AIDS & Anthropology Bulletin The Newsletter of the AIDS and Anthropology Research Group

# Tuly 2005

# Volume 17, Issue 2

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# Letter from the Chair - Doug Goldsmith

As anthropologists we cast our gaze on social behaviors in the nooks and crannies of the human pageant. We see and hear that which is in front of us; our efforts to seek out particularly illuminating and important encounters, and our attempts at careful description and insightful explication often bring us back to confront our selves – our beliefs, our models, our theories, our own humanity.

This past week, as usual, we've heard government leaders speak about ongoing human crises - our global environmental crisis and foolhardy local excesses, our extensive gulag of prisoners and foolish local excesses. Some who are in positions of leadership seem to ignore science, ignore scholarship and seem woefully ignorant of our deep, dark history of past blunders and cruelties. Kofi Annan, Secretary-General of the UN seems to be an exception to this - while noting that "It is now clear that the (HIV/AIDS) epidemic continues to outrun our efforts to contain it" he points out, with hope, possibilities to break the cycle of new HIV infections with successful prevention programs. These possibilities have been the arena in which many of those in AARG have been working diligently these past desperate years.

Hopefully anthropological insight can serve as more than witnessing, more than capturing the quandary of the victims, more than protesting discredited theorizing and vacuous models which can only lead to doomed efforts (like a Cassandra without believers in an augmenting pandemic and in mushrooming syndemics). We can speak to power, as critically as we can. And we can look, with strength, if we look carefully, to past anthropological efforts to inform crises. In this time of AIDS, the crisis is great, the need is great, and the pace at which we are learning the impact of suggested prevention efforts is swift. I urge all AARG researchers and theorists to speak out more, to write-it-up more, but with an eye to the lessons that have already been learned, to examine models that have already been modified, to rework theories that have fallen short and need to be recast.

## **Call for Nominations for AARG positions**

AARG will be holding an e-mail election for needed Officers, to be sure we have a new Chair elect before the November AAA meeting in Washington, DC. We already have a strong candidate, but we hope you may take this opportunity to nominate yourself or encourage someone to run. Fortunately the Secretary/Treasurer is willing to run again, but is also eager to know of anyone else desiring to run. Please e-mail the AARG Steering Committee at aargsc@creighton.edu, to keep names moderately private before the election.

We also fill need to fill some Steering Committee member openings. However, rather than add this to the e-mail election, for these selections we can take more time, and use the traditional face to face opportunity of the national meetings to obtain candidates. If you wish to e-mail a name for that too, by all means do so, as we need enthusiastic input here too. If you do not "e-mail" let us know somehow - we do not wish this new effort at electronic voting to exclude anyone.

# **Hope 2005**

# Letter from the Editor

This issue has many articles based on presentations at the SfAA meeting in Santa Fe in April 2005. Michele Shedlin and Carlos Decena discuss definitions of new immigrant communities, and potential implications for prevention work. Catherine Mitchell Fuentes gives a taste of her dissertation work; abused women's strategies for reducing STI/HIV risk. In Lesotho, David Himmelgreen et al. are working combating HIV/AIDS and food insecurity. Further north and east, Marita Eibl is looking at how structural adjustments are impacting HIV treatment in Tanzania. Edward Rohn is working with HIV+ African Americans and present issues of rapport and retention in his longitudinal study. Male circumcision as a prevention strategy is the topic of two articles, the first by James Stansbury and Erica Amato Krisel. Sarah Rubin is looking at AIDS dissidents, and their alternative explanations of HIV and AIDS. In Israel, Anat Rosenthal presents problems in health services to undocumented HIV+ migrant workers. Andrea Nevedal is exploring HIV risk in adults over fifty. In Nigeria Gisele Maynard-Tucker has been evaluating an HIV prevention program in the workplace. Alfredo Gonzalez works in New York City with Latino homeless men, and shares some experiences from that field. Consequences of beliefs about alcohol and anti-retrovirals among clinicians and patients is Tracev Wunderlich and Andrea Sankar's topic. Nancy Romero-Daza is presenting a community participatory approach to designing HIV awareness material in Costa Rica. The shooting gallery article by James Peterson, Shannon Mitchell and Carl Latkin also emphasizes the benefits of working with the locals, in this case the gallery operator. Finally we have the second article on male circumcision by Chris Alley, a thoughtful peace on the power relations always present in health and prevention work, which we should keep in mind.

Thank you all for your submissions! This is my last newsletter. I have been involved in 15 issues with lay-out, design, as part of an editor collective and now the last few issues more or less on my own. Colleagues at the University of Connecticut will continue as editors; Catherine Mitchell Fuentes, Dugeidy Ortiz, Lisa-Rose Rodriguez, and Luci Fernandes. Submissions should be sent to Catherine Mitchell Fuentes at catmitchell@earthlink.net

I have enjoyed the work with the newsletter, and while HIV/AIDS is still of interest to me I will now focus on my own research; organic agriculture, sustainability and biodiversity.

Warm regards, Anna Marie Nicolaysen anna.nicolaysen@uconn.edu

# **Hope 2005**

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# Scientific Sessions:

Hope 2005 The 3rd International Conference on HIV/AIDS & Alcohol/Drug Abuse will take place the 3rd, 4th and 5th of November 2005, at the Taj Hotel, Mumbai, (formerly Bombay) India. URL: <http://internationalconference2005.com/ hope2005/india/index.html This conference is organized by Drug Abuse Information Rehabilitation and Research Centre (DAIRRC), in association with The Ministry of Health, Government of India. DAIRRC is India's premier institution involved in the fight against Substance Abuse since 1983 and HIV/ AIDS since 1988. Our activities encompass all fields involved in the Prevention, Identification, Cure, Rehabilitation and Research of Substance Abuse. DAIRRC has Special Consultative status with the United Nations' Economic and Social Council. More details of DAIRRC can be obtained from our website at www.hopeconference.com **The Aims of the Conference are!** • 0 highlight the latest discoveries in the solution of addiction and HIV/AIDS related problems • 0 analyze the effectiveness of current strategies and suggest improvements • 0 promote the enhancement of joint ventures, skills, and experience in the field of Drug Demand Reduction and experience in the field of Drug Demand Reduction and HIV Prevention, among people of a wide variety of races, cultures, beliefs and disciplines and their practical applicability to today's scenario • 10 promote the enhancement of joint ventures, skills, and versatility of Demand Reduction and HIV Prevention Programmes. **Stointif Cessions:** The Hope 2005 International Conference on Alcohol/Drug Abuse and HIV/AIDS will have scientific sessions, each of which will concern itself with a distinct area of Demand Reduction, and HIV Prevention, to enable delegates having a specific interest in the subject to converge and explore relevant datas, experience and achievements. For Online Registration please visit the following page: <a href="http://internationalconference2005.com/hope2005/"india/hiv&drugs/registration/registration.html (b) (b) 🚯 distinct area of Demand Reduction, and HIV m Er.

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# Defining New Immigrant Communities: Implications for Prevention Planning

Michele G. Shedlin, PhD, Carlos Ulises Decena, PhD

Center for Drug Use and HIV Research (CDUHR), Institute for AIDS Research (IAR), National Development and Research Institutes, Inc. (NDRI)

New Hispanic Communities and HIV Risk<sup>1</sup> was designed as an exploratory study to identify new immigrant groups from the Dominican Republic, Guatemala, El Salvador, Honduras and Mexico residing in New York State. Data were collected between 2002-2005 in Northern Manhattan and in Westchester, Rockland, Suffolk and Putnam Counties in New York State. The sites allowed for a description of these populations by urban, suburban, and semi-rural residence. Qualitative methods were used to obtain information on the social context of behavior and its influence on HIV risk. The focus group and individual interview sample consisted of a total of 290 target population respondents, 141 women and 149 men. In addition, participant observation, two focus groups and 40 interviews with key informants were conducted. The research identified a range of experiences, attitudes, and beliefs shaping HIV risk behaviors among the target groups.

The overall objective of the study was to develop policy and planning recommendations to address the HIV/AIDS risks experienced by the groups. The approach identified HIV risk and protective factors embedded in immigrants' multiple cultures and sub-cultures. The theoretical basis of the methodology was that shared ethnic, experiential, and historical elements influence and shape behaviors and responses to new environmental options, alternatives, and risks (Handwerker, 2002). In this perspective, social and cultural processes were understood to influence health vulnerability for immigrants in numerous ways.

#### The Conundrum of "Community"

An important obstacle identified by the study was the notion of "community" and the expectation that target groups exist as a defined social entity. The globalization of current public health challenges and the HIV/AIDS pandemic make it increasingly necessary to define the role of "community," as it impacts individuals and families who shape its social and structural development. It is important to identify the processes by which communities become intelligible to themselves, and to establish consensus among advocates concerning the definition of "community" for science-based planning and policy formulation (MacQueen et al., 2001). Identification and consensus are especially salient for the development of community-based initiatives often thwarted by social and political expectations of group cohesion, shared goals, abilities, and desires.

The lack of consensus and the impact of inappropriate definitions of "community" become especially salient when such terms create *barriers* to effective policy and advocacy in

the face of serious health challenges to large, disparate, and geographically diverse populations. The much-used term "Latino," for example, does not fit a functional definition of "community." The debated emergence of this term in opposition to "Hispanic" is associated with the struggles of various populations of Latin American immigrants, Chicanos, and Puerto Ricans to establish pan-ethnic ties in the U.S. The "Hispanic" category obfuscates the characteristics and needs of national and ethnic populations in the U.S. When immigrants from Latin America and the Caribbean are lumped together, differences in migration experiences, health status, educational levels, and language are overlooked. Even when comprehensive categories function to direct resources, their use can privilege visible segments of the population and risk omission for those for whom visibility itself is a risk.

#### **Emergent Communities**

Networks in receiving countries structure migratory flows, sponsoring and supporting journeys as well as assuring initial survival. Study respondents discussed how their perceptions of the receiving environment influenced their decision. The North Fork in Suffolk County, for example, was seen as desirable by immigrants seeking a quiet, rural place. Regardless of the location, respondent access to the support of relatives and/or friends was a key factor in migration decisions. Most respondents reported settling in areas where pre-existing social and/or kin networks from their home villages were reforming.

In some cases, whole kin networks from small villages were reported to have migrated to smaller towns in Westchester, Putnam, Rockland and Suffolk counties. Immigrants described how these networks supported traditional norms and behaviors despite new and sometimes conflicting U.S. influences and pressures. Concurrently, they described new attitudes, behaviors, allegiances and interactions across lines of nationality and ethnicity. Supportive allegiances across nationalities and ethnicities appeared more frequently where pre-existing home networks were sparse and immigrants needed to access goods and services outside kin, ethnic and/or national networks. Most new immigrants, however, did not recognize themselves as part of any "community."

#### Obstacles to "Community"

Arduous travel and living conditions, as reported by various respondents, appeared to influence emotional and psychological dislocation. Their dislocation hindered new immigrants from considering themselves as part of a "community." "Fending for oneself," a common theme among the immigrant groups, stressed the challenges immigrants experienced in their new environments and suggested that many felt they did not belong to a larger collectivity.

Because new immigrants reported devoting substantial time to their jobs and/or job searches, the workplace was cited as a locale for social interaction with individuals from within and outside their countries. Occupational positions, together with the concentration of immigrants from specific countries, (Continued on page 4)

#### (Continued from page 3)

influenced type and form of workplace relationships. Work schedule irregularity, moreover, coupled with job competition, created a context of divisiveness and pitted immigrant groups and individuals against each other. In Westchester County, where labor recruitment sites were located, immigrant nationality was the reason often used to claim informal day laboring sites. Tensions between Mexicans and Ecuadorians, for example, required field staff to be sensitive in recruitment efforts so as to avoid sparking conflict between the groups.

Among Dominican immigrants, access to established networks suggested that the workplace was not as central to their sense of community as it appeared for Mexicans and Central Americans. Dominicans new to Westchester County generally had access to friends and/or kin with local connections that facilitated relative employment stability and the possibility of upward mobility. Social networks available to Mexicans and Central Americans were generally not as stable, established or influential in their settlement areas.

Besides job competition, the undocumented status of new immigrants limited interactions outside their immediate social networks. Thus, many of the respondents were relegated to work in the informal sector. Unfavorable working conditions, unemployment or underemployment in the winter, 10-hour workdays and employer abuse was frequent. Lack of documentation also significantly encumbered procurement of certification and service needs such as driver's licenses, insurance, and the use of banks.

Limited social exchanges with people outside their nationalities, combined with their undocumented status, encouraged respondents to think of their U.S. lives as transitory, a stage of "sufrimiento" [suffering] they had to endure for the sake of those left in the homeland. As one participant noted, "En los Estados Unidos, para ganarse 10 dólares tienen que sufrir primero," [In the United States, to make 10 dollars they have to suffer first].

Another obstacle to the cohesion of social relations and sense of community was the lack of space for socialization. Geographical locations, pre-existing networks, and social infrastructures mitigated differential access to social outlets. In Westchester, Putnam, Rockland and Suffolk counties, men had few opportunities to socialize in local bars. Instead, they met with others from different Latin American ethnic/national groups at informal sports activities. Women with school-aged children had greater social contact with other women than those without children. Unemployed young women with few friends and relatives remained alone in target social spaces, and were limited to shopping or doing the laundry with their partners.

Finally, perceived or experienced discrimination discouraged participants from establishing attachment to their receiving areas. During the demographic growth of the Hispanic population between 1990 and 2000 in Westchester, Putnam, Rockland and Suffolk counties, immigrants experienced incidents of violence, discrimination, and hostility from local authorities and residents. Identification of these issues prompted some local leaders to address the needs of new immigrants. Despite some advances, new immigrants are persistently unwelcome, often relegated to marginal sectors of the labor market and consigned to inadequate living conditions. These circumstances generate suspicion and distrust of others within and outside their groups, and lead the groups to discourage inclusion in any local communities. For these reasons, respondents avoided contribution to any "new" community, maintaining the goal of eventually returning to their homeland despite economic constraints.

