) decreasing negative feelings toward self and others living with HIV; (2) increasing planned and strategic HIV disclosure to others; (3) building supportive networks to combat fears and feelings of rejection; and (4) building skills to combat HIV-related discrimination and other forms of stigma. These areas were selected based on our prior qualitative work with adolescents newly diagnosed with HIV,³⁷ the Disability-Stress-Coping model,^{39,40} and the content areas included in Berger's HIV Stigma Scale.⁴²

Education and information about HIV was provided in an attempt to combat negative views of those living with HIV, which are often rooted in inaccurate knowledge regarding HIV transmission and progression. In the initial individual sessions the interventionist helped participants prepare for a personalized session with a medical provider; during this session they were given the opportunity to address any HIV/AIDS-related questions or concerns. In the group sessions, several activities were focused on providing accurate knowledge about HIV/AIDS and dispelling common myths. In addition, participants explored societally transmitted messages about people living with HIV, and the ways in which these messages can serve to stigmatize those living with HIV. Myths and misconceptions regarding other young people living with HIV were also challenged in the intervention through the group format that included other adolescents and young adults living with HIV, as well as the inclusion of a peer facilitator who was also living with HIV. In addition, the group sessions also included activities aimed at gaining a better understanding of self-esteem and how it affects ones' behavior and relationships, and developing strategies for enhancing self-esteem and self-acceptance.

Several activities were included that focused on increasing planned and strategic HIV status disclosure to others by building participants' skills and self-efficacy related to disclosure. In the group sessions, participants were taught decision-making skills regarding HIV status disclosure, and then participated in role-play interactions in which they had an opportunity to disclose to a significant individual. Participants also explored different potential outcomes associated with disclosure of their HIV status. These activities assisted youth with making informed and strategic decisions regarding those individual to whom they would disclose their HIV status, and those to whom they would refrain from disclosing.

In order to build supportive networks to combat fears and feelings of rejection, several intervention activities focused on building group cohesion and social support. In the first individual session, the interventionist worked with each participant to identify personal sources of support. In the second individual session, the peer facilitator shared his/her experiences and personal story about living with HIV in order to facilitate a connection with participants and decrease the sense of isolation that is common after an HIV diagnosis. In the final individual session, participants were encouraged to bring an additional "supportive other" to the session in an attempt to promote social support. As with the prior content area related to decreasing negative views of self and others, the group format of the intervention also assisted with building supportive networks for participants.

In order to address the final content area of building skills to combat HIV-related discrimination and other forms of stigma, one session was devoted to legal aid and advocacy whereby participants explored HIV-related policies at the local and national level so they could seek assistance if their legal rights were in any way violated. In order to address compounded stigma stemming from living with HIV and being members of marginalized groups (e.g., gay/bisexual young men or young women of color), gender-specific sessions provided tailored assistance with addressing issues of compounded stigma. The male-specific session discussed aspects of sexuality, with a focus on sexual orientation and dual disclosure of HIV and sexual orientation. It also explored

strategies for connecting with others in the larger gay community to assist with combating stigma. The female-specific session explored specific discrimination related to women living with HIV becoming pregnant, as well as more general discriminatory societal views regarding women's roles and responsibilities. This session also provided specific information related to mother-to-child HIV transmission and provided up-to-date education on making safer choices for family planning.

Procedures

Potential participants were approached by study staff in each of the clinic settings. Eligible participants were between the ages of 16 and 24 years, diagnosed as living with HIV and aware of their HIV diagnosis for less than 15 months (this was beyond the 12-month timeframe to allow for enrollment flexibility), and received services at one of the four selected ATN sites or their community partners. Written informed consent was obtained from eligible participants aged 18–24 years, while written informed assent was obtained for youth 16–18 years. Waivers of parental permission were obtained at three of the four sites.

Enrolled participants were then stratified based on gender with approximately 5–7 males in one group per site and 5–7 females in the other group per site. Enrollment into the two gender-specific groups occurred independently of each other in a nonrandom, sequential fashion until the group specific sample size was achieved.

Data were collected at baseline, post-intervention, at the 3-month follow-up using Audio-Computer-Assisted Self-Interviewing (ACASI). Study staff at the clinical sites administered the ACASI questionnaires at each of the specified time points. All study procedures were approved by the Institutional Review Boards of the participating sites.

Measures

General Demographic Questionnaire. Descriptive information was collected included gender, age, ethnicity, date of HIV diagnosis, experience with HIV medications, and most recent biological markers (CD4 and viral load).

