AIDS & Anthropology Bulletin

The Newsletter of the AIDS and Anthropology Research Group

July 2004
Volume 16, Issue 2

AIDS and Anthropology Research Group

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Letter from the Chair – Doug Goldsmith

During the past 20 years anthropologists have witnessed the burgeoning of the AIDS pandemic. We have sought to understand the modes of HIV transmission, and to develop strategies for risk reduction. Our chief tool has been careful observation, and we have relied on first-person explanation to provide meaning and social salience to behaviors. We have learned of grass roots and public health attempts to save lives, learned of Harm Reduction and Harm Minimization, of Love Carefully, of Bleachman, and of Needle Exchange. Many anthropologists have become observers of risk reduction strategies. We have witnessed the distribution of condoms, dental dams, and lubricants in venues such as bathhouses and strolls for use during sexual intercourse. We have witnessed the distribution of needles, cookers, and bleach in venues such as shooting galleries and get-off places for use during drug injection. With continued observation as our method, and collected narratives for interpretation, these measures have been our science based public health approach.

The AARG list serve has been the venue for of a remarkably vibrant discussion over the past year. Much of the discussion centered on the value of a formalized AIDS prevention effort that relies on ABC, but also exchanging views on a wide range of prevention possibilities, from the salience of circumcision, to the availability of microbicides.

As posted on the list serve, ABC is best described by David Satcher speaking on June 28th of the 2001 report he released as the 16th U.S. Surgeon General as “a) abstinence education; b) a focus on a need to be faithful to one partner; and c) failing these two , the use of condoms when appropriate. This has been called the ABC approach.” Dr. Satcher goes on to say “in order for the ABC approach to succeed, we must deal with values and attitudes. So we recommend ABC plus HOPE. Environments of poverty, abuse and discrimination rob persons of hope for the future and of the motivation for responsible sexual behavior.” (from, the 6/28/04 release of the International Working Group on Sexuality & Social Policy).

A July 1st posting to the list serve presented a June 29th comment by Janet Fleischman (from the Washington Post) who wrote that “The need to go beyond ABC grows out of the stark statistics … linked to social and economic factors that severely undermine women’s control over their sexual lives.” And urges that to the ABC approach be added DEF, with D encouraging disclosure of HIV status without the risk of violence, E promo- ting education for HIV knowledge and for improved economic opportunity, and F promoting female controlled prevention methods such as the female condom and microbicides. (from, Beyond “ABC”: Helping Women Fight AIDS, Janet Fleischman, The Washington Post, 6/29/04).

A posting during the recent International AIDS conference quotes Thoraya Obaid, the Executive Director of the United Nations Population Fund as explaining that “The ABC approach – Abstain, Be faithful, use Condoms – is not a sufficient means of prevention for women and adolescent girls” because “Abstinence is meaningless to women who are coerced into sex. Faithfulness offers little protection to those whose husbands have several partners or were infected before marriage. And condoms require

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From the Chair and the Editor

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the cooperation of men." (from, Women and HIV/AIDS: Confronting the Crisis, report of UNAIDS (Joint United Nations Programme on HIV/AIDS), UNIFEM (United Nations Development Fund for Women) and UNFPA (United Nations Population Fund), 7/14/04)

Why then, given these grounded observations of operational limitations, has the ABC approach been spoken of as a science based public health initiative. An answer may be evident from an earlier list serve posting from 5/13/04, which presents a viewpoint on the origins of the ABC campaign in Uganda. In this posting, Kavita Ramdas, the President of the Global Fund for Women, speaks about her work with 46 different women's organizations in Uganda, when she was interviewed on the PBS Show "NOW with Bill Moyers" by host Brancaccio for a broadcast "The real meaning of the "A" in the Ugandan "ABC" model", on 4/23/04. Kavita Ramdas says that "The ABC campaign in Uganda was used as a collective mobilizing tool … Entire groups of women in villages would get together and talk to their husbands and say "None of us are going to be having sex with you … We will have sex with you if you use a condom and stop fooling around." ... And this was combined with a sex education program that was remarkable." (from [gender-aids] What the A in ABC really means, 5/13/04)

So the equation for effective AIDS prevention, for effective HIV risk reduction, ought not exclude individuals or groups, or ignore their circumstances. The equation for an ABC approach might be augmented as "ABC + HOPE", or "ABC + DEF". Or it might be rendered "A if not B or C." But the full equation must include the additional prevention approaches that have been shown through grounded observation to have merit.

