The Impact of Stigma on Medication Adherence Among HIV-Positive Adolescent and Young Adult Females and the Moderating Effects of Coping and Satisfaction with Health Care

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Abstract

To explore whether HIV stigma negatively impacts adherence to antiviral medications in HIV-infected adolescent women, moderational analysis was conducted and factors identified that could alter said relationship. Study participants were 178 adolescent females age 15-24, enrolled between 2003-2005, from 5 different cities and 60 provided adherence information. Findings reported by this cohort of 60 adolescent women included: medication adherence, 64.3% reporting adherence at baseline and 45.0% at 12 months; HIV stigma score of 57.60 (standard deviation [SD], 11.83; range, 25–86). HIV stigma was not found to be a significant predictor when binary logit regression was run with medication adherence at 1 year. Using moderational analysis, factors that could moderate stigma's effect on medication adherence was still pursued and identified the following to be significant at 12 months: health care satisfaction (B = -0.020, standard error [SE] = 0.010, p < .05); and Coping (proactive coping strategies [B=0.012, SE=0.005, p<.05]; turning to family [B=0.012, SE=0.016, p<0.05]; spiritual coping [B=0.021, SE=0.010, p < 0.05]; professional help [B=0.021, SE=0.010, p < 0.05]; physical diversions [B=0.016, SE=0.007, p<0.05]). Factors that had no significant moderating effects included: social support measures (mean=74.9; median=74.0) and depression score greater than 16=43%. We conclude that HIV-infected adolescent women experience HIV stigma and poor adherence over time. Factors like health care satisfaction and coping may minimize stigma's effect on medication adherence. Our findings are tempered by a small sample size and lack of a direct relationship between stigma and adherence on binary logit regression analysis.

Introduction

F_{NOM} 2004 to 2007, new HIV/AIDS cases increased for youth 13–24 years old, and comprised approximately 15% of all cases in the United States.¹ Surveillance data in the United States and dependent areas revealed that adolescent women represent 39% and 30% of all HIV infections in youth age 13–19 and 20–24 years old, respectively.² Individuals afflicted with HIV report the illness to be highly stigmatizing and the societal views that since it is behaviorally acquired and contagious, makes HIV/AIDS relatively more stigmatizing than other illnesses.³ Thus, the stigma that surrounds HIV/AIDS may compromise the well-being of HIV-positive adolescent women, and may impact their use of the health care system. Of note, in a study of predictors of HIV stigma among youth people living with HIV, female gender was closely associated with perceived HIV related stigma.⁴

Generally, stigma has been defined as a negative reaction to an attribute (e.g., a physical deformity, a group of signs or symptoms, or a behavior) in an individual that is deemed as undesirable or discrediting in a social or societal setting.⁵ It is also associated with societal power structures when one

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group of individuals develops prejudicial thoughts and behaviors toward another group of individuals who share a particular attribute.^{6–8} In the context of HIV/AIDS, the literature has defined HIV/AIDS-related stigma as consisting of unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their loved ones, associates, and communities.⁹ Young men living with HIV have also been surveyed regarding HIV-related stigma revealing that disclosure concerns were prevalent and that stigma correlated with depression, social support, selfesteem, and romantic loneliness.¹⁰

Medication adherence

For individuals infected with HIV, antiretroviral medications have been demonstrated to change this illness from one that is lethal to one that is chronic and manageable. A significant association has been established between a decrease in plasma viral load and improvements in clinical outcomes.¹¹ However, greater than 95% adherence to the combined antiretroviral medication (cARV) regimens must be maintained in order for them to be effective.¹² Studies in adolescents with HIV have demonstrated poor adherence to cARVs, and declining over time, with only 24% demonstrating viral suppresson 3 years posttreatment initiation.^{13,14} In contrast, 52-74% of adults demonstrate viral suppression 3 years posttreatment initiation.^{15,16} Yet, the youth involved in these adherence studies were from sites involved in the delivery of comprehensive youth specific services. Health care sites with expertise in youth specific services boast the ability to provide psychosocial support to address issues associated with poor adherence including housing, mental health issues, substance use, and youth's fear of disfiguring effects of cARVs.17-20 Thus, addressing issues of adherence to cARVs is a significant concern and goal of providers when initiating treatment in HIV infected adolescents.