#### Summary

For public health policies to be effective, they must identify and define developing immigrant "communities" as well as the health risks of the groups that comprise them. A working definition of "immigrant community," however, must go beyond the identification of nationalities, ethnicities and geographic boundaries. Policy that facilitates planning and resource allocation to new immigrant groups should consider the various acculturative stages influencing the populations and their institutions as well as differences in levels of integration into the larger sociopolitical (and epidemiological) environment.

The non-representative, purposive sample of immigrant men and women makes generalizations about the groups problematic. However, the sample provides a range of sociodemographic characteristics, social resources, and challenges related to migration, community formation, and the health of new immigrant groups in New York State. The recognition and identification of fragmented networks, the significance of kinships and social networks, the economic, legal and cultural factors affecting stages of acculturation and the lack of institutional resources faced by these groups function to better define these communities.

The findings of this study underscore the need to develop interventions addressing the specific realities of new immigrants. The themes and patterns identified in this study suggest that key elements for achieving effective prevention interventions build upon existing norms, networks, and institutional resources to support infrastructure and community-building among the groups.

#### References

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<sup>1</sup> This research was made possible by a grant from the National Institute of Child Health and Human Development, National Institutes of Health, (HD042970).

# Contesting Health: Abused Women's Strategies for Reducing STI/HIV Risk

Catherine Mitchell Fuentes, Ph.D. University of Connecticut

#### I. Introduction:

In the U.S. domestic violence is one of the leading causes of injury among women. Injury transcends acute conditions to include substance abuse, chronic pain and fatigue, disturbed sleeping and eating patterns, chronic headaches, recurrent vaginal infections, delayed physical effects (e.g., arthritis, hypertension, heart disease), suicide attempts, and homicide. Gynecological problems, such as sexually transmitted infections (STIs), are especially salient health risks that distinguish abused from non-abused women. Resource access theory is an empirically testable theory of the foundations of violence that helps explain the association between family violence and STI/HIV risk. This theory posits that power inequalities in intimate partner relationships elicit violence whereas power equalities elicit affection. Power is the result of one person requiring specific resources, access to which is controlled by another person, known as a gatekeeper. Gatekeepers increase their power by exploiting (e.g., acting violently toward) people reliant on them for access to resources. If a woman lacks means for accessing needed resources, such as education and employment opportunities, she may, for example, engage in high sexual mobility as her only way to establish a wider network of gatekeepers. This may decrease her dependency on a single gatekeeper and so reduce his exploitation of her, but it increases her risk of contracting STIs/HIV. If she has positive means of empowerment (e.g., having a good job, her own income, help with childcare, etc.), she may be able to offset violence in ways that do not jeopardize her well-being.

#### II. Methods:

#### Sample and Instruments:

I began this research while working as a certified Connecticut sexual assault crisis advocate. I collected 28 indepth life-histories from diverse abused women throughout Connecticut in order to elicit their risk factors and prevention strategies for STIs/HIV. I asked each woman to begin by telling me about the first time she had ever experienced any form of abuse<sup>1</sup> by a loved one or family member and each successive abusive relationship after that up to the present.

Based on information obtained from these in-depth interviews, I constructed a structured survey to be selfadministered by participants. This measured substance abuse, depression/anxiety, ability to negotiate safe sex and condom efficacy, severity/type of violence/affection experienced, history of STI/HIV diagnoses and symptoms, sexual risk (e.g., number sexual partners, age first sex, history of exchange sex), sources and types of empowerment (informed by resource access theory), and sociodemographic information. A total of 215 abused and non-abused Latina<sup>2</sup>, African American, and Anglo women with and without histories of STIs/HIV completed these.

#### Data Analysis:

I conducted text analysis of transcripts of life-history interviews looking for ways in which STI/HIV risks and prevention strategies differ for different types of women. For structured interviews I employed a variety of statistical tools such as correspondence analysis, multivariate regression, and principle components analysis in order to verify and explain the relationship between family violence and STI/HIV risk. Correspondence analysis illustrates the similarity between behaviors and beliefs reported by participants, between variables, and between cases and variables. The closer any of these are located to one another, the greater their degree of similarity. Multiple regression tests for the influence of sociodemographic variables on a woman's likelihood of experiencing violence and associated STI risks

#### **III. Results:**

Abused women not only disclosed a greater number of risk factors for STI/HIV compared to non-abused women, but unique risks as well. Overall I found that the greater the abuse, the greater the STI/HIV risk. However, this does not imply that abused women can be viewed as passive victims. Many women engaged in forms of empowerment that helped them evade more serious abuse and, therefore, consequent STI/HIV risks. Findings from both life-history and structured interviews revealed the following risk and prevention strategies:

#### **Abuse-Generated STI Risks**

Women who have experienced abuse are more likely than nonabused women to: Abuse drugs or alcohol Be unable to negotiate condom use/safe sex Exchange sex for drugs or money Experience depression/anxiety Have first sex at an early age Have high numbers of lifetime and/or current sexual partners Have unfaithful and/or injection drug using partners Lack emotional/financial support of friends/family

#### Forms of Empowerment That Help Abused Women Evade Abuse and STI/HIV Risk

Less severely abused (and non-abused) women are more likely than more severely abused women to:

Have positive ways to cope with depression

Be less likely to abuse substances

Be able to negotiate condom use/safe sex

Have support (financial and/or emotional) of friends/family Have financial resources and help with childcare independent of her abuser

Avoid risky sexual behavior (older age at first sex, more time to get to know a partner before sex, fewer partners, etc.)

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# **Contesting Health: Abused Women's Strategies for Reducing STI/HIV Risk**

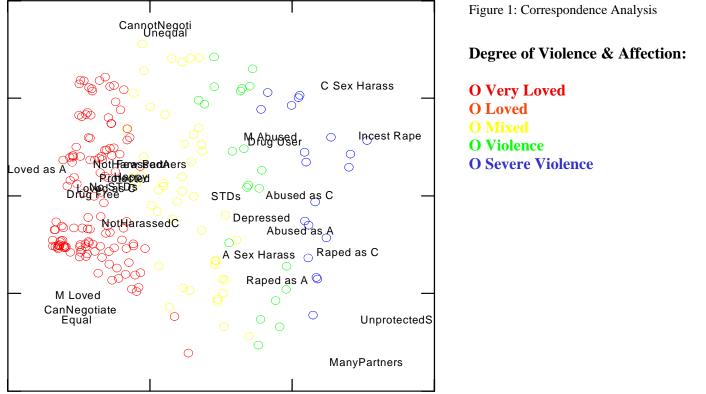


Table 1: Multiple Regression

Correspondence analysis confirms that as women experience increasing levels of abuse (abused participants represented by blue and green circles above), they also experience increasing STI risks (variables indicated in black text; C=child and A=adult). As women experience increasing levels of affection, (non- or lessabused participants represented by red and orange circles above), they also tend to exhibit greater empowerment. For example, women who have experienced child abuse, incest, and rape in adulthood are more likely than other women to suffer from depression and to contract STIs/HIV. Women who have

Variable	Coefficient Model 1	t	P (2-tail)	Coefficient Final Model	t	P (2-tail)
Constant	-1.812	-0.588	0.557	3.738	2.227	0.027
Woman's Power	3.737	4.988	0.000	4.780	7.631	0.000
Age	-0.197	-3.822	0.000	-0.249	-7.032	0.000
Number of Children	0.096	0.317	0.752			
Education	-0.020	-0.159	0.874			
Grew Up	0.490	1.554	0.122			
# in house	-0.161	-0.825	0.411			
White	1.513	0.814	0.417			
Puerto Ricn.	1.518	0.792	0.429			
Mexican	3.536	1.612	0.109			
Other	0.002	0.001	0.999			
Afr. Amer.	1.313	0.652	0.122			
N=215; Adjusted Squared Multiple R: 0.340 for final Model						

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experienced more affection than abuse are better able to negotiate safe sex, not to use drugs, and not to contract STIs/ HIV.

Multiple regression also confirms that empowered women are less likely to experience abuse and STI risk than are nonempowered women. Here a Woman's Power Index constitutes the sum of the following variables measured in the structured interview: having help with childcare, money to spend as she sees fit, family/friends to help her with money or place to stay, a reliable car, and her own income independent of her partner. Table 1 illustrates that experiences of Affection/Minimized STI risk (dependent variable) increase by 4.780 for each incremental rise in her power index (independent variable). This relationship holds independently of such things as her ethnicity or the number of children she has (see high p-values for all independent variables in black font).

#### IV. Conclusion:

Family violence intervention strategies that seek to improve abused women's lives in a holistic way must consider their unique risks for STIs/HIV. Abused women with sources of empowerment are better able to evade violence and related STI/HIV risks. This entails the need to foster women's empowerment at both the local and societal level. Three, among many, possible directions suggested by my research for accomplishing this goal include the following. First, women must have opportunities to secure their own income independently of abusers. This requires equal employment and pay opportunities for women, opportunities for education and job training so women can qualify for good jobs, and eliminating the "penalties of motherhood" often encountered in the workplace. Second, women's attempts at selfempowerment are often hindered by a lack of affordable, quality daycare. State-sponsored daycare programs in countries such as Norway, Denmark, and Sweden provide models of successful approaches to promoting women's empowerment at the state level. Finally, women with positive alternatives for coping with abuse (e.g., writing in journals, therapy, support of friends or family) were more likely than those who coped via substance abuse to evade violence and sexual risk. Therefore, abuse intervention must address substance abuse issues while providing alternative coping outlets.

<sup>2</sup> For both the in-depth and structured surveys the majority of Latinas were Puerto Rican from both the island and the mainland.

Catherine Fuentes can be reached at catmitchell@earthlink.net

# Combating HIV/AIDS and Food Insecurity in Sub-Saharan Africa

David A. Himmelgreen<sup>1</sup> David Turkon<sup>2</sup> Nancy Romero-Daza<sup>1</sup> Ipolto Okella-Uma<sup>3</sup> Jamal Mohammed<sup>3</sup> William Ouko Odenya<sup>3</sup> Mpemi Mamello<sup>3</sup> Sharon Watson<sup>1</sup>

> <sup>1</sup>University of South Florida, <sup>2</sup>Ithaca College, <sup>3</sup>National University of Lesotho

By the end of 2004 there were an estimated 40 million people living with HIV/AIDS (PLWHA) along with nearly 5 million infections and 3 million deaths. Nearly two thirds of PLWHA live in Sub-Saharan Africa, accounting for 64% of new infections and 77% of deaths. Although the entire region has recently experienced stabilization in the HIV prevalence rate (about 7.4%), southern Africa remains the most severely affected sub-region in the world with HIV prevalence surpassing 25% in some areas, reflecting a 20% increase since 1990. Today, almost one third of all AIDS deaths worldwide occur in southern Africa.

The aims of this presentation are 1) to frame the HIV/ AIDS pandemic as being made up of several epidemics, each distinct and more or less prevalent; 2) to discuss the role of nutrition and immunity in the spread of HIV and the progression from HIV to AIDS; and 3) to examine the intersection of HIV/AIDS and malnutrition in Lesotho, southern Africa and to offer suggestions on how HIV prevention strategies could be linked to nutritional support and sustainable development.

#### **Multiple Epidemics**

There is mounting evidence that the AIDS pandemic is made up of several epidemics. In most industrialized countries the prevalence rate for HIV among adults is less than 1% while in parts of Southern Africa it is over 30%. Although sexual behavior is an important factor in the transmission of HIV, there are other factors that exacerbate the problem. The terrain in which infectious disease might spread quickly or be contained depends in great part on the living conditions of people in different parts of the world.

For example, the real income of an average person in the U.S is 42 times higher than that of the average Tanzanian. Per capita caloric intake in Sub-Saharan Africa has not increased since 1970 and is still only 70% of that found in industrialized countries and public spending on healthcare pales in comparison to that found in the West. Poverty along with concomitant malnutrition, pre-existing infections, women's lack of legal status, and cultural and religious beliefs regarding the open discussion of sexual behavior and prevention likely explain worldwide differences in HIV/AIDS prevalence when comparing Sub-Saharan Africa to the West.

(Continued on page 8)

<sup>&</sup>lt;sup>1</sup> In order to reduce informant or interviewer bias regarding what constitutes "abuse," I refrained from using the word "abuse" or "domestic violence" and specifically asked women to tell me about the first time they had ever experienced hitting, punching, choking, unwanted sexual activity, being called names, etc. This list of items was compiled during previous research by employing free-listing of participants in response to the question "Tell me as many things as you can that count, in your opinion, as abuse or domestic violence?"

(Continued from page 7)

# Malnutrition: Setting the Stage for the Spread of HIV/ AIDS

The AIDS pandemic likely had its origins during the 1970s and '80s. It was precisely at this time that Sub-Saharan Africa experienced worsening poverty, drought, and malnutrition. Of the 19 famines that occurred between 1975 and 1998, 18 were in Africa. Internal and external migration contributed to most of those famines as food shortages and unsanitary living conditions first developed in refugee camps and then spread across the continent. In many cases, while infectious disease was the proximate cause of death, malnutrition and micronutrient deficiencies were the underlying causes of mortality. Additionally, inadequate health care and public health systems, further contributed to the rapidly spreading epidemic.

For decades now, researchers have documented the association between malnutrition and disease susceptibility and the mechanisms by which malnutrition compromises the immune system at the cellular level. There is increasing evidence that not only does protein-energy malnutrition (PEM) and micronutrient deficiencies (e.g., vitamin A, zinc) play a role in the onset of AIDS related illnesses in PLWAH but it also may increase the susceptibility to the disease among non-infected people and in the vertical transmission from mother to child. Today, an estimated 33% of people in Sub-Saharan Africa experience chronic hunger and 40% of Southern Africans are considered undernourished.