ABC+HOPE, ABC+DEF
A if not B or C...

Letter from the Editor

At the SfAA Meeting in Dallas, there were more than 100 anthropologists presenting their work on HIV/AIDS. Several of the presenters have written short articles from their presentations for this newsletter, thus providing us with an interesting sample of the range of foci among AIDS researchers right now.

Doug Henry summarizes the packed session he chaired at the meeting about Anthropology and AIDS in Africa. The following seven pieces are from individual papers given at various sessions. James Pfeiffer discusses the collision between social marketing messages and local perceptions of right and wrong in Mozambique. Jennifer Levy and Katerini Storeng raise another contentious issue; whether or not to breast feed if you are HIV positive and live under very poor material conditions, in this case, in South Africa. Back in the USA Betsey Brada looks at the history of pregnant women and the role of the fetus in research, in light of the emergence of AIDS clinical trials. There are two articles from college campus studies: Barbara Bonnekessen and Diane Beal discuss their survey on condom use, and Patricia Whelehan's shows how anthropological concepts are applied in a HIV intervention program. Jennifer Ward and Kathleen Ragsdale discuss the ways is which a community organization try to influence positive sexual health practices among Latina women. Jodi Nettleton focus on the unique situation and risk among women in prison. Finally, Li Dongli gives us a taste of her work among female drug users in the Gansun Province in Western China.

I would like to thank everybody who took the effort of editing their SfAA presentations to share them with us. I also would like to thank my colleagues at the Hispanic Health Council Newsletter Collective for contributing both with obtaining material and helping with the editing; Michael Duke, Susan Shaw, Erica Hastings, John Humphries, Rosemary Diaz, Rebecca Floor and Wildaliz Bermúdez.

If you didn't submit anything for this issue please send us something before the end of August, and you can be part of the fall issue!

Have a nice summer!
Anna Marie Nicolaysen
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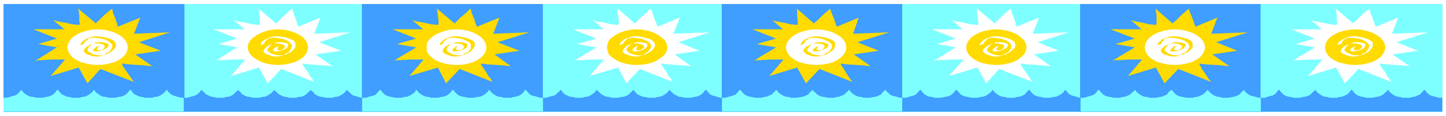

Advocacy on the Front Lines: Anthropology and AIDS in Africa.

Doug Henry, Ph.D., University of North Texas

The expertise of our panel ranged across Africa from a behavioral micro-level, to the macro-level of global and social policy, from HIV prevention to treatment of AIDS. These included Susan Hunter, anthropologist consultant, Doug Feldman, from SUNY Brockport, and Doug Henry, from the University of North Texas. Ted Green from the Harvard Center for Population and Development Studies had to withdraw his paper on Evidence Based AIDS Prevention, due to a sudden scheduling conflict. This was a real loss, as he had formed half of the panel's concentration on contemporary approaches to prevention. Marcia Sutherland from SUNY Albany also had to drop out at the last minute, with her paper on responses from the NGO world and from African Diaspora communities to AIDS in Africa. Marcia had formed half of the panel concentration on contemporary work being done towards improving access to treatment.