Medication adherence and HIV stigma

HIV-infected individuals reporting high levels of HIV stigma are three times as likely to be nonadherent with their medications compared to those with low HIV stigma concerns.²⁰ HIV stigma concerns have been documented in HIV-infected adults who were nonadherent to medications because they feared taking these medications publicly.²¹ Similarly, a study of HIV-infected adolescents (M=22 years) revealed that HIV stigma was responsible for poor medication adherence in 50% of youth who feared that in taking their antiviral medications, friends or family might discover their HIV serostatus and reject them.²²

In HIV-positive youth, stigma has been associated with other factors that may impact adherence. In one study of young HIV-infected individuals (M=23 years), individuals with perceived stigma (i.e., stigmatized person's worries of rejection, discrimination, and shame) were found to alter their behaviors in efforts to reduce or avoid enacted stigma (i.e., actual experiences of discrimination and stigma), thereby potentially affecting benefits of support and treatment.²³ Youth (M=23 years) with high levels of perceived stigma, more often avoided social contacts.⁴ Thus when HIV stigma is noted as a stressor, whether perceived or enacted, individuals with HIV will use varying forms of coping, including serostatus disclosure or no disclosure, seeking social support or isolation.

Lessening societal HIV stigma is beyond the scope of what medical providers can do within the clinical setting. Yet, we sought to investigate and identify factors that could moderate HIV stigma and its relationship to medication adherence that could be addressed within the clinical setting. A variety of individual-level and relational factors were thus identified including health care satisfaction and addressing the coping skills of HIV infected adolescents.

We wanted to explore whether HIV stigma negatively impacts adherence to antiviral medications in HIV positive adolescent women. We also wanted to explore factors that moderate this relationship that can be addressed in the clinical setting like satisfaction with health care services, social support, and coping skills. These may explain why some HIVinfected adolescent women succeed at adherence, while others fail, despite the existence of HIV stigma. This study also focuses solely on female adolescents with HIV/AIDS because of the narrow body of literature describing this special population.

Methods

Study description

This study was one of several protocols developed through the Adolescent Trials Network (ATN) for HIV/AIDS Interventions. The ATN is a collaborative network of 15 clinical (adolescent medicine) sites that have ongoing data collection activities highlighting health concerns of HIV-positive youth and those most at risk for HIV infection.

The data set for this study was obtained through a multisite, prospective longitudinal 18-month study examining the relationship among substance use, mental health disorders, and social networks (peers, parents, and guardians) and their relationship to engagement in care for HIV-infected adolescent females, aged 15–24 years. The title of the study was ATN protocol 009: Drug Use and HIV Infected Female Adolescents' Care Use, and was conducted between March 2003 and December 2005. There remains sparse information on how HIV stigma impacts adherence and whether any factors can influence youth living with HIV to adhere to medications. Thus, this study is timely in assisting providers in the care of youth with HIV infection.

Participants

HIV-infected participants were recruited from five cities including New York City, Chicago, Miami, Los Angeles, and New Orleans. Study participants were female aged 15-24 years, of all race/ethnicities, who were English or Spanish speaking and had nonperinatal, nontransfusion acquired HIV. Study participants were recruited for this study during their scheduled clinic appointments by the research team personnel at each site. All adolescent females who were HIV positive and who agreed to participate underwent an informed consent process, and then scheduled for study visits as required by the protocol. Qualitative and quantitative data collection methods were used with participants. Adolescent HIV-positive women were interviewed every 6 months for 18 months. The data for this analysis consist of quantitative data at 12 months. In order to capitalize on the longitudinal nature of our data, we examined stigma at baseline in an attempt to capture the potential influence of this construct over a

12-month period, and then measured our outcome and potential moderators at 12 months after the participants had experienced said stigma. The Institutional Review Board at all five participating ATN sites approved this study. At two sites, parental consent was required for women younger than 18 years.

Study measures

The following measures were selected for this study.

Medication adherence. Medication adherence was assessed using a self-report of HIV antiretroviral medications adherence embedded within an ACASI administered at 12 months. Using 12-item questionnaire, participants were asked to name the medications they were prescribed and the number of pills, and doses they adhered to 2 days and 1 day before the administered ACASI and whether they were delayed by 1 or more hours in their doses. They were also asked to respond to similar questions on adherence to medications on the weekend prior to the ACASI.