HIV-Related Stigma Scale.⁴² The Berger HIV Stigma Scale is a 40-item instrument on a 4-point Likert scale designed to measure perceived stigma among HIV-positive populations, and includes four subscales that assess both the external and internal aspects of the construct of HIV-related stigma previously described.^{3,10} This measure has been used previously in empirical investigations of youth who are living with HIV.^{16,25,26} The *personalized stigma* subscale measures respondents' experiences of rejection for having HIV or fears that others will reject them because they are living with HIV (Cronbach's alpha at baseline=0.93). The *disclosure concerns* subscale measures respondents' concerns related to keeping their HIV status secret or controlling who knows their HIV status (Cronbach's alpha at baseline=0.81). The *negative self image* subscale measures respondents' negative feelings toward self for having HIV, and includes emotions such as guilt, shame, or being unclean (Cronbach's alpha at baseline=0.88). Finally, the *concern with public attitudes toward people with HIV* subscale measures respondents' worries about maintaining employment and fears of dis-

crimination (Cronbach's alpha at baseline=0.91). We used Likert scale anchors that were the opposite of the original scale (4=strongly disagree, 1=strongly agree) so that increases in scores at various time points would represent improvements in stigma reduction, as opposed to increases in experiences of stigma.

Analysis

Means and frequencies of demographic characteristics for the total sample, as well as for each gender, were calculated and presented in Table 1. To examine intervention effects on HIV-related stigma, an intention-to-treat analysis was used. Values for missing variables contributing to a scaled calculation were imputed using the mean value of the remaining questions provided that 80% or more of the remaining questions contributing to the scale were answered; otherwise the scale for that participant was set to missing. Data were collected using ACASI so missing data was not a major barrier for participants that completed the assessments, as minimal missing data were found during data analysis for these specific scales.

Since each subscale had a different range of possible scores, mean baseline scores on the four subscales were

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS IN PROJECT ACCEPT

	Overall (n = 50)	Females (n = 22)	Males (n = 28)
Mean age (SD)	19.24 (2.25)	19.32 (2.6)	19.18 (1.93)
Months since diagnosis (SD)	8.36 (4.69)	-	-
Percent of Latino origin (n)	20% (10)	18% (4)	21% (6)
Race (n)			
African American	78% (39)	73% (16)	82% (23)
Asian	2% (1)	4% (1)	0% (0)
White	2% (1)	0% (0)	5% (1)
Other	10% (5)	17% (3)	7% (2)
Mixed	8% (4)	9% (2)	7% (2)
Highest level of education			
Less than high school	50% (25)	50% (11)	50% (14)
High school graduate/GED	28% (14)	27% (6)	29% (8)
In college	22% (11)	21% (6)	23% (5)
Sexual orientation			
Straight	44% (22)	95% (21)	4% (1)
Gay/lesbian	38% (19)	0% (0)	68% (19)
Bisexual	18% (9)	5% (1)	28% (8)
Percent taking ARV medications (n)	24% (12)	18% (4)	29% (8)
Self-reported viral load (n)			
< 1,000	20% (2)	20% (1)	20% (1)
1000–9999	50% (5)	80% (4)	20% (1)
≥ 10,000	30% (3)	0% (0)	60% (3)
Mean CD4 count (n)			
< 200	15% (3)	10% (1)	20% (2)
200–499	35% (7)	30% (3)	40% (4)
≥ 500	50% (10)	60% (6)	40% (4)
Percent given AIDS diagnosis (n)	10% (5)	9% (2)	10% (3)

standardized in order to compare the relative level of stigma reported by participants on each of the subscales. This was done by dividing each baseline mean score by the highest possible score for that particular subscale. Since the response scale was reversed from the original scale, higher scores indicate lower levels of stigma. Means, standard deviations, and effect sizes of each variable for the entire sample were calculated, as well as by gender, and are presented in Table 2. Effect size estimates were calculated using Cohen’s d^{43} using a pooled standard deviation, given unequal sample sizes across time intervals (pre-intervention, post-intervention, and 3-month follow-up).

Results

Participants

In total, 97 individuals were approached for this study. Of these, 21 did not meet the eligibility criteria or were not enrolled due to the following: 10 were past the defined newly diagnosed period, 3 were older than 24, 1 was perinatally infected, and 7 were not enrolled because the site had reached its gender-specific sample size goal. Twenty-four participants refused to participate in the study due to following: 11 reported confidentiality and group participation concerns, 5 had scheduling conflicts with the group session time, 2 were planning to relocate, 1 was unable to obtain parental consent, and 5 other participants did not state reasons.