Between 70%-80% of the world's 40 million people currently living with HIV/AIDS live in Africa, making Africa the center of the global pandemic. Anthropologists have long been in Africa as advocates on the front lines, critiquing donor categories of vulnerability and risk, culture and blame. Sometimes more subversively; anthropologists point out how interplays of power and politics, wealth and global inequality, racism and control, have shaped the local patterns and impacts of the epidemic. This session highlighted some of the contemporary work now being done by anthropologist-advocates, in assessing local agency, evaluating donor responses, and in moving beyond current debates, pointing the way to the future about what anthropologists could and should be doing in the years to come as advocates for the prevention and treatment of AIDS in Africa.

Susan Hunter began the session by sharing some insights from her new book, *Black Death: AIDS in Africa.* HIV/AIDS represents the worse epidemic humankind has ever known. Because anthropologists are uniquely situated between the biological and social sciences, they have been instrumental in reconceptualizing the meaning of disease in human social interaction. With HIV, however, Hunter expressed that we perhaps have forgotten our roots, becoming locked into detailed issues of prevention, while not looking at the wider implications of the disaster for the survival, structure, and interrelationships of human societies and future human interactions. Her paper highlighted some of the extraordinary demographic dimensions of the epidemic, and the impact this has had (and is further poised to have) on the interrelationship between evolution and disease.

Doug Feldman, with his paper, *Creating a Viable AIDS Program for Africa: Condoms, Condoms, and More Condoms,* addressed contemporary anthropological work with prevention. He spoke in particular about his concerns with the "Uganda model," now being championed as a model of effectiveness by some. Feldman's view is that this approach is fundamentally flawed in its interpretation of what actually occurred in Uganda since the mid 1980s that reduced the seroprevalence rate there. With only 4.6 condoms used per male per year in Africa, it is clear that much more progress needs to be made. While he lauded many aspects of the Uganda model's goals, Feldman maintained that condom promotion, access, and availability should remain central parts of any balanced prevention campaign, alongside efforts towards destigmatization, working with traditional healers, developing AIDS programs in schools and workplaces, and improving the basic health infrastructure.

Doug Henry, in *Patterns of Informal Care Given to People Living With AIDS in Sierra Leone,* focused more on issues related to treatment and care, in particular the lack of access to treatment in the form of anti-retroviral drugs, and, in their absence, the kinds of treatment given by oneself and one's family-level caregivers. In post-conflict Sierra Leone, where poverty and protracted civil conflict have limited the availability or affordability of care; aspirin, chloroquine, and irregular antibiotics currently form the core of individual-level AIDS treatment strategies. For most sicknesses, family members would normally represent the primary resource for easing the suffering of a sick relative; for those with AIDS, however, faced with tremendous societal stigma and no real treatment, this is often not an option, and families become torn apart. For the burgeoning population of commercial sex workers that have followed the prevalence of United Nations peacekeepers around the country, the situation is particularly dire. Henry concluded by lamenting the fact that, at an international level, prevention money seems to be prioritized based mostly on national prevalence rates. As anthropologists, we need to come up with better, more contextual, and more accurate indicators of social suffering (like the ability or inability of families to support and care for people), to get a sense of the burden of AIDS on people living in the poorest of the poor countries.

The discussion that followed was lively, and at times passionate, given the immediacy of our experiences in Africa during our work. Some of the questions and debates raised by both panelists and audience, especially those having to do with prevention and treatment policy, were in the best tradition of rigorous yet collegial scholarly exchange. They got right at the heart of questions about the role of an applied anthropologist as an advocate, such as how does our advocacy inform research and application, and how should we be shaping public policy.