HIV stigma. The HIV stigma scale²³ is a 40-item questionnaire used to measure HIV related stigma. This scale has been previously validated within an adolescent population.^{10,23,24} Psychometric properties of the scale support both a single higher order construct of stigma and four subscales. The measure has demonstrated good internal reliability, construct validity, discriminant validity, and test-retest reliability with a diverse sample of HIV positive individuals.^{23,25} To reduce participant burden, two of four subscales were used in this study: the disclosure and negative self-image subscales. Items included in these subscales capture both perceived and internalized stigma. Participants were asked for their degree of agreement with statements such as "People's attitudes make me feel worse about myself"; "Telling someone I have HIV is risky"; and "I never feel the need to hide the fact that I have HIV." Anchors ranged from 1 to 4 with higher scores indicating greater perceived stigma. After reverse scoring appropriate items, we summed the disclosure and negative self-image scale to obtain a global measure of perceived and internalized stigma, Cronbach α for this summed scale was 0.90.

Social support (at 12 months). Perceived social support was measured using the Social Provisions Scale.²⁶ This is a 24item scale with 6 subscales and a global score. In this study, only the global score was used. Questions are anchored from 1 (strongly disagree) to 4 (strongly agree) for a possible range of 24 to 96. Higher scores indicate higher perceived support. The scale has demonstrated adequate reliability and validity across multiple samples.²⁷ Cronbach α in this study was 0.91.

Depression (at 12 months). The Center for Epidemiologic Studies Depression Scale²⁸ (CES-D) was used to assess self-reported depressive symptoms in the last week. The measure was used with adolescents and their parents or guardians. The CES-D was developed at the Center for Epidemiologic Studies at the National Institute of Mental Health to measure depressive symptoms among adults in community surveys. This scale has been used with HIV-infected patients²⁹ and adequate internal reliability and construct validity of the CES-D with adolescent HIV populations has been demonstrated.³⁰ Anchors range from 0 to 3 with higher scores indicating greater depression. In our study, the Cronbach α for the CES-D was 0.90.

Health care satisfaction (at 12 months). Using the Client Satisfaction Survey developed by The Measurement Group health care satisfaction was measured.³¹ The 11 questions (α =0.88) assessed the participants' opinion of the quality of services provided by their HIV care provider. Scores range from 11 to 45 with higher scores representing less satisfaction.

Coping. The Adolescent Coping Orientation for Problem Experiences Scale (A-COPE) (at 12 months): The A-COPE³² is a 54-item scale that identifies 12 different types of coping strategies utilized by adolescents, including: proactive coping strategies, turning to family, spiritual coping, passive diversions, professional help, and physical diversions. A total score can be utilized to assess overall coping skills. The total A-COPE score in this study had an alpha of 0.81. Cronbach α coefficients for the various coefficients ranged from 0.56 to 0.77, with the exception of the catharsis subscale (0.385). A-COPE subscale α include: Proactive coping, 0.771; Avoidant, 0.566; Externalizing, 0.750; Social, 0.728; Family, 0.733; Spiritual, 0.680; Physical diversions, 0.702; Passive diversions, 0.600; Catharsis, 0.385; Humor, 0.561; Positive Imagery, 0.656; and Self-reliance, 0.612.

Analysis

Moderator analysis using measures at the 12-month visit. To determine if other factors interacted with baseline HIV-related stigma to affect medication adherence at 1 year, a series of binary logit regressions were run with self-reported medication adherence at 12 months (coded as 1 for 100% adherence and 0 for less than 100% adherence). Scores on the HIV stigma scale at baseline were entered as predictors, as were the following potential moderator variables: health care satisfaction, social support, depression, and the component subscales of the A-COPE. Variables were investigated for their moderating properties at 1 year. All variables were centered around their respective means by subtracting the variable mean from each participant's scores prior to being entered into the regression. Additionally, an interaction term between the stigma scale and the relevant moderator variable was included, according to the method for determining moderator effects proposed by Baron and Kenny.³³ Such variables were generated for all possible moderators under investigation. Following the initial moderator tests, significant moderators were probed using the post hoc method suggested by Holmbeck.³⁴ Two additional regressions were run in which the slope between the independent variable (stigma) and the dependent variable (probability of being adherent with medication) was observed when the moderator was artificially recentered at one SD above and one SD below its mean.