# Lesotho: A Case Study on the Intersection of HIV/AIDS and Malnutrition

Lesotho is a small landlocked mountainous country situated entirely within the borders of South Africa. Because of this unique feature, its history and development are tied to that of its all encompassing neighbor. While once considered the "bread basket" of Southern Africa, it is now a net importer of food. Loss of land, heavy soil erosion, years of overgrazing, and recurrent droughts have resulted in about 10% of Lesotho's land being arable. Moreover, with few natural resources, Lesotho has been forced to rely heavily on South Africa for employment through transnational migrant labor. Up until the mid-1990s, 60% to 75% of adult males worked as migrant labors in South Africa any given year. Even with retrenchment in recent years, 45% of Lesotho's GNP is generated through remittances.

During the 1980s and '90s Lesotho experienced an economic boom that is attributed to the infrastructural developments of the Lesotho Highlands Water Project. Additionally, with changes in international trading policies, the textile and clothing industry has flourished since the late 1990s. While this has had a positive economic impact, internal migration from the highlands to the low-lands for work in factories has created a route for further transmission of HIV-IC, the viral subtype that is predominant in Southern Africa.

Since the first case of HIV/AIDS was recorded in 1986 the disease has spread rapidly. First thought to be found only among "outsiders" and traditional at-risk groups such as

commercial sex workers and their clients, truckers, and migrant workers, today the majority of those infected have no easily identifiable risk behavior. In 1993, the initial adult prevalence (15-49 years old) rate was 4%, rising to 9.8% in 1998 and it reached 31% in 2002, making Lesotho the country with the fourth highest HIV/AIDS rate in the world. Before the onset of the epidemic, life expectancy was projected to increase to 60 years in 2003; it is now 36 years.

The Lesotho Government recently developed the National AIDS Strategic Plan (NASP) which includes a restructuring of its agencies and institutions responsible for addressing the epidemic. Increasingly, HIV/AIDS prevention strategies are not only focusing on sexual behavior but are also including food and nutrition security. Strategies which may be effective in improving food security and nutritional status include: 1) use of improved crop management and higher yield plant varieties; 2) use of improved agricultural practices and technologies to save labor and capital; 3) use of small ruminants for consumption, sale and manure; 4) nutritional gardens; 5) nutritional education; 6) labor exchange arrangements; and 6) increased access to agricultural extension services.

Additionally, programs that bring together older adults and youth and centering around the transmission of knowledge of agricultural and livestock practices could facilitate the maintenance of cultural practices and traditions that reinforce traditional social support networks. Other possibilities include: support for indigenous foods, in particular the growing of nutrient dense wild leafy green vegetables; and the growing of pumpkin, cabbage, kale, and other vegetables and fruits which are relatively easy to grow and found in many regions in Lesotho.

There are also examples of agricultural demonstration projects that could be incorporated in HIV/AIDS prevention strategies. Researchers at the National University of Lesotho (NUL) has been involved in several, including a seed potato improvement program, which has the objective of increasing the production of potatoes by using an improved and virus-free potato tuber. Additionally, NUL researchers conducted a community-based garlic research program. Their findings indicate that garlic is becoming a very popular crop in Lesotho. Although labor intensive, it is a high value crop that is highly adaptable to the climate and is being increasingly used for medicinal purposes.

In many cases, HIV/AIDS prevention is more effective if it is embedded as part of complementary services that are provided by community groups or organizations. Since people are often reluctant to participate in programs that are advertised as HIV/AIDS services, they may be more amenable if they can get other services such as education, economic, or agricultural assistance. There are many cooperative associations that may serve as conduits through which HIV/AIDS prevention could be channeled in Lesotho. Examples include stokfels (loan associations); brewing associations; and the mosobelo, a type of unbalanced reciprocity system. All are framed under the ideal of the cultural value of helping and sharing.

In conclusion, in Sub-Saharan Africa, there is increasing recognition that HIV/AIDS prevention should not only focus

# HIV/AIDS and Antiretrovirals: Accessing Treatment in Tanzania

#### Marita Eibl

#### Structural Adjustment and Health in Tanzania

Health is political and economic. Nowhere is this more apparent than at the intersection of structural adjustment policies and the HIV/AIDS epidemic. Tanzania is suffering from the most destructive pandemic of the modern era – HIV/ AIDS. There are almost 2 million people living with the disease and more women than men are infected. In this article, I draw on preliminary research carried out in Dar es Salaam, Tanzania, in 2004 to examine how AIDS patients, specifically women, access antiretrovirals, or ARVs, and what effect treatment may have on the stigma associated with the disease. First, I briefly outline the effects of structural adjustment programs on the Tanzanian health sector. Second, I draw on my observations from a nongovernmental organization (NGO) dispensing ARVs to explore issues of access and stigma.

Like many African countries during the 1980s, Tanzania was subject to the structural adjustment policies set forth by the International Monetary Fund and the World Bank. The goals of the policies were to liberalize trade in part by devaluing the currency and downsizing government while expanding the private sector. In the Tanzanian health sector, these policies resulted in a decline in health care spending per capita and an increase in user fees for services. User fees were implemented for all levels of health care by 1998. Due to funding constraints, the Tanzanian Health Ministry invited NGOs to participate as partners in health care delivery, providing an alternative between public and private institutions.

ARVs are now increasingly available through NGOs in Tanzania. ARV therapy can decrease the symptoms of AIDS,

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on sexual behavior but also address larger issues such as food and nutrition security. Increasing agricultural productivity and access to nutritious foods will help reduce PEM and micronutrient deficiencies. In achieving this goal, there is growing evidence that the risk for transmission for HIV could be reduced while the life expectancy for PLWHA will increase and there will be improvements in household nutritional status. In carrying out such programs, care must be taken to insure that they are based on a community participatory model in which HIV/AIDS prevention is embedded as part of other complementary services.

For additional information and reference list contact: David Himmelgreen, Department of Anthropology, University of South Florida, 4202 E. Fowler Ave, SOC 107, Tampa, FL 33620. Email: <u>dhimmelg@cas.usf.edu</u> increase quality of life, as well as decrease a person's viral load. Yet, only 2,000 Tanzanians are on ARV therapy. As the average annual income in Tanzania is only \$600, the cost puts the drugs out of reach for most.

#### Access, Stigma, and ARVs

I turn now to my fieldwork at AMANI, a Catholic NGO, located in a working class neighborhood of Dar es Salaam. The doctor in charge of the clinic is an English woman, Dr. Michelle, who has worked for over thirty years in Tanzania. After feeling "enough was enough", she collected private donations from churches in the United Kingdom, Ireland, and the U.S. to start an ARV pilot program.

The program began in July 2003, and treats 22 individuals – half adults, half children, and mostly women. Individuals were chosen on the basis of three factors.

1.) People who had been coming to the organization the longest had priority. The doctor and clinic workers were aware of who had been sick the longest.

2.) Individuals who were thought would "adhere very well" to the program were preferred. Compliance is important because it affects the efficacy of treatment, may prevent resistant strains of HIV from emerging, and helps ensure program success.3.) The clinic also accepts "crisis cases".

Using the funding from abroad, the clinic bought generic drugs from India. Dr. Michelle feels that the clinic could treat up to 300 patients. The clinic, however, is slated to be a part of the Bush administration's "President's Emergency Plan for AIDS Relief", or PEPFAR. PEPFAR assessed the clinic as having the capacity to treat 600 patients. Dr. Michelle will try and meet this requirement so as to ensure funding. The Tanzanian government, which has its own national protocol, states that generic drugs be used for first line treatment. The clinic will not be allowed to use PEPFAR funding to buy generic drugs from India, which are fixed-dosed, meaning patients take two pills a day. Instead, when using PEPFAR money, the clinic will be required to use U.S. name-brand medications, which are complex multi-pill regimens.

By looking now at two patient cases, Mary and Rose, I examine how treatment and stigma interact. Mary has been on ARVs for almost four months. Like many patients at AMANI, Mary is a widow. She has five children and has been coming to the organization since 1994. After a positive HIV result at a dispensary, she was referred to AMANI. Mary decided to tell her relatives because she thought they could assist her, but they refused. As Mary said, in describing what stigma meant to her, "they didn't like to see me". She suffered what Galvao terms a "civil death" – although physically alive, she was ignored by her family as if she were dead (2000). ARVs have helped Mary gain weight and she says that friends are surprised by her appearance. People, she said, are nicer to her now and neighbors no longer whisper about whether or not she has AIDS.

Rose, though, has yet to disclose her status to her family. She is 24 years old and lives with her mother, three sisters, and a brother. She was diagnosed in 2000 at a state hospital. Rose (*Continued on page 10*)

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traveled to a church for help, but did not go to the church her family attends as she was afraid someone might tell her mother about her condition. Scared and contemplating suicide, she was taken by a priest to AMANI. Rose started treatment in November 2003. She keeps her status a secret from her family because, "For family, it is a big thing. If you get AIDS, you are going to die... I don't see anyone to tell". In other words, families feel shamed by HIV/AIDS.

Even though Rose's family does not know about her health status, Rose comes to AMANI to give talks to other individuals with HIV/AIDS about living with the disease. In this way, she is part of a supportive community, although this part of her life is kept separate from the other areas. Furthermore, Rose feels she avoids stigma and a civil death.

These two cases raise questions about the relationship between ARV treatment and the stigma associated with the disease. Recent studies suggest that ARVs will reduce the stigma associated with AIDS (Farmer et al. 2001, Ramotlhwa 2003, Coetzee et al. 2003). Mary and Rose, both on ARV treatment, still felt that stigma, or the threat of it, was a part of their lives. This research suggests that treatment alone may not be sufficient to stop stigma as it does not address the issues of shame, blame, and the social inequalities produced by stigma. As treatment becomes more prevalent in Tanzania, perceptions of the disease may change as more people observe that HIV/ AIDS is no longer an immediate death sentence. ARV treatment may be one part of the battle to fight stigma.

In addition to facing social constraints, Mary and Rose had to negotiate their own financial constraints as well as those of the health care systems in Tanzania. The state cannot guarantee ARV therapy for all those who need it. The private sector remains out of reach for most patients. Many AMANI patients, in addition to receiving ARVs, also receive food, powdered milk, and small amounts money in order to take a bus home. For them, AMANI was not just a third choice between the state and private clinics, but the only choice. Although the state might be considered the "natural authority" to carry out health care, as Meredith Turshen notes, it often becomes a villain when it cannot provide – taking attention away from a global political economy that reinforces that system (1999).

To conclude, this preliminary study raised questions concerning ARV distribution and access. During its pilot program, AMANI decided who received treatment. The women I interviewed had been coming to or were brought to AMANI by someone else who came there. Not all individuals will have social ties to a particular organization or know someone who has those connections. Will an organization "niche" exist for the majority of those living with HIV/AIDS since the state has not guaranteed ARVs for all who need them?

As AMANI becomes part of the PEPFAR plan, PEPFAR will have a voice in determining access criteria of the clinics it funds. Yet, the Tanzanian government maintains its power by enforcing its own protocols on PEPFAR. International political economy and local knowledge will intersect in ARV access and treatment, indicating that more research is needed to find out how these processes take place and how they affect the health of those suffering from HIV/AIDS.

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# **Submissions**

We would like to receive articles (800-1500 words), and announcements or shorter messages that are relevant to AIDS and Anthropology. Preferred format is a word file as an e-mail attachment to:

#### catmitchell@earthlink.net

Please keep references to a minimum, preferably just with direct quotations.

# **Rapport and Retention in a Longitudinal-Qualitative Study of HIV+ African-Americans**

Edward J. Rohn Wayne State University

This paper presents challenges and a set of responses to longitudinal qualitative data collection from HIV+ individuals. The examples are taken from the HAART Project, an NIHfunded anthropological study of adherence to antiretroviral therapies among HIV+ African Americans (N=135) living in the greater Detroit, Michigan area. The project design requires participants to be interviewed eight times over three years. Each interview includes narrative, semi-structured, and standardized components that query adherence practices specifically and allow participants to describe their lives and the broader context in which this adherence takes place. HAART Project interviewers have found that factors that can challenge adherence – poverty, substance use, mental illness, stigma, and the risk of disclosure – also pose difficulties for retention and data collection. In order to retain participants and obtain honest and reflective responses to interview questions, interviewers and participants must negotiate an array of potential barriers towards the development of a minimal level of mutual trust and, ideally, respectful and interested relationships. Important patterns have developed during the data collection period and strategies have emerged to ensure the comfort of and continuing collaboration with research participants in order to preserve the validity of the data they choose to provide.

#### Methods

Interview staff consists of students enrolled in MA or PhD programs. Each has received extensive training in qualitative interviewing techniques and benefits from ongoing careful supervision by project management. To assess how research staff have negotiated retention difficulties and to understand how they have built rapport with participants, each interviewer (N=4) participated in a single, in-depth interview regarding how they manage their caseload. Each was asked to discuss specific participants who posed challenges in terms of retention or rapport, as well as those that did not pose challenges. Analysis prioritized both frequency of reference and degree of emphasis for identifying the strategies described below. Therefore, if not quite a consensus, the discussion that follows represents the shared emphasis of our interviewer staff.

#### **Retention Challenges:**

Scheduling interviews is the primary retention mechanism and all interviewers noted that some permutation of "real life intervention" has lead participants to cancel appointments or "no-call/no-show." These included things like work, school, childcare issues, or moving. Further, financial shortfalls have lead to phone lines being disconnected; depression has been cited as a cause of forgetfulness; and drug addiction, relapse, and treatment has caused participants to disappear or become engaged in time-consuming recovery programs.

#### **Response:**

After three years of data collection, a shared protocol has emerged for locating and scheduling appointments with challenging participants. First, persistent phone calls are required, up to twenty calls in order to schedule a single interview. If the phone is disconnected or calls are not returned, letters are sent to the participant's home provided this will in no way threaten their confidentiality. Interviewers may approach the infectious disease clinics affiliated with the HAART Project to acquire updated contact information. Dates and times of upcoming clinic appointments may also be acquired allowing interviewers to attempt to meet the participant at the clinic. This approach was described in the subject information sheet of the informed consent form which all participants signed. It is handled according to Human Subject and HIPAA guidelines, informing the participant's nurse or physician that the interviewer is hoping to speak with their patient. The participant, of course, retains the right to refuse the request.