A total of 50 participants (28 male, 22 female; mean age=19.24 years) diagnosed with HIV (mean time since diagnosis=8.36 months) were enrolled into the study from four selected ATN sites (Bronx, NY; Chicago, IL; Memphis, TN, and Miami, FL). The majority of the participants identified as African American (78%) and/or Latina/o (20%). The primary difference between the male and female subsamples was sexual orientation—97% of males identified as gay or bisexual, whereas only 5% of females identified as bisexual and none identified as lesbian. The majority of youth were currently in school (60%) and 50% had at least a high school diploma or GED. At the time of enrollment, 24% were on ARV medications and 10% of the participants were given an

AIDS diagnosis. See Table 1 for demographic characteristics of the sample.

All participants completed the baseline assessment, while 92% of participants completed both the immediate post-intervention and 3-month follow-up assessments. A total of 3 participants were prematurely discontinued during the course of the study (2 lost to follow-up and 1 withdrew consent). Overall, an overwhelming majority of participants attended both the individual sessions (100% for sessions I and II, 86% for session III) and group sessions (84% attended > six group sessions). However, only 30% of participants attended all nine group sessions.

In order to explore the impact of the intervention on HIV-related stigma, we examined the four factors from Berger’s HIV stigma scale⁴²: (a) *personalized stigma* (i.e., social rejection), (b) *disclosure concerns*, (c) *negative self-image* (i.e., internalized shame), and (d) *concern with public attitudes about people with HIV*. Standardized scores for these scales were calculated separately for females and males (Fig. 1), and revealed that at baseline females reported lower levels of perceived stigma across all four subscales than males (*personalized stigma*: female=0.73, male=0.66; *disclosure concerns*: female=0.52, male=0.47; *negative self-image*: female=0.71, male=0.63; *concerns with public attitudes*: female=0.71, male=0.64). In addition, *disclosure concerns* was the subscale with the lowest standardized scores indicating the area with the highest level of baseline stigma.

For the overall sample, *personalized stigma* related to HIV status improved post-intervention (M=51.05, SD=11.23), with an effect size of $d=0.11$. The effect size estimate is positive, as higher scores on the subscales indicate lower levels of stigma, thus increases in scores over time indicate reductions in stigma. Improvements were more substantial for males (M=49.65, SD=12.21) than for females (M=52.74, SD=9.99), with effect sizes of $d=0.16$ and $d=0.01$, respectively. Observed improvements in *personalized stigma* did not hold through the 3-month follow-up. Changes in levels of *personalized stigma* differed between genders, with men reporting improvements in *personalized stigma* (M=48.82, SD=14.2, $d=0.09$) across both time periods, while

TABLE 2. DESCRIPTIVE STATISTICS AND EFFECT SIZES FOR STIGMA SUBSCALES

Outcome (range)	Time	Overall			Females			Males		
		M	SD	d	M	SD	d	M	SD	d
Personalized stigma (18–72)	0	49.80	12.15		52.63	9.43		47.64	13.66	
	1	51.05	11.23	0.11	52.74	9.99	0.01	49.65	12.21	0.16
	2	49.08	12.01	-0.06	49.41	8.83	-0.36	48.82	14.20	0.09
Disclosure concerns (10–38)	0	19.57	5.95		20.7	6.13		18.69	5.78	
	1	20.05	5.19	0.09	19.68	5.74	-0.18	20.32	4.84	0.31
	2	19.44	5.43	-0.02	19.58	5.77	-0.19	19.35	5.28	0.12
Negative self-image (13–52)	0	34.70	8.65		37.11	8.77		33.00	8.31	
	1	36.24	8.25	0.18	36.16	9.09	-0.11	36.32	7.72	0.42
	2	34.84	8.30	0.02	34.05	8.07	-0.37	35.46	8.60	0.30
Concern public attitudes (19–64)	0	54	12.6		56.9	12.6		51.58	13.25	
	1	53.76	10.75	-0.02	54	11.37	-0.24	53.57	10.46	0.17
	2	52.78	10.51	-0.11	50.75	7.58	-0.54	54.33	12.25	0.22

Time 0=baseline; Time 1=post-intervention; Time 2=3 months following intervention; d=Cohen’s d effect size, as compared with Time 0, with positive values representing favorable results.