Results

Demographics

There were 178 adolescent women who participated in the ATN 009 study, however, only 46% (n=82) reported

adherence data at baseline. At the 12-month follow-up the retention rate of young women still participating was 75.8% (n = 135). There were 60 who had adherence data at 12 months and 45 who had adherence data at both baseline and 12 months. Since our analyses were looking longitudinally (using baseline data to predict 12-month adherence outcomes), our final sample consisted of these adolescent and young adult females on cARVs (n = 60). The mean age was 20.6 (SD 2.0) years. The adolescent and young adult females were primarily African American (73%) and Latina/Hispanic (20.8%). Latinas were more likely to identify as either Mexican (46%) or Puerto Rican (22%), with those from Central America representing the third largest Latina group. English-speaking only was reported by 75% of this cohort with 19% reporting speaking both English and Spanish. The interviews and surveys were conducted in Spanish for those who were Spanishspeaking only (Table 1).

Adherence measure

Approximately one third of the study participants provided an answer on adherence. In comparison, those who did not provide adherence data were more depressed, more likely to use externalizing coping strategies, and had better outcome expectancies of alcohol.

For the purpose of our analyses, "Adherence" was based on one item of self-report in the 12-item self-administered questionnaire, "Over the past 4 days, has there been a day when you missed taking all doses of your meds?" Those who said no were coded as adherent. At baseline, 64.3% reported adherence, while at 12 months, 45.0% were still adherent. Since there was no association found in our prior work between age and stigma,³⁵ and since the HIV stigma scale was previously validated for use in males and females ages 13 to 24,^{10,23,24} we

TABLE 1. DEMOGRAPHICS FOR ADOLESCENT WOMEN
with HIV Prescribed Combined Antiviral
Medications $(N=60)$

	(%)
Age: Mean age 20.6 (SD 2.0). Race/ethnicity:	Mean age 20.6 (SD 2.0) years
Asian/Pacific Islander	0.6%
Black/African American	73.0%
Native American/Alaskan	1.1%
White	1.7%
"Other"	2.8%
Hispanic	20.8%
Hispanic/Latino identified:	
Central American	16.2%
Cuban	5.4%
Dominican	8.1%
Mexican	45.9%
Puerto Rican	21.6%
Mixed Hispanic	2.7%
background	
Language:	
English speaking only	74.7%
Spanish only	4.5%
Some of both	18.5%
Another language	2.2%

SD, standard deviation.

chose not to control for this variable. Further, place of birth, previous homelessness status, parents being born outside the United States were not associated with adherence status. Race/ethnicity was also not associated.

HIV stigma scale

Adolescent women self-reported experiencing HIV stigma with a mean score of 57.60 (SD of 11.83); range of scores: low score was 25, high score was 86. There was low intercorrelation between stigma and the moderator variables tested within the study.

To test whether stigma itself had an effect on medication adherence, a binary logit regression was run with medication adherence at 1 year, coded dichotomously as 100% adherence or less than 100% adherence, regressed on stigma at baseline. Stigma was not a significant predictor within the regression (B = -0.012, SE = 0.020, p > 0.50). Despite the lack of a direct relationship between stigma and adherence, we continued with the moderational analysis given the lack of empirical data with this population and prior qualitative data suggesting the impact of stigma on adherence with this population.²²

Social support

No significant moderating effects were found for the social support measure. The social support measure had a mean of 74.9 and a median of 74.0, revealing that this cohort of adolescent women reported relatively good social support. However, again, no significant moderating effects were found for this measure (Table 2).

Depression

Of the 60 youth in the final sample, 43.3% registered above the clinical cutoff for depression (greater than 16). The mean score was 18.52. However, no significant moderating effects were found for depression.

Health care satisfaction

Health care satisfaction at 12 months moderated the relationship between stigma and adherence. In the initial moderator analysis, the interaction between health care satisfaction and stigma was significant (B = -0.020, SE = 0.010, p < 0.05). *Post hoc* analyses revealed that at low levels of health care satisfaction, stigma was negatively related to medication adherence while at high levels of health care satisfaction, stigma was not related to medication adherence. Thus, at low level of satisfaction with health care, increasing levels of stigma will be associated with lower levels of adherence (Table 2).