Questions or comments can be addressed to Doug Henry, a medical anthropologist at the University of North Texas. dhenry@scs.unt.edu

Condom Social Marketing, Pentecostalism, and Structural Adjustment in Mozambique: A Clash of AIDS Prevention Messages

James Pfeiffer, PhD, MPH
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Over the last 20 years "social marketing" has emerged as the dominant approach to health promotion and communication in the developing world, in many instances replacing community outreach, empowerment, and participation programs. The social marketing (SM) concept, which centers on the use of commercial advertising techniques and private sector distribution of health products to promote "individual behavior change", has been institutionalized in many public health schools that now routinely train students in the "four P's" of SM: product, price, place, and promotion. Condom social marketing (CSM) has become the centerpiece of AIDS education and prevention in many sub-Saharan African nations. However, this successful global diffusion of social marketing techniques has not been driven by a thoroughly demonstrated efficacy in improving health by motivating behavior change. Rather, the widespread embrace of social marketing by many international non-governmental organizations (NGOs) and Ministries of Health, especially in Africa, can be traced more directly to the promotion of privatization and free market economics in the era of structural adjustment across the region. The key tenets of social marketing provide a tight ideological fit with the broader economic adjustment reform packages promoted by the World Bank and IMF in Africa. Major bilateral and multilateral donors, including USAID and the World Bank, have increasingly channeled much of their public health funding into social marketing campaigns, usually managed by international NGOs such as Population Services International (PSI). Their rationale parallels the logic used to justify health care privatization more broadly within the politics of imposed austerity. Wallack perhaps provides the clearest critique of SM, distinguishing the "information gap" that social marketing seeks to fill, from the "power gap" that underlies most health behavior issues. He also writes, "Traditional public health communication strategies [i.e. SM] tend to see individuals and groups as part of an audience to be addressed in a one-way communication. At best, if the 'audience' is included in the planning, it is after major boundaries of the issue have been set".

The gradual but hastening roll back in public sector primary health care services, led by structural adjustment programs (SAPs) that have generally reduced spending for government services and privatized local economies in Africa, has coincided with the deepening AIDS crisis and placed local Ministries of Health in apparently insurmountable dilemmas. Social marketing, and its Western NGO and donor proponents, arrived with a prepackaged approach to AIDS prevention that emphasized "cost-effectiveness". However, this paper briefly describes an eight-year-old national condom social marketing (CSM) project in Mozambique promoting a brand called "*Jeito*" that appears to have produced a troubling backlash in some communities; a reaction that underscores the shortcomings of SM approaches to complex community health problems such as AIDS prevention. Over 20% of the adult population in several regions of Mozambique is HIV-positive, so the need to frankly assess interventions such as the Jeito campaign has taken on added urgency.

This article is not a formal evaluation of the program but derives from nearly four years of fieldwork with a United States-based public health NGO in central Mozambique that included the periods 1993-95, 1998, five weeks in 2000, three months in 2002, and five weeks in 2003. In 2002, a representative survey of 616 individuals, which focused on participation in Pentecostal churches and included questions on the Jeito campaign, was conducted in three contiguous peri-urban *bairros* (neighborhoods) in the city of Chimoio in Manica Province in central Mozambique.

Over the last decade Mozambique has been slowly rebuilding from war, however growing national GDP figures conceal the deepening inequality that has left most Mozambicans mired in poverty. In the community described here, the CSM campaign implemented by PSI encountered a society where deepening social inequality and economic insecurity produced by a SAP in the 1990s is believed by many to have heightened the reliance on sex work for survival among the poor. This ensuing "moral panic" in Chimoio has destabilized relationships, families, and households, and provided church movements with a thematic focus for their proselytizing and healing discourses. During this period, Pentecostal and AICs church membership jumped from an estimated 10 percent of poor peri-urban populations to over 50 percent. Into this volatile social and economic climate lands the "Jeito" condom social marketing campaign in 1994, dispersing its packaged set of controversial images, moral assumptions, innuendo, and suggestive slogans. The churches' message concerning AIDS prevention, delivered to nearly 50% of the population in some cities, clashes directly with the Jeito campaign.