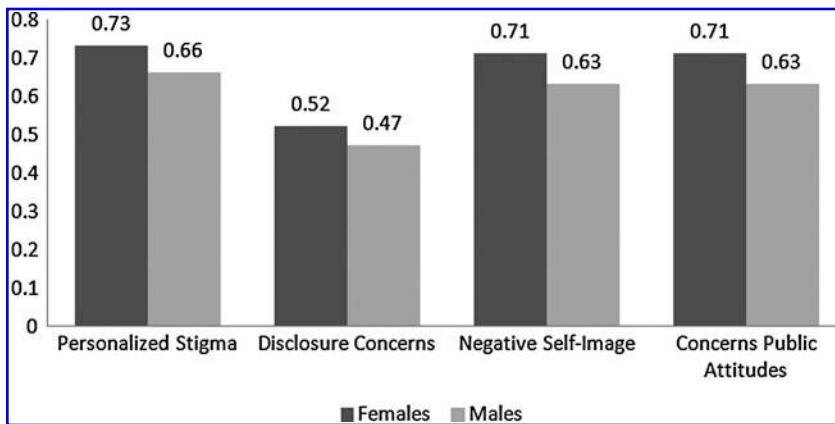


FIG. 1. Relative levels of stigma reported at baseline by gender.

women reported increased *personalized stigma* ($M=49.41$, $SD=8.83$, $d=-0.36$) at the 3-month follow-up.

Disclosure Concerns, for the overall sample, improved post-intervention ($M=20.05$, $SD=5.19$), with an effect size of $d=0.09$, but did not hold through the 3-month follow-up ($M=19.44$, $SD=5.43$, $d=-0.02$). Improvements in *disclosure concerns* post-intervention were only observed for males ($M=20.32$, $SD=4.84$, $d=0.31$), and improvements in *disclosure concerns* from baseline continued at the 3-month follow-up ($M=19.35$, $SD=5.28$, $d=0.12$). Females reported increases in *disclosure concerns* stigma at post-intervention ($M=19.68$, $SD=5.74$, $d=-0.18$), and these increases were maintained at 3-month follow-up ($M=19.58$, $SD=5.77$, $d=-0.19$).

Negative Self-Image, for the overall sample, improved post-intervention ($M=36.24$, $SD=8.25$), with an effect size of $d=0.18$. Observed improvements in *negative self-image* were not as strong at 3-month follow-up, but still demonstrated an improvement over baseline ($M=34.84$, $SD=8.3$, $d=0.02$). Post-intervention improvements were only present for males ($M=36.32$, $SD=7.72$) and were maintained, but to a lesser degree, at the 3-month follow-up ($M=35.46$, $SD=8.6$, $d=0.30$). Females experienced increases in *negative self-image* stigma across both post-intervention and 3-month follow-up, with effect sizes of $d=-0.11$ ($M=36.16$, $SD=9.09$) and $d=-0.37$ ($M=34.05$, $SD=8.07$) respectively.

With regard to stigma related to *Concern with Public Attitudes*, no appreciable change occurred post-intervention for the overall sample ($M=53.76$, $SD=10.75$, $d=-0.02$) but a change from baseline was observed at the 3-month follow-up ($M=52.78$, $SD=10.51$, $d=-0.11$). For males, there was a decrease in stigma related to *concern with public attitudes* at post-intervention ($M=53.57$, $SD=10.46$, $d=0.17$), and at the 3-month follow-up ($M=54.32$, $SD=12.25$, $d=0.22$). For females, there was a reported increase in stigma related to *concern with public attitudes* post-intervention ($M=54$, $SD=11.37$, $d=-0.24$), and this difference was even greater at the 3-month follow-up ($M=50.75$, $SD=7.58$, $d=-0.54$).

Discussion

This article describes a group-based intervention for adolescents and young adults newly diagnosed with HIV, and its impact over time on four dimensions of HIV-related stigma.

The overall Project ACCEPT intervention was guided by the Disability-Stress-Coping model,^{39,40} prior qualitative work examining socioecological stressors experienced by youth newly diagnosed with HIV³⁷ and Social Cognitive Theory.⁴¹ HIV-related stigma was addressed in a holistic manner during the intervention by providing HIV/AIDS-related information, facilitating the acquisition of coping skills, and providing contact with other youth living with HIV in order to improve social support.