The proceeding retention challenges and accompanying strategies should in no way lead to the belief that a majority of our sample population poses retention challenges, only that considerable care and attention are required for those that do. In fact, retention is actively facilitated by the benefits that come with participation. Every interviewer stressed the value participants expressed receiving from talking and having an interested audience. Further, by maintaining a non-judgmental approach, interviewers convey the message that there are no consequences in being candid. Financial compensation was referenced by half of the interviewers as a significant motivator. However, our sample population includes a diversity of socioeconomic classes, many of whom remain actively engaged in the research without the need for the financial incentive. Finally, conveying respect and being polite is crucial. Interviewers are often guests in participants' homes and to act accordingly conveys the value we place on their participation. Notice that the therapeutic value of the interview process, the non-judgmental approach, respect and politeness all suggest a type of relationship that conveys trust and embodies deepening relationships - the development of rapport.

#### **Rapport Challenges:**

In speaking with interviewer staff, rapport emerged as a complex interaction that entailed a two-way exchange of engagement and feeling – rapport from the point of view of the participant and again from the point of view of the interviewer. The participants place their own constructions on the research, its purpose, and the ultimate ends it serves. At times, these constructions were matched or at least similar to those held by interviewers; at other times, less so. The examples below illustrate this point. Rapport, in this context, is broadly defined as the collaborative effort to address directly the social and personal constraints on the interview process.

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'Cognitive impairment' and 'mental illness' were heavily emphasized by the interviewers as posing challenges to communication, causing agitation for participants who have trouble understanding, and discomfort for the interviewer who must attempt to negotiate a safe social space in which to address research questions. By way of example, one interviewer relayed the experience of being accused of being a space alien. The participant threatened the interviewer because he believed the interviewer to be working for the government.

Conflicts between interviewers and participants have led to aggression or frustration from participants, leaving some of our staff intimidated. For example, one participant revealed a history of abusing women. This led directly to a new policy at the HAART Project – interviews with participants of the opposite sex are now conducted at the Project offices.

'Emotional distress' refers to the difficulty interviewers have in hearing sometimes troubling accounts of people's lives. This reflects an interesting dynamic, in that the participants feel close enough to the interviewer to relay these stories, but the interviewers expressed apprehension in hearing them. Actively attending to this dynamic is important in mitigating interviewer burnout.

Finally, some participants have been hesitant to trust their interviewer because of past untrustworthy relationships. This has, in most cases, been overcome by repeated interviews and assurances of confidentiality. In summary, rapport challenges, both for the participants and the interviewers, may lead to interviewer burnout and confrontations, which points to the need for maintaining professional boundaries.

#### **Response:**

Professional distance becomes important at the HAART Project because of repeated contact with research participants and the highly-sensitive nature of the collected data. Interviewers often find themselves being asked to fill roles for which that they are not trained. We are seen as representatives of the local clinics, as therapists, case workers, and even nurses. This power differential forces careful consideration of the role of "interviewer" and the need to convey the limitations of this role to participants, repeatedly if necessary, in order that realistic expectations are preserved. Maintaining professional distance facilitates continued longitudinal work, preserving research validity and the emotional health of the interviewer staff. As a result a number of useful strategies have been developed to address these issues.

Verbally reasserting one's role as an interviewer and only an interviewer is usually a successful first step. Also, having available resources to recommend to an emotionally distraught participant can assist in asserting one's role by shifting the onus to help onto professionals trained to assist. Conscious emotional distancing is a private strategy where the interviewer realizes that he or she is being emotionally affected and mentally attempts to narrow this connection. Debriefing is an activity used at the HAART Project allowing interviewers to voice concerns about the events that occur during data collection to other interviewers, staff, and project supervisors.

## Evidence and Ambivalence: Why Studies of Adult Male Circumcision Won't Speak for Themselves

James P. Stansbury, Erica Amato Krisel University of Florida

Based on a Presentation at the Annual Meeting of the Society for Applied Anthropology April 9, 2005, Santa Fe, NM

This presentation reviewed recent public health evidence for a protective effect in HIV transmission resulting from male circumcision (MC), and considered its use as a preventive option in African contexts. While much of the anthropological literature has addressed the contested meanings and questions of unequal power that surround HIV/AIDS interventions, our goal was a more modest evaluation of the published science on its own terms. We set out first to examine MC's effectiveness on the bases of probability, plausibility and adequacy criteria. We then addressed concerns about feasibility and acceptability that will prove to be the real limiting factors in promoting circumcision as an intervention in African contexts where its

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Like the participants, interviewers benefit from having an interested audience and a safe place to vent their feelings. Finally, we've benefited from connections with the infectious disease clinics in Detroit in the form of expert in-services with counselors and social workers who can help strategize ways for maintaining the interviewers' emotional health.

#### Conclusions

A number of practices have been outlined that have been successful for the HAART Project, not only in terms of retaining participants and maintaining rapport, but in mitigating interviewer burnout. High retention rates are the result, in large part, of the careful attention interviewers give to their job performance and the seriousness with which they engage in research. A non-judgmental approach and strict adherence to confidentiality helps foster trust with the participants in the sample population. In developing ways to address retention, rapport, and burnout, the HAART Project has changed and evolved. The project has benefited from the experience of other HIV workers, our own amassed research experiences, and feedback from the participants that give their time and trust to our endeavors.

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deployment has most often been discussed. Although we touched on an array of issues in the MC debate including biological plausibility (which is reasonable while not definitive) and the inadequacy of using the ethnographic record as a living guide to intervention, this summary focuses on epidemiologic and health promotion concerns.

In an important article having relevance for the MC discussion, Victora, Habicht and Bryce (2004) suggested that reliance on randomized controlled trials (RCTs) as a gold standard for evaluating public health interventions can have serious limitations. RCTs of drugs are experiments that maximize internal validity, and in the best of all possible worlds, establish unbiased probability statements about therapies for clinical medicine. But a preventive public health intervention like MC poses different challenges, due to relatively more complicated causal pathways than drug therapies. There may be so-called effect modifications based on 'antagonism' (e.g. unmeasured, frequent, unprotected sex in an environment where HIV prevalence is high might mask a protective effect) or 'synergism' (e.g. reduced numbers of partners or consistent use of protection might conversely inflate an effect that is trivial). Simply put, there are lots of confounds that are difficult to control for, and in the case of MC, an association with Islam that may reflect ethos and behavior as surely as a biological protective effect.

Now if a randomized experiment seems forced given the messiness out there in the real world, there is some hope in the fact that consistency seen in multiple observational studies can establish plausibility. Plausibility is further enhanced if a few of the potential confounds can be controlled for in the studies. What's important about Victora, Habicht and Bryce's argument is that plausibility criteria can often provide as much or more confidence in our evaluation of an intervention than a costly and time consuming experiment that is excessively artificial. Systematic reviews can help us sort the evidence out.

The best evidence for a protective effect from MC is based on observational epidemiology, primarily from Africa, but also conducted in India and the US. The work up to 2003 includes both general population studies and work with high risk groups—defined in these studies as STD clinic attendees, truck-drivers, TB patients, and hospital patients. Studies are largely cross-sectional with a handful of cohort studies. Three RCTs are reportedly being conducted with one of the earliest to yield some data in 2007. Fortunately, the existing work to 2003 has been summarized in systematic reviews, including a meta-analysis of studies in Africa.

What is less fortunate for us is that the conclusions in different reviews have proven contradictory. Often thought to represent the state-of-the-art in evidence-based reviews, the Cochrane Collection report by Siegfied et al. (2003) took a scientifically conservative stance after looking at 34 studies, noting "insufficient evidence for interventional effects of male circumcision on HIV acquisition in heterosexual men." This conclusion emerged despite strongly consistent results for a protective effect in the high-risk group studies, with less clearcut evidence in general population studies. The authors based their reticence on the lack of RCTs and an assessment of study heterogeneity that led them to forego use of meta-analysis. Weiss et al. (2000), on the other hand, meta-analyzed 27 studies from sub-Saharan Africa, finding that "male circumcision was "associated with significantly reduced risk of HIV infection among men in sub-Saharan Africa." The analyses were likewise consistent for high-risk groups and also for population studies that adjusted for comorbid STIs, age, social status, and some measure of sexual exposure. The problem was that tests of study heterogeneity undermined confidence in the pooled point estimates (i.e. the odds ratios that tell us the degree to which MC is effective are not really secure).

The bottom line is that while probability estimates, in this case based on meta-analyses of observational studies, are not as reliable as we might hope for, the plausibility evidence, particularly among the "high-risk" groups is considerable. The consistency in the direction of a protective effect is in fact compelling. The evidence has continued to mount in studies reported during 2004 and 2005. So while more cautious voices in the debate seek the assurance of RCT evidence before proceeding, the volume and consistency of observational evidence suggests that this degree of scientific and medical conservatism may be unwarranted (and not always disinterested if we consider the 'big science' involved in clinical trials).

A substantial body of careful evidence tells us that male circumcision helps, so is there reason for further ambivalence? For those not adhering to circumcision-as-mutilation arguments, the most substantial caveats remain the feasibility of implementing interventions and addressing the acceptability of MC in the rich cultural diversity of sub-Saharan Africa. Some sense of the challenges involved emerged in Chris van Vuuren's excellent presentation at the SfAA session, looking at cases of malpractice in Xhosa circumcision and the politics of controlling ritual in both the Eastern Cape and Ndebele contexts. His work has examined the complexities and challenges involved in implementing safe and effective MC procedures where MC remains associated with traditional practice, local power and in the Xhosa case, the proliferation of informal practitioners.

The issues of acceptability have also begun to be addressed. Bailey and colleagues have conducted work in Nyanza province, Kenya and in Uganda, and both qualitative and quantitative evidence suggest generally positive perceptions toward male circumcision. A range of studies in populations where MC is rare indicates survey preferences from 60-70%. However, concerns about the potential for unintended consequences remain another stumbling point. In one South African study, for example, 9% of circumcised and *(Continued on page 14)* 

# **Evidence and Ambivalence**

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7% of uncircumcised men believed that men with MC did not need condoms. A recent conclusion from this work is quite clear: "promotion of circumcision must be done in the context of the full spectrum of other HIV prevention tools" (Matson et al. 2005).

It is safe to say that acceptability and feasibility will prove to be local matters. The cultural and political contexts for African interventions will vary, as will the ability and willingness of local health systems to implement and regulate projects. Interest will depend not only on the acceptance of local populations, but the buy-in from local providers and regulators. It goes without saying that clear messages about the limitations of male circumcision's protective effect are an ethical precondition, and gauging the risks of unintended consequences resulting from misapprehension of circumcision's protective effect remains an ongoing concern. MC is not a vaccine, 'armor plating', nor is it as efficacious as a condom. But neither should its potential contribution be ignored. Male circumcision will plausibly emerge as a useful intervention should it prove acceptable to those who would employ and undergo it-African communities and individuals in them will provide the final word about implementation, regardless of how we read the evidence.

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# HIV Does Not Cause AIDS: "AIDS Dissidents" and the Construction of Knowledge at the Intersection of Experience and Science

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Presented in a longer version at Society for Applied Anthropology conference Santa Fe, New Mexico April 6, 2005

Each decade since the 1980s has had a brief, but significant "AIDS controversy" that discredited scientists, plunged politicians into infamy, infuriated health practitioners, piqued the interest and outrage of the public and mobilized groups of activists and dissidents<sup>1</sup> (Epstein 1996). Now, as global powers' increased commitment and funding has expanded HIV/AIDS prevention and treatment programs, combination therapies have improved treatment outcomes, vaccine trials are underway, and AIDS deaths mount, the "AIDS controversy" has lost salience and faded from public discourse. But it has not disappeared for everyone. For one woman, and her supporters scattered throughout the world, there is still a strong case to be made that HIV does not cause AIDS, and furthermore, that a virus that causes "human immunodeficiency" does not even exist. She is the founder of an organization called "HIV+ and Healthy"-a pseudonym-that seeks to disseminate information, scientific studies, and other sources of knowledge that either question "mainstream" AIDS science, or espouse their own "alternative" explanations of HIV and AIDS-related phenomena.

The paper derived from this exploratory research is a case study of the founder and director of the organization "HIV+ & Healthy," whom I call Thea. My analysis focuses on the interplay between bodily experience and scientific knowledge in Thea's formulation and acceptance of dissident information. She emphasizes that all the information she disseminates through HIV+ & Healthy is scientific fact; and that she does not simply believe or trust information about HIV and AIDS—from either side of the debate. Her rhetoric draws heavily on scientific knowledge and jargon, but she relies just as much on personal experience and the anecdotes of friends and acquaintances. She uses both experiential knowledge—i.e. bodily experience—and scientific knowledge to formulate a synthetic understanding of HIV and AIDS.

I argue that dissident science/knowledge is both constructed within the illness experience and contributes to the construction of the illness experience. Thea deems science "good" or "bad" depending on its match to her perceived healthy, "non-infected" self; likewise, her healthy, non-infected self achieves validation by accepting the truth of dissident science. This case study provides a unique and provocative example of how illness and knowledge are simultaneously constructed and contested within a lay epistemological framework that gives primacy and authority to bodily experience.

Diagnosed as HIV-positive in 1992, and after becoming disillusioned with what she perceived as the narrow-minded orthodoxy of mainstream AIDS organizations, Thea founded HIV+ & Healthy in 1995 in order to publicize scientific studies, like those of Duesberg, whose conclusions run counter to the established views of HIV and AIDS. The material she provides includes a number of marginalized statements: that HIV does not cause AIDS, that the HIV antibody test is nonspecific and does not indicate that someone is actually infected with HIV, that there is no proof that HIV actually exists, and that the so-called "African AIDS epidemic" is based on statistics distorted by mislabeling those that die of TB, malaria, and starvation as "AIDS victims."

