NONSTIGMATIZING WAYS TO ENGAGE HIV-POSITIVE AFRICAN-AMERICAN TEENS IN MENTAL HEALTH AND SUPPORT SERVICES: A COMMENTARY

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This commentary illustrates a hospital/adolescent-clinic based model for providing support services and for increasing medical adherence among HIV positive inner city African-American adolescents. This commentary reviews the racial/ethnic disparities in HIV disease among adolescents and describes a successful program model for overcoming stigma. Traditional support groups were rejected by youth with HIV/AIDS. Seven elements common to successful programs were identified. Successful programs built on designs described in the research literature. Focus groups composed of HIV-positive adolescents identified what they wanted and needed. Stigmatizing labels were avoided in naming programs. Practical barriers to access, such as transportation and childcare, were eliminated. Programs were skills oriented, culturally sensitive, and life affirming, focusing on healthy living. HIV-positive inner city African-American youth can be successfully recruited and engaged in hospital based programs. Although these programs were qualitatively evaluated by youth as successful and attrition was low and attendance averaged 50%, rigorous quantitative research is needed to evaluate the effectiveness of such programs. We need quantitative research to successfully advocate for government funding. Stigma needs to be addressed openly in public health. Future research is needed to evaluate interventions to overcome the health consequences of stigma on utilization of available medical and mental health services. (*J Natl Med Assoc.* 2003;95:196-200.)

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Surgeon General Satcher's report on "Mental Health: Culture, Race, and Ethnicity"[1] identifies stigma as one barrier to the use of medical and

mental health services by racial and ethnic minorities. Mirroring this, it was our experience early in the HIV epidemic that it was difficult engaging inner-city, HIV-positive, African-American youth to join a support or psychotherapy group. Not only is there cultural stigma concerning individuals who acquire HIV through sexual activity,[2] but there also is the perception that needing social/therapeutic support is an additional stigma.[3] The challenge for clinicians is to provide treatments and to design interventions that are not stigmatizing and positively perceived by patients. We describe a non-stigmatizing clinic-based model of

support and mental health services for HIV-positive, inner-city, African-American adolescents. Currently, we have the clinical experience and knowledge to provide youth-based, comprehensive life-skills programs for high risk youth that are less stigmatizing, than direct or traditional approaches to mental health or HIV services.

RACE/ETHNIC DISPARITIES

African Americans and Hispanic youth have been disproportionately affected by the HIV/AIDS epidemic. Although less than 16% of the adolescent population in the United States is African American, nearly 50% of AIDS cases through June 2000 among 13- to 19-year-olds were among African Americans.[4,5] More females than males are now being diagnosed with HIV in the 13- to 19-year-old age group.[6] Among females, heterosexual transmission is foremost and the majority of these adolescents are African Americans.[4] In a venue-based sampling intended to maximize people at risk and ethnic/racial minorities in localities that have a high prevalence, among men who have sex with men (MSM), aged 15 to 22, 14.1% of African-American men were found to have HIV.[7] Most did not know that they were infected. The Centers for Disease Control and Prevention (CDC) reported HIV prevalence rates among MSM at

STD clinics of 40% among African Americans, 26% among Hispanics, and 21% among whites.[5] Although progress has been made in the treatment of HIV, these treatments have benefited African-Americans the least.[4]

HIV SERVICES

Since 1988, the Burgess Clinic at Children's National Medical Center has provided care for HIV-infected youth. We have created a model of care where a specialty program exists within a full-service adolescent health center. HIV-positive teens are cared for within this context, removing isolating, identifying, or stigmatizing treatment. The Burgess Clinic has served more than 200 HIV-positive adolescents, aged 12-21, of whom 94% are African American and 85% receive Medicaid. Two-thirds of our behaviorally infected patients are females who acquired their infection through heterosexual transmission. Initially, most of our male patients deny same-sex contact. With time, however, the majority of our African-American male patients acknowledge having had sex with men. Only one patient has identified injection drug use as the mode of transmission.