Although the risk factors outlined in the Disability-Stress-Coping model^{39,40} influenced the content and focus of the overall Project ACCEPT intervention, the development of the HIV stigma reduction activities was guided by this model's focus on resistance factors that impact an adolescent's adaptation to his/her chronic illness (i.e., intrapersonal, socioecological, and stress-processing/coping skills). The creation of these activities was also influenced by the conceptualization of HIV-related stigma as being manifested through external negative attitudes or acts of discrimination aimed at people perceived to be living with HIV, as well as internal negative feelings, beliefs or actions experienced by people living with HIV.^{3,10} Thus the intervention attempted to build and promote resistance skills that would impact the external and internal aspects of HIV-related stigma, working both at the individual/intrapersonal level as well as at the group/interpersonal level. This is reflected in Project ACCEPT's inclusion of both individual and group sessions that promoted individual-level coping skills and group-based social support focused on: (a) decreasing negative feelings toward self and others living with HIV; (b) increasing planned and strategic HIV disclosure to others; (c) building supportive networks to combat fears and feelings of rejection; and (d) building skills to combat HIV-related discrimination and other forms of stigma.

Intervention outcome results from the combined sample of male and female participants revealed that youth who participated in the intervention reported small overall reductions in HIV-related stigma in three areas: (a) *personalized stigma* (experiences of rejection for having HIV or fears that others will reject them because of their HIV status); (b) *disclosure concerns* (concerns related to keeping their HIV status secret or controlling who knows their HIV status); and (c) *negative self-image* (negative feelings toward self for having HIV). These overall effects were not maintained at the 3-month

follow-up for *personalized stigma* or *disclosure concerns*, and were only minimally maintained for *negative self-image*. The effect sizes for the *concern with public attitudes* toward people with HIV subscale (worries about maintaining employment and fears of discrimination) revealed that there were no changes either post-intervention or at the 3-month follow-up for the overall sample for this domain of HIV-related stigma.

Baseline levels of HIV-related stigma indicated that the lowest standardized subscale score for both male and female adolescents was *disclosure concerns*, indicating that youth were most concerned about keeping their HIV status secret or controlling who knows their HIV status. This predominant concern with disclosure mirrors qualitative data from other samples of both female and male adolescents/young adults living with HIV, which have indicated the centrality of HIV status disclosure in the lives of these young people.^{33,37,55} These data also are similar to a study of 42 young men who have sex with men living with HIV, where participants reported experiencing greater stigma related to disclosure concerns than the other three subscales of the Berger HIV Stigma Scale.⁴⁴

Gender differences in stigma reduction

When comparing baseline levels of all four domains of HIV-related stigma across genders, it was revealed that female participants began the intervention with lower levels of reported stigma than male participants (Fig. 1). Gender-specific intervention outcome analyses also revealed a different pattern of results for female and male youth, even though there were minimal differences in the intervention content received by the female vs. male participants. The only HIV-related stigma reduction component of the intervention that differed across genders was the focus on building skills to combat HIV-related discrimination and other forms of stigma. In order to address compounded stigma stemming from living with HIV and being members of marginalized groups, gender-specific sessions provided tailored assistance with addressing issues of compounded stigma. The male-specific session discussed aspects of sexuality, with a focus on sexual orientation and dual disclosure of HIV status and sexual orientation. It also explored strategies for connecting with others in the larger gay community to assist with combating stigma. The female-specific session explored specific discrimination related to women living with HIV becoming pregnant, as well as more general discriminatory societal views regarding women's roles and responsibilities. This session also provided specific information related to mother-to-child HIV transmission and provided up-to-date education on making safer choices for family planning.

The intervention appeared to reduce stigma for male participants across all four types of stigma, and those effects were maintained at varying levels at the 3-month follow-up. The strongest effects for male participants were for *disclosure concerns* ($d=0.31$) and *negative self-image* ($d=0.42$), with the latter approaching Cohen's definition of a medium effect size and also having the highest level of maintenance at the 3-month follow-up ($d=0.30$). Although the post-intervention effect size for the *concern with public attitudes toward people with HIV* subscale was small ($d=0.17$) for male youth, it was the only one that increased at the 3-month follow-up ($d=0.22$).

Only one subscale demonstrated a decrease in stigma at post-intervention for female participants (i.e., *personalized stigma*). The other three types of stigma (i.e., *disclosure concerns*, *negative self-image*, and *concern with public attitudes*) revealed increases in reports of stigma at post-intervention for female youth and these effects continued to be reported at the 3-month follow-up assessment. The largest increase in stigma for female participants was on the *concern with public attitudes toward people with HIV* subscale, which demonstrated a negative effect size at post intervention ($d = -0.24$) which increased at the 3-month follow-up ($d = -0.54$).