Thea considers herself to be healthy. Her health is the experience that most informs and influences her understanding of HIV and AIDS. Her dissent grows out of the mismatch between the expected experience of HIV and her lived experience. The expected experience of HIV is formulated by the biomedical construction of the physiological progression of HIV-infection— HIV as a *disease* (see Kleinman 1988). This is in contrast to illness, which is the "lived experience" of the problem that includes sensation and suffering, explanation and categorization, and help seeking. Thea interprets her persistent health as a clear indication of the *absence* of illness. Because she identifies herself as HIV-positive *and* healthy (both markers are needed to make her case), her experience of health can be seen as an "illness experience."

In Thea's case, dissident knowledge and the illness experience are dialectically co-constructed. From one perspective, dissident scientific information is sought after, evaluated, incorporated or dismissed based on how well it resonates with her bodily experience (that of health). From another vantage point, her healthiness becomes part of her "illness experience" rather than an exception to it because dissident science explains how an "HIVpositive" person can be "healthy"—i.e. they are not actually infected with a human immunodeficiency virus.

On one hand, being healthy is in contrast to the diagnosis of HIV, and in the mismatch between diagnosis of disease and experience of health, an opportunity arises for dissent. The dissonance leads to resistance against the mainstream explanation of HIV and AIDS and the creation and validation of "dissident science." On the other hand, however, the resistance and dissidence do not lead to the casting off of the disease category, rather to the construction of an alternative experience and understanding of HIV. Thea's "illness experience" of HIV is a dissident experience, one of health, hope, resistance, and belief that she is not infected with HIV. Her construction of HIV relies on science that rejects mainstream understanding of HIV.

Epstein, Steven, <u>Impure Science: AIDS, Activism, and the Politics of</u> <u>Knowledge</u>, University of California Press, Berkeley, California, 1996. Fassin, Didier and Helen Schneider, "The politics of AIDS in South Africa: beyond the controversies," *British Medical Journal*, 326, 2003:495-497. Kleinman, Arthur, <u>Illness Narratives: Suffering, Healing and Human</u> <u>Condition</u>, Basic Books, 1988.

<sup>1</sup> In March 1987, Duesberg published an article in *Cancer Research*, claiming that HIV could not cause enough damage to the immune system to cause AIDS. Before Duesberg entered the debate in 1987, there were "dissenting voices on the causation of AIDS" but they were "marginalized;" Duesberg's emergence helped to (briefly) legitimize both scientific and lay voices of dissent because he was recognized as a leading scientist and expert in virology (Epstein 1996). Steven Epstein cites a resurgence of the power and popularity of scientific unorthodoxy in mid-1991. This second-wave of dissidence was marked by strong anti-AIDS-drug rhetoric, as well as critiques of the orthodoxy's lax adherence to the scientific method. The controversy reignited in 2000 when Thabo Mbeki, the President of South Africa, wrote a letter "to world leaders expressing his doubt that HIV was the exclusive cause of AIDS" (Fassin and Schneider 2003) and invited dissident scientists such as David Rasnik to share and evaluate current scientific information on the etiology of AIDS.

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# Battling for Survival, Battling for Moral Clarity: "Illegality" and Illness in Everyday Struggles of Undocumented HIV+ Women Migrant Workers in Tel Aviv<sup>1</sup>

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Undocumented migrant workers living with HIV/AIDS in Israel, like their counterparts elsewhere, are doubly abject due to their lack of legal status on one hand and their ill health on the other. Unlike Israeli citizens living with HIV/AIDS, who can access an array of state funded treatments and support services, undocumented migrant workers living with HIV/AIDS are marginalized both by the state's exclusive immigration regime and by its efforts to shake off responsibility for their health needs. At the same time, HIV treatment and care are generally unavailable in migrants' countries of origin. Despite the state's exclusionary orientation and in contradiction of official policies, certain forms of HIV treatment are available to undocumented migrants through the day-to-day efforts of a small array of activist Israeli NGO's, publicly employed doctors and state officials.

The tension between these simultaneous, oppositional processes of exclusion and inclusion generates a "gray area" – a zone of competing values, claims and interests – in which undocumented migrants living with HIV/AIDS and these other stakeholders search for new options and possibilities while continually taking pains to protect their own varied, and often competing, interests. Actors thus constantly negotiate with laws, health policies, and one another in a collective battle not only over migrants' chances of survival, but also over the rationality and the morality underlying the state's – and their own – decisions and choices.

Anchored within this complex, indeterminate zone, the present study draws upon ethnographic field research conducted among undocumented African migrant women living with HIV/AIDS in Tel Aviv between 2001 and 2003. The tensions and complexities of the field are examined through the stories of three groups of social actors providing different angles on the same reality.

The first group includes undocumented (Continued on page 16)

#### (Continued from page 15)

migrants living with HIV/AIDS in Israel. The women I met were aware of their rights, and lack of them, and constantly negotiated their options while dealing with their lack of legal status and their HIV status as two inseparable facts of life leading to a reality of contradictions.

The second group of actors is composed of NGO activists from an array of fields who believe they have a humanitarian obligation to help undocumented migrants despite of their lack of legal status. Activists provide humanitarian assistance while simultaneously advocating for changes in policy on the basis of a commitment to health as a basic human right independent from humanitarian needs.

The third group of social actors includes doctors working in AIDS clinics at government hospitals. These doctors are familiar with the law regulating treatment for citizens and non-citizens and the loopholes in it, and they juggle two different, and contradictory, moral positions: the ethical one, based on the belief that doctors must help everyone, and the rational-medical one which regards the untreated sick as a public health risk.

In presenting three stories – first, of an undocumented migrant struggling to secure medical care, second, of an activist who believes it is her duty to help everyone regardless of legal status, and third, of a doctor torn between contradictory professional and ethical obligations – the study explores the ways in which different social actors deal with illegality and its effect on their lives. In exploring the positions of these social actors, their stories, their stakes, and their "local moral worlds,"<sup>2</sup> the study aims to understand the nature of the "gray area" and how social actors operate within it.

These social actors' actions and stories reveal a reality in which contradictions rule not only the nature of the social arena but also the nature of the actors' practice within it. Their choices and actions can be seen not only as the manifestations of power or powerlessness, or as gate keeping and border crossing, but also as illustrations of a complicated reality entailing different perspectives and different stakes in their "local moral worlds." Social actors thus negotiate, and at times manipulate, the contradictory nature of this complicated reality, thereby stretching the boundaries of "legality" and "illegality." For some actors, namely migrant women living with HIV/AIDS, negotiating this "gray area" involves a struggle for survival. For others, including NGO activists and publicly employed doctors, the stakes of the struggle are different: to achieve moral clarity.

<sup>2</sup> Kleinman. A., Kleinman, J. (1991). "Suffering and its Professional Transformation: Toward an Ethnography of Interpersonal Experience". *Culture, Medicine and Psychiatry. Vol.*5(3). Pp. 275–301.

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## An Exploration of HIV and Adults Over Fifty: Age Ain't Nothing But A Number – Or Is It?

Andrea Nevedal, Wayne State University

#### HIV+ Older Adults: Significance & Background

Since its beginning the HIV/AIDS pandemic has profoundly impacted the lives of people in the USA and across the globe. By helping uncover how cultural beliefs and values shape the way we view health and illness, anthropological research contributes to knowledge of the HIV/AIDS epidemic and to insight on the lived experiences of having the virus.

Early on, young adults comprised most of HIV/AIDS diagnoses, while older adults were a small fraction of all HIV/AIDS cases (Kun et al, 1998). Researchers assumed the few early cases of older adults with HIV were due to contaminated blood transfusions, not sex or drug use behavior (Williams & Donnelly, 2002).

The advent of strict blood screenings since 1985 has virtually eliminated HIV transmission via blood transfusions. Yet at present, adults age 50 and older account for over 10% of newly diagnosed cases of HIV in the United States annually and composes one of the fastest growing HIV-infected groups, even more than younger adults (Weaver-Moore & Byron-Amurgey, 2000). Why are rates of HIV/AIDS among older adults steadily increasing? Part of the problem may be that public health awareness about older Americans' HIV risk is limited in large part by cultural beliefs that older people do not have sex or engage in intravenous drug use. Older adults are still generally neglected and overlooked in research, prevention, awareness, testing, and media. As a result we do not know what older adults think about HIV/AIDS, how they respond to HIV/AIDS and antiretroviral therapies, and statistics reflecting the burden of HIV/AIDS on older adults may still underestimate the total number with the virus. To address these issues, I conducted a study among adults age 50 and older to (1) discover and describe meanings of HIV, (2) to identify the sources of knowledge and awareness about HIV, and (3) explore perceptions of HIV risk and related risk behavior.

#### **Design & Methods**

Data for this pilot study were derived from eleven, cross-sectional, semi-structured interviews with an ethnically diverse sample of people fifty years or older to examine the sources of knowledge about HIV and to explore the cultural beliefs and misperceptions that are associated with HIV risk behavior. Participants were purposively selected to represent Detroit, a high risk area for HIV. The sample consisted of:

<sup>&</sup>lt;sup>1</sup> Presented at the Society for Applied Anthropology Annual Meetings, Santa Fe, NM, (April 5-10, 2005). The author thanks the Department of Sociology and Anthropology and the Shaine Center for Social Research at the Hebrew University of Jerusalem for their support.

# An Exploration of HIV and Adults Over Fifty

Sample Description Total (N=11)

60

- Age in years (mean)
- Ethnicity

   African-American
   Latino-American
   Euro-American
   Gender
- Male 5 Female 6

#### Education

•	Luucation	
	High School	3
	Some Post-Secondary	2
	College	5
	Graduate School	1
•	Marital Status	
	Single Never Married	1
	Married	2
	Divorced	6
	Widowed	2

A snowball sampling strategy from personal social networks such as friends, family, neighbors, and colleagues recruited participants for the study. One time in-home interviews were conducted with questions designed to elicit and explore knowledge of HIV and exposure to HIV media, experiences with counseling and/or discussions about HIV and perceptions of HIV risk and attitudes about HIV. Content analysis, pile sorting and coding techniques helped to identify emergent categories and to summarize key topics and themes.

#### **Results: Older Adults & HIV**

In response to questions about knowledge of HIV and its transmission, most participants emphasized body fluids as a method of transmitting HIV. However, 7 of the participants were unable to name the particular types of body fluids that transmit the virus and their modes of transmission. As a sixtynine year old African American woman explained, "It's transmitted through body fluids, that's my understanding... Maybe if you have a running nose, was that it? But that is a body fluid." This research on older adults' perceptions and knowledge of HIV revealed incomplete and inaccurate explanations among members of the sample (n=7) of how HIV is transmitted. Other data revealed feelings of not knowing enough about AIDS, and a lack of interest or spending little personal time learning more information about HIV/AIDS. The uncertainty expressed regarding HIV transmission raises concerns about how older adults protect themselves and/or know when they should or should not be concerned about contracting HIV (e.g., runny nose).

In discussing public health messages about HIV, all of the participants interviewed reported never seeing HIV media specifically geared towards older adults. Instead many emphasized how HIV messages appear to focus more on ethnic groups, younger people, gays and gender. A fifty-six year old Latino Detroiter expressed this sentiment, "I think they are trying to educate minorities. I think so because they are the ones who don't believe in anything...I can say for myself when I was young and everything you'd tell me...it would go through one ear and out the other." Results from this study emphasize the lack of HIV media targeting older adults while also underscoring the ever increasing need for these types of messages.

Monogamy emerged as a key strategy identified by 6 of the participants to protect themselves from HIV. A different Latino Detroiter commented, "Everyone should be tested. Unless you are in a martial situation then you shouldn't be tested because are having sex with one person...." A sixty five year old African American male described his feelings about HIV risk, "No, I'm not...Its only one partner, and that's been 15 years with one partner...that still doesn't guarantee that she isn't out doing something but I trust that." Perceptions of what constitutes safe and unsafe relationships play an important role in how older people assess their risk for HIV.

The participants constructed their perception of risk of infection on membership in commonly identified risk groups, rather than on risky behaviors like unprotected intercourse. They focused on stigmatized groups such as gays, "bar flies", young and/or promiscuous people as being at high risk for acquiring HIV. A fifty-four year old Euro-American male underscored this perception of risk, "Absolutely number one homosexuals!" Ten of the participants acknowledged that older adults do engage in HIV related risk behaviors (i.e. sexual activity and intravenous drug use) and can contract HIV. A seventy year old African American woman talked about sexual activity among older adults, "Very sexually active! A lot of people think seniors are not active but they are... and that is just another part of life that they would continue on with." However, while the participants expressed concern about HIV among older adults, the majority of the participants did not personally feel at risk for HIV and some felt their age protected them from contracting HIV. A fifty-seven year old Euro-American woman stated, "Say I met a man and he's like in my age group and you would think no [he doesn't have it]. We know that we are smarter and we are older and we don't run around." Almost all of the participants felt they were not currently at risk for HIV (n=10).

Despite the fact that 7 people felt they had previously been at risk for the disease, most of the sample did not feel they needed an HIV test (n=8). Only 3 people actively sought testing and an additional 3 were tested for surgery or insurance policies; the remaining 5 never received an HIV test. As a fifty-eight year old African American man explained, "I haven't been tested because I don't figure that I'm in a real risky relationship and also I've had discussions with my doctors...they didn't push it and I didn't." These findings suggest that many older adults do not actively seek testing.

#### **Discussion & Suggestions**

This paper has identified several factors that put older Americans at risk for HIV: 1) low knowledge of HIV

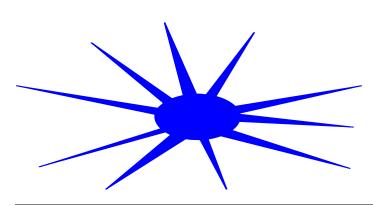
(Continued on page 18)

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transmission and awareness, 2) cultural values emphasizing trust embedded in understandings of monogamous relationships and marriage, which may create a false sense of security against HIV infection, 3) outdated ideas about "risk groups" and a sense of low risk because they are not members of stigmatized groups, 4) cultural beliefs about aging influencing change/decline of feeling at risk for HIV with increasing age despite HIV related risk behavior, 5) active HIV testing among only a small percentage of older adults. Results from this study support a pathway for creating comprehensive and culturally sensitive public health programs about HIV and geared towards older people.