Because of the stigma attached to this disease, our patients tend to be socially isolated. We know from our surveys of HIV positive youth that approximately half do not disclose their HIV status

Table 1. GROUP BASELINE OF PSYCHOSOCIAL STRESSORS (N=40)

	HIV-Positive (n=20)	At Risk (n=20)
History of Runaway	88%	54%
History of Acting Out (shoplifting, threatening others, etc.)	88%	54%
History of Physical Abuse	63%	45%
History of Sexual Abuse	50%	27%
High School Drop-Out	50%	27%
History of Depressed Mood	50%	54%
Psychiatric History	35%	64%
History of Suicide Attempt	25%	9%
History of Arrest	25%	18%
History of Sex for Drugs/Money/Sex Industry	13%	9%

to their sexual partners, and even fewer disclose to friends,[8,9] fearing rejection, as well as other serious negative consequences. Failure to disclose to sexual partners and failure to practice protected sex have serious consequences: for themselves by increasing the risk of infection with other sexually acquired pathogens or a new strain of potentially more dangerous virus; for their sexual partners by increasing the risk of HIV transmission.

Among Burgess patients half have been diagnosed and treated for a mental illness prior to diagnosis with HIV,[10] 85% had a current Axis I disorder, 60% reported ongoing mood disorders, and 60% met criteria for any lifetime substance abuse or dependence.[11] In a multicenter study of HIV infected youth, virtually half of the HIV-infected adolescents rated themselves as depressed.[12] Higher levels of depression also have been associated with unprotected sex in HIV-positive adolescents.[12] In addition, depressed HIV-infected youth in this study were more likely to endanger their lives through nonadherence to highly active antiretroviral therapy (HAART).[13]

The data on HIV risk in adolescents with severe mental illness are reviewed by Smith.[14] Many HIV positive patients do not receive optimal care, because their psychological distress presents a barrier to medical care and adherence to medical regimens.[15]

ELEMENTS OF NONSTIGMATIZING MENTAL HEALTH INTERVENTIONS

We offered support groups assuming that having a chronic illness is associated with needing help and social support. Yet, Fine and Ash[3] suggest in their work on disability and stigma that this is a misunderstanding of the experience of the stigmatized and a perpetuation of unsubstantiated assumptions. Patients we targeted for participation rejected traditional support groups in favor of five skills-based programs: A transitions group, an adherence group, a rites-of-passage group, a job-skills group, and a male and a female HIV prevention/sex education group. Seven elements common to the programs were identified.

First, we based the groups on adaptations of successful programs described in the *research* literature. Second, we conducted *focus groups* with our patients and their families, brainstorming with them to help create a program. Third, we did *not label* our patients, recognizing that patients with HIV do not want to be defined by their illness. Moreover, groups were offered at times that minimize the disruption of the normal routines of daily living, such as school attendance.

Fourth, we *removed practical barriers* and provided incentives for participation. Surveys indicate that for poor, lower and middle class families, transportation is the major obstacle to keeping the medical appointments of their children. We combined medical visits with group visits. We provided bus tokens or vouchers. We provided childcare during the day; evening group participants received a petty cash voucher to pay for babysitting. Although we learned that monetary incentives were not necessary for participation, we did provide a tangible tool or a token of appreciation to participants.

Fifth, we made our interventions *skills-oriented*, with concrete, easily recognizable benefits to the patient or family, consistent with Boyd Franklin's[16] observation that assisting clients with concrete problems and life skills is one way of connecting with them and building trust.