Although data from the combined sample revealed intervention effects for three of the four stigma subscales, gender-specific analyses suggest that these effects were being driven by the positive intervention effects found for male participants, while data from the female participants actually demonstrated some increases in experiences of HIV-related stigma post-intervention and at the 3-month follow-up. This gender difference may be driven by resilience-focused supportive factors associated with the primary sociodemographic difference between the male and female youth in the study, which was sexual orientation—male participants predominately identified as gay or bisexual (97%) while female participants predominately identified as straight (96%). This is reflective of the HIV epidemic among adolescents and young adults in the US, as 85.7% of new HIV infections among female individuals ages 13–24 were attributed to female-to-male sexual contact, and 87.1% of new HIV infections among male youth in the same age range were attributed to male-to-male sexual contact.⁴⁵

Since nearly three-quarters of the 12,200 new youth infections in 2010 were attributed to male-to-male sexual contact, and these rates are continuing to increase among this population,⁴⁵ the HIV epidemic among adolescents and young adults in the US is vastly becoming an epidemic among young men who have sex with other men. Many of these young men identify as gay or bisexual, as prior reviews of US national HIV seroprevalence studies focused on adolescents and young adults who reported male-to-male sexual contact demonstrated that 86–95% of these youth self-identified as gay or bisexual.⁴⁶ Although it is alarming that such increases are being evidenced among gay/bisexual young men, the fact that the vast majority share a sexual orientation identity and thus may be part of a larger “gay community” that has existing social support structures and mechanisms to support people living with HIV^{18,47} may be beneficial with regard to addressing the potentially damaging effects of HIV-related stigma. Acceptance of one's sexual orientation, which is often accompanied by connections with similar others, has been shown to be associated with increased rates of engagement in care among gay/bisexual male adolescents living with HIV.¹⁴ In addition, gay and bisexual adolescents may evidence strength and resilience related to their shared sexual orientation culture and the supportive relationships that may exist for them in the larger gay community.^{46–49}

Heterosexual young women living with HIV often have different life experiences than gay/bisexual young men living with HIV, as several authors have suggested that women living with HIV experience various forms of stigmatization in their relationships with others.^{50–52} Quantitative studies have

revealed that women living with HIV experience more social rejection, shame, discrimination, violence, and overall perceived HIV stigma than men with HIV/AIDS.^{50,51} These gendered experiences may also be associated with psychological distress and participation in health risk behaviors.^{16,25,26} Thus, the gender differences revealed in this study are likely related to the many differences that exist with regard to how gay/bisexual male youth and heterosexual female youth are (or are not) connected with communities and social interactions that are supportive and affirming, as well as the type of romantic and sexual relationship they have.

The largest positive effect size post-intervention and at 3-month follow-up for male participants was seen for the *negative self-image* subscale. Several activities in the intervention attempted to decrease negative feelings toward self and others living with HIV, such as increasing knowledge of HIV transmission and progression, dispelling myths about people living with HIV (through activities and interactions with peers), exploring societal messages about people living with HIV, and enhancing self-esteem. Since participating in this group was the first time that many of the young men had shared their status with other youth like themselves, it may be that the intervention started the process of helping these young men to see themselves and others living with HIV as just “young men” as opposed to “people living with HIV.” Given their affiliation as gay or bisexual young men, they also had an increased opportunity to leave the group and see other models of gay/bisexual men living with HIV within the larger gay community (whether in their physical communities or in the media) over the course of the intervention, further affirming a positive self-identity that was not primarily focused on their HIV status.

Female participants, on the other hand, did not demonstrate reductions in the *negative self image* aspect of stigma at post-intervention or at follow-up. Although these young women experienced the same intervention activities, it may be that they did not share a common identity and connection as may have been the case with the gay/bisexual young men. It also may be that the female participants would have benefitted from more or different intervention sessions where they could have developed supportive connections with both their fellow female participants, as well as other women living with HIV in their local communities, in an attempt to change their views of women living with HIV (both their views of self and of others). Unlike the gay community, there has not been as strong of a cohesive and unifying collective response to HIV among heterosexual women, so these women may not have found such supportive role models and community members to help them alter their views of others living with HIV. In addition, given the smaller numbers of women living with HIV in the US as compared to gay/bisexual men,⁴⁵ female participants were less likely to have encountered and interacted with other people living with HIV outside of the intervention. This lack of interaction with and connection to others living with HIV outside of the intervention group may have increased their negative feelings about self and others living with HIV.