- Design age relevant HIV media and prevention programs that address risk behavior among older adults and misperceptions about HIV. Older adults should take part in designing these media messages
- Develop ways in which testing can become accessible, affordable, and a priority among older adults. It is important to emphasize diverse arenas for HIV testing among older adults (i.e. church, assisted living centers, nursing homes, community and activity centers, workplace)
- State specific facts about how HIV is transmitted in HIV messages geared towards older adults
- Reject popular misperceptions of "risk groups" and the safety of "monogamous" relationships in HIV messages and emphasize how all older adults can be at risk
- Focus on the positive effects of early HIV detection and advancements in antiretroviral therapies in prolonging life, and improving health and well being while living with HIV to reduce the stigma and fear often associated with HIV/AIDS

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## Peer Education in the Workplace: HIV Prevention in Lagos, Nigeria

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This study examines an HIV prevention program in the workplace and reports on peer educators' training and the constraints and benefits of the program implemented in Lagos, Nigeria.

Nigeria has 130 million habitants divided into 250 ethnic groups. The major ethnic groups are: Yoruba in the southwest who are animist and Christian. Hausa in the north, who are Islamic and Igbo in the southeast who are animist and Christian. Each of these groups competes for oil revenues. The political situation of the country is very tense because of frequent changes of leadership and the involvement of the military in politics (leadership changed 20 times in the last 6 vears). The ecology has suffered from the exploitation of petroleum in the Niger Delta. Because Nigeria does not have any law that mandates restoring the ecology following oil drilling, contamination from oil drilling has contaminated fisheries and agricultural communities. In addition international oil companies have given little compensation to the communities that suffered from this ecological devastation. Another major Nigerian environmental problem is the intensive logging of its original forests and the destruction of animal habitats.

National statistics report that about 6% of the population is infected with HIV in the age groups 15-49 years old. In nine of Nigeria's 36 states, HIV prevalence increased more than 10% between 1995 and 1999. Transmission is mostly heterosexual, perinatal and through blood products. National efforts to control HIV infection did not start until 2000 because government leaders denied the existence of HIV/AIDS at the beginning of the epidemic. Among many variables associated with the spread of HIV are: Poor health, extreme poverty, prostitution, multiple partners, polygamy, inaccurate information about HIV transmission, high prevalence (25%) of STIs among risk groups, and only 10% use of condoms.

The SMARTWork (Strategically, Managing AIDS Responses Together in the Workplace) program developed by AED (Academy for Educational Development) and administered by Development Associates was implemented in 2002 in Lagos. The program funded by the US Ministry of Labor consisted of a small grant (one million dollars for 4 years) and had as its objective to reduce HIV risk behavior among factory workers and their families and to reduce the level of discrimination against people living with HIV/AIDS. In doing so, the program included workshops for leaders and training for workers/peer educators (male and female). Workshops provided information about HIV prevention with lectures, reading material, and videos, and promoted peer education in the workplace and the formulation of policies against discrimination of infected workers. The training for workers/peer educators included information about HIV modes of transmission and prevention and communication skills to enable them to pass that information on to others. The training was given by two instructors (a male nurse and an assistant) and lasted two days. This included lectures, viewing videos and role-playing. At the end of the training, trainees spoke with a woman who had contracted HIV during blood transfusion. A few weeks after the initial training a follow up meeting was scheduled with peer educators in order to assess their knowledge and their need for more information. Meanwhile, peer educators were asked to disseminate HIV information to friends, family, and to their respective religious, sport, and youth associations in the communities.

In order to evaluate the SMARTWork program, in April 2004 six national and international factories located in Lagos and its vicinity were visited for data collection. A total of 88 informants were interviewed through focus group discussions along with phone and private interviews by the investigator and two facilitators. Informants represented the staff of the factories, workers, NGOs' personnel, trainers, union labor members, stakeholders, medical personnel and journalists. Questions inquired about knowledge of HIV prevention, understanding the modes of transmission, behavior change, opinions about SMARTwork's training, constraints, and the need for further information.

The following are workers' quotes about their opinion of the training.

"Without the program, I do not think we would have known how to avoid HIV/AIDS."

"SMARTWork has really helped stimulate people to understand the HIV/AIDS problem."

"They (instructors) really help people to know more and are assisting for education."

"After the lecture, I have been so careful; I am only with my wife now."

"Before SMARTWork came, I did not know what to do with my positive (HIV) colleagues, now, I am aware and can be of help."

"I have been expanded and empowered by SMARTWork to help others."

"Every one needs to be concerned and involved, and can't just do it at work; you have to do it at home and around the people in your household."

"I now care more for PLWHA (people living with HIV/AIDS)." "As a result [of SMARTWORK peer education training] everyone at Cadbury knows about HIV/AIDS, the peer educators are disseminating the word one-on-one with their co-workers."

All of them said that the training influenced their behavior because they felt that HIV was real and was among them. The HIV infected woman had children and grandchildren, was in her fifties, had contracted HIV through blood transfusion, and was dedicated to talk about her story. During the training peer educators were moved by this woman's talk and this helped change their attitude and also permit participants to ask questions about her symptoms and ways of copying with her sickness.

Programmatic constraints were mostly related to limited

human resources (two instructors and one secretary) and limited financial resources, along with the factory owner's economic hardship of allowing the program.

The major benefits of the project were related to the establishment of collaborative ties with other organizations and the labor union that took a great interest in reducing discrimination in the workplace. Another bonus was that many factories had clinics in the workplace and the implementation of HIV prevention did not require additional funding. Because the project mobilized various stakeholders it also strengthened collaboration with government leaders, union leaders and NGOs. Since the project's implementation, new policies institutionalized at the national level have developed against the discrimination of PLWHA in the workplace and there is a strong support of workers' rights by union leaders.

What are the lessons learned from this project? One lesson is that collaboration with organizations, leaders and the media is very important. Also, workshops were very beneficial in communicating the goals of the project to government leaders, union leaders and various stakeholders. Because these persons were also involved on HIV prevention, their experience and collaboration facilitated training and formulation of policies. In addition, the inclusion of journalists in meetings and workshops helped the diffusion of the goals of the project. Many articles were published in local newspapers on the need for HIV prevention in the workplace and the need to reduce discrimination and stigma. In addition, factory's owners were shown that HIV prevention could be implemented in the workplace and that prevention would eventually minimize their medical expenditures.

Another important determinant to the success of this project is associated with the voluntarism of the peer educators and their willingness to change their behavior and to make a change for the better in their communities. Peer educators felt that they had a mission to accomplish and were eager to learn more communication skills in order to reach the persons who were not convinced that HIV exists around them. During training, peer educators received accurate information about the modes of transmission of HIV/AIDS and participated in role-playing where they took the role of someone with HIV and were faced with reality. In addition, they could ask questions if they did not understand the lecture and were able to converse with the PLWHA. Interaction with instructors and the PLWHA provided peer educators with more accurate information and they were able to counter erroneous information about the modes of transmission, thus promoting a change in their behavior and attitudes.

Finally, the project is replicable and easy to implement without international help. Sustainability requires factory owners' approval and sponsorship, collaboration with partners, voluntarism of peer educators, a well-structured training program, follow up sessions, and the dissemination of accurate information and instructors' involvement.

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# Juntos Pero No Revueltos<sup>1</sup>: Giving Respect to Difference and Building Intimate Bridges in HIV and Sexuality Research with New York City Latino Homeless Men.

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The debate on "native" anthropologists has centered on the advantages and disadvantages of studying one's own cultural group. In it, shared ethnicity is the core assumption and the ability of the ethnographer to transform it into trust is its main benefit (Jones 1970; Aguilar, 1981; Harrison, 1991). However, trust cannot be assumed among a racially and nationally diverse population like Latinos/as.

Being a *Latino* "native" anthropologist is a complex assignment. Both categories, *Hispanics* or *Latinos* denote US society as social milieu and both, to different ends, erase these peoples historical, cultural, and legal diversity (Flores 2000). The Latino/a "native" anthropologist needs to have a keen sense and know when national, regional, or racial prevail and when they melt into the monolithic ethnic label.

To meet the Latina/o *native*, the Latina/o anthropologist does not journey into *Otherness* to return an anointed *hero* (Clifford 1988). The encounter of Latinas/os anthropologists and *natives* is the encounter of part others and part selves. Their differences may (or may not) be breached by language. The construction and/or (re)discovery of a common politics may be a more effective road. However, no alternative can guarantee a positive outcome. Recognition can be elusive.

Recognition may only take place in searching for the *self* into the *other* (or vise versa), and (re)creating a politics centered common cultural space. This process is fraught with risk. As the Latina/o anthropologist searches into the Latina/o *native*, s/he has to assist the informant's search: be prepared to stand as a Latin American yin and yang whose diversity supports its alliance.

During my research among homeless men in New York City I had to develop rapport with other Latinos and explore their experiences and beliefs about HIV infection. The initial challenge was establishing myself as another Latino without reducing their experience of *Latinidad* to mine; that is, conveying connection without erasing difference. I offered my migrant experience as a link to my informants, but that did not readily resonate with US born Latinos. For them, references to the city's barrios were a better credential if not of *Latinidad*, at least of knowledge of Latino turfs. Still, I encouraged my informants to lead the discussion of our differences, avoiding implying sameness or that their lives were *knowable* to me.

Meeting Latinos in a homeless shelter or drop-in center was loaded with class implications. Very few of my Latino informants were unfazed by the stigma of homelessness, and discussing it with me seemed very embarrassing for some of them. I hoped my political and economic analysis of homelessness, immigration, and racial politics assured them I did not blame them for their homelessness, but I noted that in particular recent immigrants lived their shelter stays as failures.

Perceived class differences, often recreated the distance *Latinidad* may have breached. A gay man, slightly older than me once told me upon hearing I was an anthropology student: "so your dad has money, huh?" In his mind inherited wealth was the only reason a Latino could pursue such an unprofitable profession. He looked at my watch, which he knew had belonged to my father, and asked: "how much is that worth?" Questions of this nature were hard to field without sounding defensive, and recalling my employment history was often more effective in conveying social proximity to my informants.

The experience of the HIV epidemic was often the most difficult topic to open up for candid discussion. Contributing my own stories of fear, uncertainty and loss first facilitated the discussing of HIV infection. The risk of opening my heart in the field was standing emotionally naked in front of an apathetic informant. A few times I stood exposed before an indifferent man, but most often I was rescued from my revelation by warm expressions of support and accounts of lives ravaged by HIV. Once this type of exchange took place with an informant, our relationship often turned into friendship and loosing objectivity became the risk.

Obtaining frankness about sexuality from my informants resulted from personal risk taking. I did not ask about HIV or sexuality until some rapport was established, and always spoke of sexuality making reference to emotions. Once I shared my sexual interests, most men used my openness to talk about their sexual and emotional adventures, misfortunes, and uncertainties with men or women. Some took the lead in the discussion, as their *gaydars*<sup>2</sup> informed *Queens* and *Homos*—two shelter-specific categories—of my sexual orientation.

The disclosure of my sexuality needed some fine tuning through my fieldwork. I started telling my informants I was *Gay*, but in the stories they responded with, I noted their struggle to refer to themselves as *Gay*. Since I had called myself *Gay*, they corrected their speech to be understood. They thought of themselves as *Queens*, *Homos*, or *Locas*, and in using the word "gay," I predetermined their taxonomies. I went on to confirm that, with exception of the two or three *Gay* men at the shelter, the homeless men I met did not participate in the life of the gay community.

The methodological strategies of my HIV and sexuality research among homeless men in New York City, and in particular the challenges I faced as a "native" Latino anthropologist, find theoretical support in Faye Harrison's chapter in *Decolonizing Anthropology* (1997[1991]:88-110). In it, she writes about her work as a "native" anthropologist in Jamaica and describes her research strategy, *dialogical ethnography* (Harrison 1997[1991]:101-105), and its intimate relation to the notion of *double* or *dual consciousness*, or the ability to *see out of more than one eye* (Harrison 1991 [1997:89-91]).

By *dialogical ethnography*, Harrison means that the anthropologist engaged in a decolonizing practice can—or *must*—offer informants strategic information about the larger

system in which their political and cultural praxes are inserted. This implies a brake with traditional ethnography in that information flows toward the anthropologist, but also toward the informant.

In my work, I never had doubts that I would provide HIV education, as well a critique of the US health care and housing establishments. But a great deal of the experience of confronting HIV, is also lived in the realm of the emotions and providing information about how I and other people dealt with pain, helped my informants contextualize their emotions and understand the dimensions of the epidemic.

The ability of native anthropologists to capture levels of socio-cultural life hidden to others is the result of *double consciousness*, and informs the *dialogical ethnographic* effort. For the Latina/o "native anthropologist" *double consciousness* may include knowing the extent and limitations of continuity and difference that keep us *juntos pero no revueltos*. The ability to see historical and cultural diversity where the Bureau of Census sees continuity, to see joint political aims in spite of historical and cultural distinctiveness, and to know when to use the fusing or the discriminating lenses, may reside in the gift of *seeing out of more than one eye*.

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<sup>1</sup> "Together, but not scrambled," or "side-by-side, but not intertwined."

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## Consequences of clinician and patient beliefs about the effects of alcohol on anti-retrovirals and implications for adherence

Tracy L. Wunderlich & Andrea Sankar

Presented at SFAA April 7, 2005 Santa Fe, NM

Over the last decade, HIV has been transformed into a chronic condition with all the associated issues of living and coping with a chronic illness (Pequegnat & Stover, 1999). Currently available medications (HAART, high acting antiretroviral therapy) can greatly improve the lives of individuals who are HIV+; but this requires an adherence rate of 95% or more (Paterson et al., 2000). Non-adherence is thus a major factor in HIV care, and failure to adhere can further jeopardize the health of those who are immune-suppressed. Although research has, to date, failed to identify demographic or other patient characteristics that predict adherence, patient beliefs can be a factor negatively affecting adherence levels (Horne et al., 2004). In this paper, I will discuss patient and physician beliefs about mixing alcohol and HAART.