With encouragement from USAID, in 1994 the Ministry of Health's National AIDS Control Program (NACP) embraced the concept of condom social marketing promoted by PSI. Through focus-group testing, the term "Jeito", which means "talent", "flair", or "style" in locally spoken Portuguese, was selected to become the condom brand name. Billboards, radio messages, TV spots, community theater, and vendors on bicycles market the condoms in local communities, while Jeito are also sold in bars, nightspots, restaurants, hotels, and shops throughout the country. PSI's own research claims project success based on product sales and self-reported behavior change. However, other surveys in the region suggest continued low utilization of condoms, and no independent evaluation of the campaign has been conducted. And, in the three-bairro survey of 616 people conducted in 2002, 86 percent of Pentecostal and AIC members responded that Jeito brand condoms had been specifically forbidden in their respective churches. Among the eighteen church pastors interviewed in 1998 and the twenty in 2000, each used harsh terms in referring to the Jeito campaign and blamed it for the increasing sex work and promiscuity in the city. This comment provided here is representative of the attitudes expressed by all the pastors interviewed.

> With Jeito, we are teaching people to live a bad life [*ma vida*, immoral life], we're teaching this country to use Jeito and live a bad life… Because of this we have a country of prostitution because we are promoting the use of Jeito to do prostitution… Because of this we prohibit it in our church. We don't need it. Because of this we speak very little of AIDS.
>
> Pastor, African Assembly of God

The negative perceptions of the Jeito campaign extended beyond church memberships as well. Perhaps most alarmingly, many informants described a widely circulated rumor that Jeito brand condoms actually brought the HIV virus to the province and that Jeito could therefore give the user AIDS. A male respondent stated, "Yes, youth say its true [Jeito causes AIDS]. Some say that using Jeito prevents AIDS while others say that it [Jeito] has AIDS inside [*la dentro*]". Medical anthropologists have long recognized that such persistent and widespread rumors can indicate deeper community misgivings and lack of trust around health campaigns. Among other revealing comments, one respondent stated, "Yes, they [youth] buy them but only to show-off [*exhibir*] and not to use them." In one group of local youth leaders, one participant stated, "The tendency to change [behavior] exists, but above all girls want money to support themselves, so they forget this sickness AIDS."

Genuine community dialogue would have shown that the moral panic concerning fidelity and intrahousehold distrust was widespread within an environment where resort to sex work is increasing amidst deepening economic disparity. Addressing these community concerns, for better or worse, became the central mission of most Pentecostal and AICs that discovered a traumatized population apparently eager to embrace their message. The Jeito campaign avoided local community involvement and dispersed a set of messages that may have created greater barriers to condom promotion while deepening mistrust between the aid world and the communities it purports to serve.

To recognize this clash of messages is not to argue that the church approach should be embraced by the public health community, as the ABC approach has been, or that AIDS funding should necessarily be redirected toward churches. Rather these movements represent a profound social transformation in poor communities that health promotion efforts must acknow-ledge, understand, and engage. The failure of the Jeito CSM campaign and others in public health to recognize the significance of these movements and this clash of messages reveals the striking dissociation that is produced between the international aid world and poor populations when community participation and dialogue are disregarded. The Mozambique experience suggests that a primary goal of new approaches should be the creation of frameworks for long-term dialogue between health workers and communities to establish trust and channels of communication, rather than focusing on the top down imposition of a packaged message, whether it is sex-positive or ABC oriented. The recent initiation of ARV treatment programs in Africa provides an opportunity for new participatory approaches to AIDS prevention that build upon the powerful positive influence of successful treatment. More careful and critical scrutiny of CSM may steer international aid resources back toward participatory approaches that will both reveal and hopefully begin to address the most important determinants of vulnerability to AIDS: poverty, inequality, lack of public sector safety nets, and declining access to well-funded public sector health services.