The other larger effect size for males at post intervention (and to an extent at 3-month follow-up) was the *disclosure concerns* subscale. Several activities in the intervention focused on increasing planned and strategic HIV status disclosure to others by building participants’ skills and self-

efficacy related to disclosure. Given the higher prevalence of HIV among gay/bisexual young men as opposed to heterosexual young women, it is likely that male participants had a wider range of potential friends, romantic/sexual partners, and/or family members to whom they could disclose their status that already had contact with other people living with HIV or were actually living with HIV themselves. In addition, many youth chose to practice HIV status disclosure to dating and sexual partners in the intervention, and may have actually had disclosure conversations outside of the intervention. Since young men were primarily focused on disclosure with sexual and romantic partners who were also gay/bisexual males, the role plays in the intervention were likely more realistic since they were conducted with the actual population to whom they would be disclosing in “real world” situations. In addition, if they engaged in disclosure conversations outside of the intervention, they were more likely to be disclosing to someone who had experienced such a situation with a prior partner or who was also living with HIV.

Female participants, on the other hand, did not demonstrate any stigma reduction related to *disclosure concerns*, and even reported slightly greater levels of disclosure stigma post-intervention and at the 3-month follow-up. Since female participants were likely focused on disclosing to male sexual/romantic partners, the intervention role-plays may have not been as realistic given that all group participants were females. In addition, it may be that additional sessions were needed to focus more on relationship dynamics with male sexual and romantic partners prior to HIV status disclosure. Also, given the lower prevalence of HIV among heterosexual young women and their potential sexual partners (i.e., heterosexual males),⁴⁵ if they engaged in a disclosure conversation outside of the intervention, it is less likely that the individuals to whom they disclosed had experience with sexual/romantic partners living with HIV or were living with HIV themselves. Power differentials in male–female romantic/sexual relationships that place young women in more subordinate roles also may have played a role in increasing the anxiety and/or concern these young women experienced in disclosing their HIV status to their sexual/romantic partners.

The increases in various forms of stigma reported by females over the course of the intervention raise questions about the ability of this intervention in its current form to reduce HIV-related stigma for female adolescents and young adults living with HIV, and call for additional qualitative explorations of gender-specific stigma concerns for adolescents living with HIV. As reported elsewhere, female participants did benefit from the intervention in other areas of psychosocial functioning, as general intervention results for the overall sample demonstrated increases in HIV knowledge and self-efficacy for disclosure of HIV status, as well as improvement in peer and formal social support across both time periods.³⁸ Gender-specific analyses revealed that females demonstrated improvements in their self-efficacy related to sexual discussions, improvements in their use of effective coping strategies (i.e., increases in their use of proactive coping strategies and decreases in their use of avoidant coping strategies), and a small improvement in self-esteem at 3-month follow-up.³⁸

It may be that the gender-specific component of the intervention that focused on building skills to combat HIV-

related discrimination through tailored assistance with addressing issues of compounded stigma may have had an iatrogenic effect by heightening participants' awareness of discrimination focused on women living with HIV, becoming pregnant, and the biological risks of mother-to-child HIV transmission. Although this information is critical for young women living with HIV, it may be that more time was needed to process the impact that such awareness and information had on their feelings of self and subsequent internalized stigma. Another potential factor that may have contributed to the increase in stigma is that the intervention may have activated a heightened awareness of the challenges and potential consequences of HIV status disclosure, since disclosure was a salient feature of the intervention. As with information related to mother-to-child transmission, this information was critical to the intervention but it may be that differential social stigma associated with young women living with HIV and the lack of community supports available to females⁵⁰⁻⁵² contributed to growing concerns regarding how family, friends, and romantic partners would react to their disclosure. Prior qualitative work with female adolescents living with HIV has documented some young women's tolerance of emotional abuse following disclosure of their HIV status to family, friends, and romantic partners due to lack of self-worth and fears of subsequent rejection if they terminate current relationships and seek others.⁵⁴

Therefore, it may be that future interventions for female youth living with HIV need to more fully address the development and maintenance of healthy relationships that provide support to these young women as they learn to live positively with their HIV status. This could involve additional individual sessions to explore reasons for current unhealthy relationships, as well as couples or family sessions. In addition, since issues of pregnancy were addressed in detail in the female-specific module on sexuality, it may be that this heightened awareness of upcoming challenges in childbearing related to HIV status also contributed to gender-specific increases in stigma over the course of the intervention. Such concerns could be addressed in additional sessions or through an expansion of current material on pregnancy and childbearing.