The study reported here is part of a larger study (HAART Project), funded by the National Institute of Allergies and Infectious Disease, and focuses on patient adherence understandings and practices.

#### Background

Recent literature suggests that alcohol is a major source of non-adherence to anti-retroviral therapy (Fiellin, 2004). It is suggested there that the mechanism by which alcohol affects adherence is through forgetfulness caused by inebriation. In interviewing participants enrolled in the HAART Project, we noticed in "side-talk" that a number of individuals said they shouldn't drink while taking their medications or reported that they decided to skip their medications altogether while drinking. This instigated the development of a supplementary questionnaire designed to understand better the following research question: to what extent do patients and clinicians think that you shouldn't drink while on anti-retrovirals and what is the influence of this belief on adherence practice? In order to answer this question, we administered a brief questionnaire consisting of ten open-ended questions. In the analysis, these data were combined with the demographic and assessment data (clinic data & standardized assessments) collected in the parent study. Qualitative content analysis of interview responses and statistical tests of the quantitative portions of the data were conducted.

#### Sample

The patient sample for this study consisted of the first 50 patients enrolled in the HAART Project; all are HIV+

 $<sup>^{2}</sup>$  *Gaydar* (gay + radar), an emic category referring to the presumed ability of Gays and Lesbians to recognize each other without words, is the *embodiment* of the maxim, "it takes one to know one." Heterosexuals do not have *gaydar*. To my knowledge, there are no studies exploring this ability. In my impressionistic assessment there is a perceptual range in determining sexual orientation that goes from the crass (using mannerisms and self-presentation), to the subtle (identification of the observer with the observed, and trying to read what "the gaze" conveys).

#### (Continued from page 21)

African Americans. All subjects were drawn from two infectious disease clinics with a combined census of 2,800 sero-positive patients. The age range of informants was 23 – 62 and the group consisted of eighteen females and thirty-two males. The clinician sample for this study also included 16 health care providers caring for patients at these two clinics.

#### Patient Beliefs about mixing alcohol and HAART

When patients were asked the following question, "In your opinion, what is the relationship between drinking and taking HAART?" 82% reported that they don't mix, while 18% thought that it was acceptable to drink in moderation. One informant told us, "You're never supposed to drink alcohol when you're sick. You know what I'm saying? A lot of people do it, but I stopped." Another response was: "My doctor told me that they don't mix, you're not supposed to take alcohol when taking the medication – period."

To assess patients' rationales for saying alcohol and taking medications don't mix, we asked people what they thought would happen with different levels of alcohol consumption. Specifically, we asked them what would happen if: they had one drink with a meal and took their medications; had three or four drinks in an evening and took HAART; or were very intoxicated and took their medications. In analyzing the data, we identified five categories of responses: (a) problems with side effects, (b) problems with drug efficacy, (c) no problems from drinking, (d) wouldn't attempt drinking and taking medications, and (e) don't know what the effects might be. When patients were asked what would happen if they had one drink, almost 50% said that it was okay, but with intoxication, almost 80% of the sample thought it was a bad idea. Of these, equal numbers (29%) thought that getting intoxicated and taking medications would result in side effects or in the medication not working.

Participants (79%) believed that as the amount of alcohol ingested increases, the effects on the body increase as well. For example, when patients mentioned the problem of side effects, this problem was perceived to increase with the amount of alcohol ingested. In other words, more drinks equal more side effects. The number who reported no effect of drinking with their medications also decreased with the amount of alcohol ingested. Patients generally thought that drinking and taking their medications was a bad idea, becoming worse with increasing alcohol consumption; the source of this belief is unclear.

# The Relationship between patient beliefs and self-reported adherence

We next investigated how patient adherence behavior was affected by their beliefs that drinking alcohol and taking medications is unacceptable. Over one-third reported that they would take their pills early if they anticipated consuming alcohol. Moreover, a substantial 46% said that if they were drinking, they would forgo their medications completely.

For example one respondent said, "If I know I'm drinking alcohol, I won't take my meds that day," and another reported,

"I knew that I was going to have a drink that day. And so I just said okay, I'll just take medicine early in the morning...I'll take this one now, and then later I won't take the other pills if I'm going to drink." Thus, significant non-adherence is due to patient beliefs about drinking and taking medications – beliefs that do not necessarily lead to less drinking, but only lead to taking fewer medications.

#### Physician Attitudes & Doctor/Patient Communication

To determine the influence of physicians on these beliefs, we elicited patient beliefs about clinician views on alcohol and discovered the following: 66% of patients believe that there is no point in talking to their doctor about alcohol and medications because they would simply be told not to mix the two. Thus, for a majority of patients, there is a perceived agreement with clinicians that does not rely on direct communication. Those patients who talked to their doctors concerning alcohol received a wide range of information/ recommendations which included (as reported by patients): (1) treatment should not be initiated if the patient is currently drinking; (2) medications are ineffective if taken with alcohol; and (3) drinking in moderation may improve the appetite, and should therefore be encouraged.

Patient views about drinking alcohol and taking their medications, and their reports of clinician attitudes led us to hypothesize that the origins of patient beliefs might stem from how clinicians communicate with their patients. To elicit clinician views on alcohol and taking medications, we asked their opinions concerning the impact of alcohol on HAART. While 13% reported that it was harmless to drink with the medications, 82% thought that the alcohol had a negative effect due to behavioral and/or drug interactions. Examples of clinician responses are as follows: "Physiologically, I don't think that alcohol really will have a great effect on blood levels or response to the medicines although there may be some small effects" and, "I think it increases the risk of non-adherence to therapy."

To determine exactly what physicians told their patients about mixing alcohol and HAART we asked clinicians about the advice they gave their patients. Fifty-three percent reported that they told patients alcohol was detrimental because patients tended to forget to take their medications when intoxicated. An additional 27% of clinicians told patients that alcohol was detrimental because of physical interactions with HAART. Finally, 20% told their patients that drinking with their medications was not a problem. The following are examples of clinician responses: "I tell them that they can have their beer or their daily wine, but not to drink excessively" or, "To be frank, that's not an issue that I've brought up enough."

However, only 50% of clinicians reported that patients ever broached the subject. This is consistent with what patients reported and thus, there is no strong evidence to suggest that the widespread tenacious beliefs of patients are due to information given to them by their physicians.

#### Implications

Patients have a strict view that alcohol and medications

## Design of HIV Awareness Materials in Rural Costa Rica: A Community Participatory Approach

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Between October 2004 and March 2005, Nancy Romero-Daza, Ph.D. (USF), Oriana Ramirez-Rubio, MD and Elsa Batres-Boni, BS (both affiliated with the Monteverde Institute, in Monteverde, Costa Rica) conducted a pilot intervention project that involved rural Costa Rican women in the creation of culturally appropriate HIV/AIDS awareness materials for their families and peers. The project, funded by the USF Globalization Research Center, was based on the findings of a previous study conducted between 2003 and 2004, which focused on community perceptions of the potential impact tourism may play in the spread of sexually transmitted infections (STIs) including HIV/AIDS in rural Costa Rica. Both of these projects were conducted in Monteverde, a rural area in central Costa Rica. Originally an agricultural and dairy-farm region, Monteverde has become one of the main tourist attractions in the country. The main tourist industry

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#### (Continued from page 22)

don't mix. Clinicians reported a wide range of beliefs about alcohol consumption and taking medications. However, both patient and physician beliefs are generally unsupported by pharmacological studies which indicate that there is no negative interaction caused by consuming alcohol when taking HAART (Paolo et al, 2000). Despite strongly held beliefs on both sides, patients and physicians on the whole do not communicate about drinking and taking medications.

These findings suggest the need to develop clinical practice guidelines that clearly differentiate behavioral outcomes of drunkenness from physical outcomes of drug interactions. Patients fearing drug interactions are likely to forgo their medications. Addressing this misunderstanding can potentially obviate some practices that lead to reduced adherence and improve physician and patient communication.

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revolves around eco-tourism, which each year brings thousands of travelers from around the world as visitors to the protected forests which are rich in fauna and flora. In addition, the region also attracts long term visitors who remain in the area for extended periods of time. Among these are students enrolled in language studies, researchers, and volunteers that work in different development programs. Given that there had been no previous research on STIs and on HIV in the area, our research was exploratory in nature.

The main goal of the research project was to collect data from various sectors of the Monteverde population about their perceptions of the extent of the STI problem (including HIV/ AIDS) and specifically, about the role that tourism may play in the spread of these diseases. The research team (Romero-Daza, Andrea Freidus, Noe Vargas, and Sophia Klempner) conducted 57 in-depth interviews with individuals from several groups including: people directly involved in the tourism industry (e.g., hotel owners and operations, bar tenders, tourist guides), health care practitioners, teachers and school administrators, religious leaders, local government officials, parents of teenagers, and community leaders. In addition, we facilitated ten focus groups with a total of over 60 teenagers and young adults, and collected survey data from 160 shortterm visitors (i.e., tourists who remain in the area for less than two weeks). Finally, we conducted extensive participant observation in many of the settings where tourists an locals congregate. Data collected from bars, discos, restaurants, and internet cafes were especially useful for the assessment of behaviors (e.g., drinking, use of other drugs, and "hooking-up" with potential sex partners) that may contribute to the spread of STIs including HIV/AIDS.

One of the main findings of the research project was the overall concern about the impact that tourism is having on sexual and drug-using behaviors among residents of the Monteverde area, both youth and adults. According to the participants, these changes include increased use of alcohol, marijuana, cocaine, and heroin, and involvement in sex with casual partners, group sex, and same-sex relations. As reported, many of these sexual relations may be unprotected, given the limited availability of condoms. Most of the study participants reported concerns about the lack of HIV/AIDS awareness materials in their communities, and stressed the need to raise awareness about the disease among local residents.

Following this recommendation, we conducted a pilot intervention project that involved 40 women from four rural towns in the creation of HIV/AIDS awareness materials. The project's format had been developed and tested by a group of four students<sup>1</sup> who participated in the 2004 Globalization and Health Field School run by the University of South Florida in association with the Monteverde Institute, the University of Illinois at Chicago, and Mount Holyoke College. The intervention project was based on the principles of Participatory Action Research and consisted of a series of three to five workshops in each town. During the first workshop session, the researchers assessed basic knowledge about HIV through individual surveys as well as through group activities,

# **Design of HIV Awareness Materials in Rural Costa Rica**

and provided HIV education as needed. The second session involved the participants in individual and group assessment of existing HIV/AIDS materials such as posters, pamphlets, etc. During the final sessions, the women in each town developed their own awareness materials. We sought the assistance of local artists for the reproduction of the original designs and for the "mass production" of materials to be distributed throughout the participating communities. In the first town the participating women created a 12-page wall calendar with culturally appropriate images and messages intended for the entire family. The participants in the second town created several key chains with HIV/AIDS awareness messages for both men and women. In the third town, the women created notebooks/ address books intended specifically for young women and teenage girls. Finally, in the fourth town the participants created posters that targeted the growing number of foreign tourists that visit Monteverde. The official closing of the project was marked with a day-long community celebration in which all of the participating women, the local artists, and special guests from the governmental and health sectors came together for the presentation of final materials. Romero-Daza and her colleagues are currently working on an NIH application to expand this project to other demographic groups (e.g., men, youth) and to different areas of Costa Rica.

<sup>1</sup> Special thanks to Renee Cudzow, Leslie Gross, Katherine Klein and Oriana Ramirez-Rubio.





Development of initial designs



Working with local artists



Wooden key chains

Note books made with banana paper



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# **Design of HIV Awareness Materials in Rural Costa Rica**



Calendar Pages

donde hay flesta, comida, matrimonio y mucha diversión. Pero también hay mucho rlesgo de contraer alguna enfermedad.

Tenga culdado, protéjase, Use condón!!!!!



M Pack your 0 rubbers... N Т E

> V E

> R

D E



Posters for tourists



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End of project celebration

# The Shooting Gallery: Opportunities and Implications for the Introduction of an Ethnographic HIV Prevention Intervention

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Key Words: Ethnography, HIV prevention, Shooting Gallery, Injection Drug Use, HIV prevention intervention

This report presents preliminary findings from an ethnographic pilot investigation examining the characteristics of a Baltimore city shooting gallery and its suitability as a venue for the dissemination of innovative harm reduction strategies. The rationale for this project is two fold 1) many injection drug users (IDUs) in Baltimore city are or have been exposed to the needle exchange program (NEP) and therefore are in possession of there own syringes. However, because of their impoverished circumstances, these IDUs have to share the cost of the drugs and then have to split the drugs once they make their purchase. These drug splitting episodes are high risk opportunities for transmitting HIV and other blood borne infections: and 2) risk reduction messages and targeted interventions do reach a number of IDUs. However, many of these individuals are relegated to living their lives outside the societal margins and conventional outreach methods, such as street outreach and recruitment to services, may not beextended to them.

Shooting galleries are primary venues where IDUs congregate to inject drugs. Many of the IDUs who use shooting galleries are represented among those individuals who do not show up at community-based programs and other organizations for services or are not accessible by street outreach methods. Therefore, implementing prevention strategies in this setting can prove to be important for mitigating disease transmission through intravenous drug use.

As such, we gained access to a Baltimore city shooting gallery. A relationship was developed between the ethnographer (first author of this document) and the gallery operator also known as "G" (a pseudonym used for purpose of this writing). Progressive strategies for splitting drugs were introduced to the "proprietor" who then shared the innovation with his gallery patrons and made them available for use at the gallery. The three drug splitting innovations include:

- The "Neutral Needle" is a separate syringe which is marked and used only for splitting the drug solution (figure 1);
- The "Even-Steven Splitter" is laminated squares of graph paper; used for dry splitting (figure 2); and
- The "New Jack" is a plastic syringe type apparatus (infant medicine dispenser/irrigation syringe) which has no needle and cannot be used for injecting (figure 3).