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Contingent Choice: HIV and Infant Feeding

By Jennifer Levy and Katerini Storeng

Policies about infant feeding in the context of HIV are constructed at the interface of various scientific, political, and activist discourses. These policies are formulated on the basis of insufficient scientific knowledge and are explicitly predicated on the concept of informed choice. Ethnographic fieldwork with HIV positive mothers in Cape Town, South Africa, however, reveals that operationalising the notion of informed choice is problematic, not only for health planners, but ultimately for HIV positive mothers who must make real life choices about infant feeding.[1]

It is estimated that in the absence of medical intervention, 15 percent of HIV positive women will transmit the virus to their child through breastfeeding (the combined risk of intrauterine, intrapartum, and postpartum transmission is 35 percent). The specificity of risk estimates vary from study to study, because the risk of transmission is determined by factors such as maternal viral load, duration and pattern of breastfeeding, the presence of infant oral thrush, and breast problems including mastitis, fissures, and abscesses. It is not only the relative risks of breast milk transmission that is complicated. Women also have to carry out a calculus between the risk of HIV transmission through breastfeeding and the increased risk of infant morbidity and mortality from diarrhea

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and malnutrition when breast milk is withheld.

Since 1985, when the US Centers for Disease Control and Prevention made the first reports that HIV can be transmitted through breast milk, international policy on infant feeding and HIV has vacillated. Until 1996, WHO, UNICEF and UNAIDS advised all women in developing countries to breastfeed, even if HIV positive. In contrast, women in resource-rich settings were advised to use replacement feeds. In 1997, revised recommendations were put forth by the UN and remain in effect today; these reflect a human rights' perspective on reproduction irrespective of HIV status and call for informed choice on infant feeding. The guideline states, "when replacement feeding is acceptable, feasible, affordable, sustainable, and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life and then should be discontinued as soon as it is feasible".

In South Africa, changing international health policy and evolving scientific data is played out in the local policy arena. Infant feeding has been described as *the* major policy issue for the South African government in relation to the prevention of mother-to-child transmission (PMTCT) program, but there is little consensus on how this issue should be addressed. This is partly because arguments about infant feeding reflect adherence to different health system philosophies and advocacy agendas. The government of South Africa's Western Cape Province mediates between a commitment to health system development and the requirements of activists. They attempt to situate feeding debates within larger discussions about health sector reform by promoting a policy of informed choice, while acknowledging the structural constraints that shape these choices, and also by making formula freely available to HIV positive mothers for the first six months of their babies' lives. However, the policy on infant feeding is not straightforward and often changes to reflect current national and international pressures as well as shifts in the accumulating "evidence" on good practice regarding feeding.

One Department of Health official describes how the provincial policy on infant feeding and HIV has changed since the implementation of the PMTCT program in the Cape Town township of Khayelitsha in 1999, and the challenges that rapidly changing policy creates in the delivery of maternal health services. At the program's inception, women did not have a choice about feeding options: "When we started in Khayelitsha all these baby friendly initiative people were very unhappy with us. We were saying 'yes, breast is best, but if you are HIV positive and you are going to go onto the antiretroviral programme, you are going to have to formula feed'."

With increasing scientific knowledge of the mechanisms of HIV transmission through breast milk (e.g. evidence that exclusive breastfeeding is associated with only slightly higher risk than avoidance of breastfeeding), the policy changed to encourage choice between exclusive breastfeeding and exclusive formula feeding. At the same time, however, "choice" has created a lot of confusion within service delivery about what is the right message to convey to women. Moreover, the policy does not offer any directive in terms of how to deal with the known difficulties of sustaining an exclusive feeding method. Many women express reluctance to formula feed because formula feeding has come to be associated with HIV, and exclusive breastfeeding is difficult to sustain because it is not culturally normative.

The shortage of material resources and labour within the South African health system has contributed to the creation of a group of semi-professional lay counsellors and mentors who drive the country's Voluntary Counselling and Testing programs. It is this group of people who take on the daily responsibility of bridging science and policy to women living with HIV. The policy of informed choice makes the role of lay counsellors and mentors extremely difficult and vital.