Coping

Several subscales of the A-COPE were found to moderate the relationship between stigma and medication adherence. Specifically, proactive coping strategies at twelve months (interaction term B=0.012, SE=0.005, p<0.05), turning to family at 12 months (B=0.012, SE=0.016, p<0.05), spiritual coping at twelve months (B=0.021, SE=0.010, p<0.05), professional help at 12 months (B=0.021, SE=0.010, p<0.05), and physical diversions at twelve months (B=0.016, SE=0.007,

Table 2.	Moderator	VARIABLES
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Moderator variable	Initial moderator test	Post hoc
Social support Depression Health care satisfaction at 12 months	No significant moderating effects No significant moderating effects (B = -0.020, SE = 0.010, p < 0.05)	Low levels of health care satisfaction,
		stigma was negatively related to medication adherence while at high levels of health care satisfaction stigma was not related to medication adherence.
Component subscales of The A-COPE		
Proactive coping strategies at 12 months Turning to family at 12 months	(interaction term B=0.012, SE=0.005, <i>p</i> <0.05) (B=0.012, SE=0.016, <i>p</i> <0.05)	At low usage of the moderator, stigma was negatively associated with adherence. At high levels
Spiritual coping at 12 months Professional help at 12 months Physical diversions at 12 months	(B=0.021, SE=0.010, $p < 0.05$) (B=0.021, SE=0.010, $p < 0.05$), (B=0.016, SE=0.007, $p < 0.05$)	of usage, stigma was no longer related to adherence

SE, standard error.

p <0.05) all showed significant moderating effects. *Post hoc* analyses showed that in all cases, at lower usage of the moderator, stigma was negatively associated with adherence, while at higher levels of usage, stigma was no longer related to adherence (Table 2).

Discussion

HIV stigma, perceived and or experienced, is widely reported by individuals with HIV infection and noted to be a barrier for care.²³ Caring for adolescents with HIV infection should entail comprehensive medical care that is developmentally appropriate and addresses psychosocial concerns including the impact of HIV stigma on medical treatment. Adherence to medications reported by this cohort of youth declined over a 12-month period with less than 50% reporting adherence and is similar to what is reported in the literature.¹³

HIV-related stigma was reported in this cohort of HIVpositive adolescent women (mean 57.60 [SD of 11.83]; range, 25-86), which appears low compared to other published studies of individuals with HIV. HIV-related stigma scale measures across domains and scores can vary depending on the number of subscales employed in any targeted population.²³ However, it is challenging to compare the rate of HIVrelated stigma across studies due to the use of different measures.³⁶ For example, it would be difficult to compare the score of our cohort of adolescent and young adult females to a study of 48 HIV-positive adolescents from an urban clinic, where only 10 items from 2 subscales on the HIV stigma measures were used, and wherein said study found that HIV stigma correlated significantly with personalized stigma, negative self-image, depression, and alcohol use in the previous 30 days.²⁴ Thus, comparisons of the stigma scored by screening and assessment tools reported by HIV infected individuals in the literature, including adolescents, is difficult.

This study, like previous studies, confirms that HIV positive individuals, including youth, experience HIV stigma. Furthermore, HIV-related stigma, by itself, was not found to significantly affect medication adherence. However, given the small sample size and low experiences of stigma we cannot conclude firmly that stigma does not directly affect medication adherence. When we conduct the moderation analysis we found that HIV-related stigma does indeed impact medication adherence. Noteworthy is that when health care satisfaction is low, stigma does appear to influence medication adherence, but high satisfaction with health care providers seems to help ameliorate the potentially negative influence of stigma on adherence.

Other variables were also found to moderate medication adherence in youth in the presence of HIV stigma. Higher usage of proactive coping—turning to family, spiritual coping, turning to professionals for help, and engaging in physical diversions—decreased or cancelled HIV stigma's impact on medication adherence. They all appear to be active coping strategies, which implies that when youth experience stigma, those who actively engage in coping behaviors are better off. Thus, addressing the relationship between the moderating effects of HIV stigma and the above mentioned variables within the clinical context may help to improve medication adherence.