Sixth, we created *culturally sensitive* interventions, which respect and appreciate the history, reality, and life experiences of our patients and their families.[17] Among many African Americans, non-blood kin are often defined as family.[18,19] This is true for some of our patients who are asked to identify a trusted adult "family" member to return with them for their testing results and to act as a treatment buddy in some groups. Many African Americans expect and experience discrimination in medical settings[20] and many are aware of the historical experience of harm in research,[21] such as the Tuskegee study. These realities pose surmountable, but significant, obstacles to our patients and their families establishing trust with the treatment team and the hospital, as this distrust can generalize to all majority institutions. In 1998, a *New York Times*[22] article reviewed some of the

conspiracy theories about HIV among African Americans, including the belief that HIV is not the cause of AIDS and the belief the World Health Organization is trying to commit genocide through vaccines tainted with HIV. Most of our groups include a session on Myths, the Media, and HIV to address these concerns directly. A final character-istic of our programs is that the interventions are *life affirming,* focusing on healthy living with HIV, not on the disease itself, for example, by focusing on work or the transition to adulthood.

Group Structure

Each group had a fixed-time and skills-based curriculum, ranging from eight weeks to 30 weeks. For the youth and family a time-limited group means they need not organize their lives around the illness indefinitely.[23] Groups were limited to a min-imum of eight and a maximum of 15 participants. Sessions were 90 minutes, with 30 minutes for eat-ing prior to the start of the group. Sharing food builds group cohesion and models healthy eating. Groups are co-facilitated by two staff with mental health training. We try to balance the ethnicity and gender of the co-facilitators and the participants. Each group is open to all HIV-positive patients, except those who are actively homicidal. Attrition averaged 10%. The majority of participants attend-ed more than half of all scheduled sessions.

CONCLUSIONS

Despite the well-documented stigma associated with HIV/AIDS, mental illness, and substance abuse, dually and triply diagnosed youth with HIV/AIDS can be recruited and engaged in hospi-tal-based youth development models. Depression, substance abuse, and a history of being sexually abused or exploited pose significant obstacles to self-care, care for others, and an optimum quality of life. Comprehensive, skills-based groups illus-trate a process for program development of partic-ular importance to primary and secondary preven-

Table 2. LIFE FORCE GROUP CURRICULUM

Week 1	Ground rules of the group, confidentiality and outline of the curriculum
Weeks 2-3	Communication Skills & What Do Employers Look for in an Employee
Week 4-5	Filling Out Applications/Writing a Resume
Weeks 6	Attitude, Dressing for Success, Role Play Telephone Interviews
Week 7	The American's With Disabilities Act – Your Rights and Responsibilities
Week 8	Managing Rejection. Coping with Anger on the Job
Week 9	Coping with Stress on the Job. Cool down. Relaxation. Visual Imagery.
Week 10	Problem Solving on the Job.
Week 11	Healthy Coping/Managing Conflicts with Co-workers
Week 12	Healthy Coping/Managing Conflict with your boss
Week 13	Staying Healthy/Immunizations, STIs and Contraception
Week 14	Staying Healthy/Talking to Your Doctor
Weeks 15-20	How do I get there from here? – Guest speakers from the community:
	Entry Level Positions in a Hospital Setting
	Becoming a Para Legal
	Becoming a Writer
	Becoming a Mortician
	Entry Level Positions in the Computer Field
	Entry Level Jobs in Working with Animals
	How to Build and Operate Your Own Barber Shop
Weeks 21-30	Jobs and/or Externships
Mentoring provided by co-facilitators of Life Force Group	

tion of HIV. While these programs are qualitatively highly valued by our HIV positive youth, as providing benefits in domains in addition to the skills-based goals of adherence with medications or getting a job, such programs do not have sufficient power to be evaluated quantitatively.

It is our clinical experience that youth-based programs that target youth developmental issues at multiple levels are more successful than a direct approach to risk reduction, mental health treatment, and medication adherence. This clinic-based model for providing support and mental health services for HIV positive, African-American, inner-city adolescents needs to be formalized and tested in a randomized clinical trial. Currently, the adherence group is being tested at multiple sites, funded by the Centers for Disease Control (CDC). Only in this way can we effectively resist the trend for the government to cut back on similar youth development programs and advocate for their continuation.

Future research also is needed to evaluate interventions to overcome the health consequences of stigma on the utilization of available medical and mental health services. There is a need for disease and culture specificity that distinguishes the framework for applied international health research from the larger body of social research on stigma. [26]

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