Limitations, strengths, and future interventions

Methodological limitations should be considered when interpreting the results of this study. Since this was a small pilot trial of the Project ACCEPT intervention, the sample size ($n=50$) limited the ability to assess statistical significance of intervention outcomes and prohibited a more nuanced exploration of gender differences or differences based on other key sociodemographic variables such as race/ethnicity. The lack of a comparison condition due to the use of a single-group pretest-posttest design limits the ability to determine if the changes observed are part of the natural psychosocial progression for adolescents newly diagnosed with HIV, or if they can truly be attributed to the intervention. In addition, youth self-selected to participate in the intervention and were not randomized; therefore the generalization of these results to the larger population of adolescents living with HIV is limited. The study outcome measures were all based on self-report; therefore some reporting bias may have occurred, although the use of change scores to assess

intervention effects lessened the possibility that findings resulted from biases related to social desirability.

Despite these limitations, there were several strengths associated with the intervention and study design. The Project ACCEPT intervention is theory-based and was developed utilizing qualitative data from both youth living with HIV and care providers who provide services to this population. The delivery of two individual sessions followed by multiple group-based intervention sessions offered youth the ability to first prepare for being engaged in a group setting with other youth living with HIV through the more specialized attention and guidance of the individual sessions. The group-based sessions allowed for participants to build social support within the groups, and to create a supportive network of other young people living with HIV. The stigma measure used in this study was multi-dimensional, thereby offering insights into the potential differential influence of the intervention on various types of stigma. Gender-specific exploration of the study findings was another strength and offers insights into how future interventions will need to more fully address the unique challenges faced by female adolescents and young adults living with HIV. Finally, including participants from four geographically diverse regions of the US (i.e., Chicago, New York, Miami, and Memphis) increases the potential to generalize the study findings beyond one city.

Future interventions to reduce HIV-related stigma among adolescents living with HIV can benefit from the findings of the current study. Although Project ACCEPT was focused on intervening with adolescents and young adults early after their HIV diagnosis before negative societal messages are fully internalized, such interventions would likely be effective for young people who have been living HIV for longer periods of time as well. It may even be that some components of the current intervention that did not produce immediate and/or sustained stigma reduction results may have a different effect on youth living with HIV who are not in the early stages of learning to accept and manage their HIV status.

Although not directly explored in this study, given the relationships between stigma and health risk behaviors, stigma reduction interventions should continue to address participation in health risk behaviors and assess such changes. Future interventions should also consider replicating the model of intervention implementation used in Project ACCEPT whereby groups were conducted by an interventionist with a mental health background and a peer facilitator who matched the participants with regard to gender, age, and HIV status. The inclusion of a facilitator with a mental health background allowed this individual to address emotional distress concerns that occurred in the course of the intervention and to provide referrals to mental health services for those youth who required additional support. In order to support the long-term maintenance of intervention effects future interventions may consider additional structured "booster" sessions after the intervention has concluded, less structured support groups where participants can discuss continued stigma reduction challenges, and/or online resources where participants can access information, post questions/challenges for professionals, and "chat" with other youth living with HIV.

Given the gender differences in the intervention outcome results and the disparate experiences of gay/bisexual male youth vs. heterosexual female youth, it appears that young

women living with HIV may need a different type of intervention to reduce stigma than young men. Such an intervention should focus increased time on helping participants to combat discrimination and negative societal stereotypes regarding women living with HIV, especially related to issues of pregnancy and mother-to-child transmission. Additional time should also be spent on disclosure of HIV status, and the concomitant emotional distress that often accompanies such a task. According to Sandelowski et al.,⁵⁰ women engage in a process of making, reversing, and remaking decisions about disclosure every time they encounter social interactions with others. This process can be very taxing on the individual's sense of control and decision-making and may lead women to full or selective concealment, as well as denial of health care services to prevent disclosure to others. In addition, in Hosek et al.'s⁵⁴ qualitative study of young women living with HIV participants acknowledged that disclosure of their HIV status is a lifelong and difficult process. Thus, whether the young women in our sample chose to keep their secret or share their HIV/AIDS status with others, the decision most likely resulted in increased distress.⁵³ Finding ways to assist young women with managing the psychological challenges associated with both their HIV diagnosis and HIV disclosure, while also providing them with the skills and support needed to combat HIV-related stigma which may be perpetuated by multiple societal forces, should be addressed in future stigma reduction interventions.

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