This study also suggests that providers can improve medication adherence in the presence of HIV stigma by addressing issues that may impact health care satisfaction. In adults with HIV infection, satisfaction with health care has been documented as working with their health care providers within shared and trusting relationships, and being kept well informed of their illness.³⁷ Having trusting, positive working relationships with primary care providers and being satisfied with the health care they receive, may be a powerful tool for HIV positive youth to adhere to their treatment and to combat HIV stigma, as suggested in this study. Given busy clinic schedules and limited time to spend with each patient, the promotion of positive copings strategies can also be addressed in group interventions for these youth that specifically address adherence.

Of note is that the health care provided in this cohort of youth occurred primarily at adolescent medicine sites, with adolescent medicine trained providers where services are designed specifically for youth and are inclusive of medical care, nursing, case management and, at most sites, mental health (which often is inclusive of support groups addressing issues of adherence). Regrettably, the needs of youth infected

with HIV and their satisfaction with health care is often overlooked as these youth may be placed in health care models (directed for adults or young children with HIV) that have little or no experience with adolescents. In addition, providers may seek to offer services that are more often responsive to policies that place more emphasis on the rights of parents.³⁸ Thus, providers should survey HIV-infected youth on the health care services that are provided and needed, and implement policies that can respond to the identified needs of this population.

This study also highlighted the importance of individuals engaging in active strategies of coping that can moderate the relationship between stigma and treatment adherence. Women with HIV infection have been documented to have fewer active coping strategies and less social support relative to community norms.³⁹ Yet in this cohort of young women with HIV, coping, especially the level or degree of proactive coping, that is turning to family, spiritual coping, physical diversions, and turning to professionals significantly helped them to adhere to medications despite stigma. This study suggests that providers should seek to strengthen the problem and emotion focused coping skills (adaptive coping) of these adolescent women that may also improve adherence. Assisting these youth with being able to turn to family and professionals for support can reduce the negative effects of HIV stigma on medication adherence. In addition, physical diversions like physical exercise, outings, field trips, summer camps, art and music activities may also serve as strong coping strategies for these youth.

We also found that depression or social support did not moderat the stigma-adherence relationship. Prior research has revealed that depressive symptoms and medication adherence, are strong correlates of stigma-related experiences and suggests that HIV related stigma increases the individual's vulnerability to depressed moods. However, no causal relationship between depressed moods and stigma has been established. Thus, there is no confirmed evidence that depressed moods heightens stigma.⁴⁰ Furthermore, studies focusing on social support have revealed that social support from a partner positively impacts medication adherence, but not social support from a friend or family.⁴¹ This may explain why depression and social support did not alter or moderate the relationship between stigma and medication adherence.

Limitations of this study are that the findings may not be applicable to HIV positive youth receiving care at sites that are designed for just pediatric or adult patients and at sites that are rural. In addition, the sample size is relatively small (n=60), and larger sample sizes may yield information that could further add to our understanding of the moderating effects of coping, physical diversions, satisfaction with health care services on HIV stigma and medication adherence. Furthermore, given the lack of empirical data with this population and prior qualitative data, and despite the lack of a direct relationship between stigma and adherence on binary logit regression analysis, we continued with the moderational analysis that suggested that there was impact of HIV stigma on adherence with this population. Thus, the results should be interpreted with caution. Yet, our findings add to the growing knowledge and concerns of HIV stigma and its impact on the care of individuals with HIV, and especially the care of youth with HIV. Our study participants shared with us information

that reflects the growing need to reduce the potentially negative effects of HIV stigma by identifying moderating variables that can affect medication adherence so that they and others like them may benefit from the very services that may extend their lives. Although addressing HIV stigma may be overwhelming within the context of the clinical office, findings in this study reveal that it may be possible to overcome the negative effects of HIV stigma at the individual level, and within adolescents.

Clinical implications

HIV-infected adolescents report HIV-related stigma and demonstrate poor adherence to their antiretroviral medications. HIV related stigma unto itself is not a sufficient condition to influence the adherence patterns of these adolescents. Factors like social support and various coping strategies in the presence of HIV- related stigma may influence said adherence. Thus, adolescent service providers that focus on strengthening the social support and coping strategies of HIV infected youth, in addition to provision of comprehensive HIV services, may help adolescents adhere to their antiretroviral medications, despite the presence of HIV-related stigma.

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