Figure 1

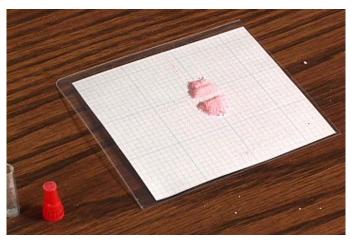


Figure 2



Figure 3

The innovations provide methods for reducing risk of disease transmission during drug splitting

episodes. The New Jack seemed to gain the most approval and popularity among the patrons of this shooting gallery. As a matter of fact, one of the tools obtained its name "New Jack" from the gallery operator. Among the three innovations, the New Jack will be the focus of this discussion because of its level of acceptance among the shooting gallery patrons. The ethnographic research methods used in this investigation provide a framework for not only systematically gaining access to a traditionally marginalized population but also exploring the feasibility of implementing prevention strategies within an indigenous setting. The data collection methods used in this study include: 1) interviews with the shooting gallery operator and patrons of the shooting gallery; 2) informal focus groups with shooting gallery patrons and 3) ethnographic observations in the shooting gallery and the neighborhood.

Initial findings indicate mixed reactions to the introduction of the drug splitting innovation, the New Jack. Favorable responses center on feeling a sense of accomplishment for adopting risk reductions skills. Primary objections concern the time it takes to prepare the drugs for injection. The following discussion introduces the gallery operator, the shooting gallery, and provides excerpts from field notes recorded from preliminary observations in the shooting gallery.

#### G – The Gallery Operator

The shooting gallery operator, G, is a 64 year old African American male, injection drug user. His primary drug of choice is heroin, however, he reports that he occasionally injects cocaine, speedballs and may smoke crack and marijuana when available. He states that he has been in the "drug game" for more than forty years. During his drug using career G has traveled and had many experiences which enhance his wellseasoned demeanor and ability to operate a shooting gallery for the last 12 consecutive years. G lives in and operates the shooting gallery. As the operator of the shooting gallery, he provides several services and resources, such as administering injections, purchasing drugs and selling syringes. The following passage is from a field note and is intended to provide a sense of G in operation within the active shooting gallery:

I noticed right off that G, with no prompting or instructions began to take charge of the situation. Three pills were brought out and placed on the table. G began to retrieve the necessary equipment and materials to prepare the drug solution. He began grabbing items from different places around the facility. It was really hectic keeping up with all that was going on. There were individuals going back and forth to the bathroom; the traffic flowing to and from the kitchen area also increased. In the meantime I decided I would attempt to keep my attention focused on G.

#### The Shooting Gallery

While G is unquestionably in charge of the gallery and the gallery operations, the gallery itself presents it own set of characteristics that are important to understanding the setting.

The gallery has been in existence for approximately 12 years. It is a 24-hour operation. Located on a major thoroughfare in the city, the unit is situated within a large, well know public housing complex in the city. It is also open to

individuals who smoke crack. In this regard, the shooting gallery environment is somewhat flexible and various types of individuals may show up in the gallery for different reasons. There are those individuals who come to the gallery to purchase syringes at two dollars per syringe. Others come and pay, either drugs or money, for a covert location in which to ingest their drugs. The operator, in many instances, determines the general atmosphere of the shooting gallery.

As stated, cash or drugs are paid to use the gallery to consume the drugs on site and for certain ancillary services. The ancillary services offered in the gallery include "copping" or buy drugs for gallery patrons, "hitting" or performing the functions of a "street doctor" or someone who is proficient at injecting individuals who cannot inject themselves and renting or selling syringes and supplying "works" or other injection equipment (e.g. cotton, cooker, etc).

#### Introducing the New Jack

Introduction of the New Jack to this setting created some mixed reactions. While some of the shooting gallery patrons saw it as a good thing, others were not so welcoming of adding another piece of equipment to the injection episode. The mixed reactions on several occasions changed the usual flow of the gallery's atmosphere. The following is a field note excerpt:

Several interesting issues came up during this event. First, was that using the New Jack has limitations and advantages. Having individuals present who were pro-New Jack and individuals who were anti-New Jack was an advantage. However, I gathered from a conversation with G that it was not a good thing for him. As a matter of fact I suggested to G that we set up a conversation with those individuals and get their feedback about the why and why not for using the drug splitting tool - the New Jack.

The idea in the previous excerpt is that the introduction of a new apparatus in a already established setting had its challenges. The gallery operator had expressed on a couple of occasions that people had totally disapproved of the New Jack. While the gallery patrons continually expressed concerns about injection related illnesses, G mentioned two basic oppositions to the strategy 1) the additional amount of time it took to split the drugs with the New Jack; and 2) there was some distrust from patrons about getting their fair share of the split. Over time the drug splitting tool proved to have limited acceptance among the gallery patrons.

#### Acceptance of the New Splitting Method

The use of the New Jack in this shooting gallery was met with mixed reactions from the gallery patrons. However, having elicited cooperation and approval from G, the gallery operator, made entrée and the introduction of the New Jack less disruptive to the gallery milieu than otherwise might have been. An example of this observation is expressed in the (Continued on page 28)

# **Ethnographic HIV Prevention**

(Continued from page 27)

following field note excerpt: I was curious about the various experiences that he might have encountered. He mentioned that he had been touting the "New Jack" method. The use of the normject (New Jack), G stated, was fairly well accepted. He mentioned that the major opposition to using it was the amount of time it took to get the shot. He stated however, that he would be open to eventually go with it 100% in his shooting gallery. I found his motivation toward implementing the strategy to be rather refreshing. If he was bullshitting me then at least for the moment it was worth the effort.

Significance of the influence of the gallery operator in this situation merits further exploration. G had expressed that most of the regulars to the gallery or individuals with whom he had established rapport were more likely to be accepting of the New Jack. He stated that he experienced most of the opposition and distrust from individuals who may have come in with his regular customers.

#### Conclusions

This exploratory ethnographic investigation has far reaching implications and public health significance. Attempts at implementing risk reduction and prevention intervention strategies directly in these high risk situations can provide opportunities to reach members of the injection drug using community that may otherwise not get the messages. The shooting gallery has the potential to function as a setting for implementing innovative strategies for disease prevention/health promotion and reaching injection drug users with important HIV prevention materials. Also, the shooting gallery operators may serve as an important individual for the diffusion of HIV prevention materials as well as a catalyst for change.

This brief reports provides an overview and some preliminary finding of ongoing work. Further research is needed to better understand more comprehensively investigate the implication of such endeavors and the diffusion of the innovations discussed here.

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# Understanding "Circumcision-as-HIV Prevention" in Terms of Power Relations

#### Chris Alley, NDRI

Diverse global anti-circumcision constituencies are gaining momentum in their opposition to dominant medical procircumcision narratives. The authors of those dominant procircumcision narratives have historically responded to challenges to their authoritativeness by re-asserting circumcision's medicinal legitimacy according to changing epidemiologic exigencies of the day. The most recent expression of this dynamic is a mounting resistance to circumcision in the face of claims that the surgery will protect against HIV infection in African populations. Broadly, this paper asks the questions: is biomedicine making increasingly extravagant claims about the benefits of male circumcision, and how do growing concerns about iatrogenic harm from the surgery throw into relief this pattern of widening medical claims?

HIV prophylaxis may merely be the latest, most epidemiologically exigent propulsion for medical circumcision advocates who have historically re-invented rationales for the surgery in order to perpetuate certain power-arrangements: namely, medical authority over male sexuality. But the goal of this paper is not to directly challenge this or any of the surgery's other variously claimed prophylactic or therapeutic efficacies. Nor is it to evaluate the validity per se of scientific literature that has effectively codified the medicinal legitimacy of male circumcision in parts of the West at various times; much work has already been done in this area, and it suffices to say that conclusions vary widely enough to perpetuate this surgery-asprophylaxis.

Rather, what is recognized here is a specific historical pattern in that scientific literature that always seeks new justifications for circumcision (be they preponderantly evidence based or not) once other existing rationales for the operation have been recanted or deemed insufficient to continue justifying a policy of universal circumcision. Note that medical authorities have claimed to be able to prevent numerous diseases by male circumcision. An incomplete list of the diseases targeted for prophylaxis over the years includes masturbation (as moral disease), penile cancer, prostate cancer, cervical cancer, sexually transmitted diseases, urinary tract infections, and now HIV infection. (Several other maladies that do not have infectious etiologies [e.g., phimosis or paraphimosis] have also been seen as indicating circumcision, but these have perhaps been less persuasive reasons for universalizing the surgery.)

The following is thus a contextualization of this pattern of unrelenting circumcision justifications. By placing it within terms of power relations by recognizing the emergence of a multiplicity of oppositional socio-cultural movements, and by noting the exclusion from these movements of most African populations, many for whom medicalized circumcision is now being urged in some quarters, the following question becomes very interesting: What are the cultural processes at work amid this dynamic of an apparent redoubling of medical circumcision rationales on the one hand, and a growing resistance to the institutionalized imposition of preputial amputation on the other hand?

Observe that the recent resurgence of pro-circumcision rationality follows after an ostensible retreat from a policy of routinizing the surgery at the institutional level, as seen for example by 1) the policy reformulations of various North American medical associations since the 1970s, 2) the end of many insurance reimbursements for physicians who perform the procedure (including Medicaid), 3) recent Swedish and Dutch legislation curtailing the frequency of the surgery, and 4) perhaps of most direct significance, the steady drop in reported circumcision rates in North America since the 1970s.

Consider also the non-establishment anti-circumcision movement that has emerged at about the same time. What does it mean that all manner of constituencies from the local to the global, resolved to the apoplectic, and circumcised to the foreskin-intact are attracting an increasingly larger following with their assertions about the intrinsic harm of male genital cutting? Dozens of anti-circumcision organizations now exist. Practically all have an internet presence, or have coalesced in the information-age1; it is arguable their discourse of resistance has gained momentum only among those with internet access.

What does it mean, then, that medical circumcision is forging ahead nonetheless, but this time in Africa? It is suggested here that one of the widespread social results of anticircumcision discourse is a growing reluctance to accept "prophylactic" circumcision in the West and that this reluctance is leading the surgery's advocates to establish its newest pretext (i.e., HIV prophylaxis) in populations that are not as well informed about the medical history or collateral harm of the operation...specifically in Africa.

This pro-anti circumcision dynamic can be understood by referring to one of Foucault's clearest propositions about the nature of power. He says, "Where there is power, there is resistance..." And just as he says that power is exercised from innumerable points, so does he say that "...[resistances] too are distributed in irregular fashion: the points, knots, or focuses of resistance are spread over time and space at varying densities, at times mobilizing groups or individuals in a definitive way..." He goes on to say, "it is doubtless the strategic codification of these points of resistance that makes a revolution possible..."

As previously suggested, the strategic codification of resistance to circumcision, hastened by the internet, has allowed opponents of the practice, who may have previously been marginalized and isolated by fear of transgressing a taboo subject, to recognize and support each other, surmounting geographic boundaries at the same time they challenge cultural norms. Consequently their voices are coalescing into a movement increasingly able to effectively assail the practice of medicalized circumcision at the institutional level, at least in their own countries.

While it may be important to identify who circumcision opponents and advocates are, it is also useful to understand how and why their constituent groups change over time. In the case of opponents to the surgery, the world-wide-web has already been cited as a major influence. But what about proponents of medical circumcision? How and why do they keep changing? Changing their rationales, changing their populations for targeted intervention... Foucault, in giving his methodological prescriptions for understanding power in sexuality, says "We must not look for who has the power...We must seek rather the pattern of modifications which the relationships of force imply by the very nature of their process...Relations of power-knowledge are not static forms of distribution, they are 'matrices of transformation.'"

The issue of HIV prophylaxis in Africa via circumcision can be considered one such "matrix of transformation." It is interesting to note that biomedicine has begun to export its own waning policy of universal male circumcision to African populations at the very time when genital cutting practices are under greater lay-person and scientific scrutiny than ever before. Whereas those Western populations that have previously practiced male circumcision - or that appear to be in the process of turning away from it - are directly influenced by internet-facilitated discourse critical of circumcision, the same cannot be said for most African populations that are excluded from such potentially empowering sources of information. These African populations also now bear witness to the dreadful decimation wrought by the HIV epidemic, are withheld sufficient supplies of effective drug therapies by capable Western governments, and therefore may be more receptive to even the most intrusive, unproven, or even harmful prevetion strategies.

Perhaps the move to export circumcision to previously uncircumcising African populations is occurring now in part because more of those "innumerable points" in the West - the kind of which Foucault says power derives, but is always shifting - are coming to realize that those enthusiastic authors of the dominant pro-circumcision narrative are in fact part of an increasingly extravagant tendency in medicine to justify circumcision for a seemingly inexhaustible list of maladies. In the face of this mounting resistance, in the easy exploitation of power differentials and a climate of fear, and in the placation of that curious cultural compulsion to carry on the cutting of genitals, the redistribution of the practice of medical circumcision from the West to Africa is a "matrix of transformation" that deserves much closer attention.

Note: 1. A search of the internet for the word "circumcision" brings ups dozens of websites opposed to male circumcision. Websites expressing support for circumcision are comparatively rare.

#### Reference:

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#### AIDS and Anthropology Research Group 2005 Membership Form

AARG continues to work hard to enhance its position as an active site for networking and organizing among scholars like you. This includes developing new and expanded opportunities for you to network with colleagues who share your commitment to the use of anthropology in understanding, preventing, and reducing the harm caused by HIV/AIDS.

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<u>Remember, even if you are a non-paying member, we must hear from you once a year to know that you are still active (a note through email for our international members is fine!). If you would still like to continue your membership with AARG, please remember to renew and support AARG by paying your annual dues.</u>

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