Counsellors try to take into account that the information they are communicating is complex and that choices ultimately have to be made within the circumstances of individual lives. Bulelwa, a professional counsellor, describes how she communicates information on HIV to women: "The terms have to be simple. So, if you understand that person's language you sort of play around with things. You won't begin with the theory kind of information, but with the simple kind of information that is suitable for that person."

Whilst counselling on feeding options is supposed to be non-directive, this goal is not always achieved. On the one hand, reconciling elective bottle-feeding and the promotion of breastfeeding is very difficult for nurses and counsellors in hospitals that have struggled for years to be accredited as a WHO Baby Friendly hospital. On the other hand, the high uptake of formula feeding in some centers indicates that choice is heavily influenced by lay counsellors who see formula feeding as the only way to completely control the risk of mother-to-child transmission. Many of the counsellors have personal biases on what is the right choice, often based on their own experiences as HIV positive mothers feeding their own babies.

Stephanie, a mentor and HIV positive mother who has been through the PMTCT program, helps further contextualize this issue: "Say for instance we find out you are going to bottle-feed your baby. Now you are staying in a shack. You are poor. You are not working. You don't have access to running water. You have no money to buy electricity and sanitation; you know it's unhygienic. I can't tell that woman to bottle-feed her baby. You might as well put your baby to the breast and the baby will live for the next four years. Because if you are going to bottle-feed your baby, your baby will die within the first six months of life or in the first three months of life of diarrhea and all those other things. But, on the other hand, if they are staying in a house, if they have electricity, if they have money to buy milk substitutes, if they have clean utensils, if they can sterilize the baby's bottle and know how to mix the breast milk substitutes properly, then well I will say 'good choice, you will bottle-feed your baby'."

Stephanie knows that the difficult choice on infant feeding may have more to do with resources than "choice," but also understands the personal anxiety that is experienced as one waits and fears that their baby could be HIV positive. It is this latter factor that makes scientific probabilities more difficult to evaluate and makes formula feeding more attractive to many HIV positive women, even if other factors stand as barriers. The way in which risks and probabilities are subjectively interpreted illuminates the difficulty in premising policy on a personal evaluation of competing risks.

Policies designed to promote choice displace responsibility away from political decision-makers and place it firmly within the realm of women and the semi-professional healthcare workers who become the interlocutors of complex scientific knowledge. Unfortunately, this downloading is not always accompanied with the necessary resources to facilitate appropriate decision-making and assist women in carrying out their chosen infant feeding option. In this context, choice is more contingent than informed, since information is ambiguous and "choice" is largely predetermined by social, political, and economic constraints.

[1] This exploration is based on two anthropological fieldwork projects conducted during 2002 on women's experiences living with HIV (Levy) and the creation of the Prevention of Mother-to-Child Transmission (PMTCT) program (Storeng), while the authors were MSc students at University College London.

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Bodies of Evidence: The Emergence of AIDS Clinical Trials Group (ACTG) 076

Betsey Brada, University of Chicago

The AIDS Clinical Trials Group (ACTG) clinical trial 076 demonstrated the effectiveness of AZT in reducing the rate of transmission from HIV-positive pregnant women to the children to whom they gave birth. The shape the protocol took, I will argue, was predicated upon an understanding of the fetus as a recipient and potential beneficiary of pharmaceuticals. This recognition shaped the regulation of pregnant women's participation in clinical trials, which was conceptualized alternately as either dangerous or potentially life-saving. ACTG 076 required a reframing of clinical trials as an activity from which fetuses stood to benefit by virtue of pregnant women's participation – but this reframing required a prior recognition of fetuses as legitimate objects of human subjects protection.

The federal government began restricting the participation of pregnant women in clinical trials in the wake of the thalidomide disaster in the late 1950s and early 1960s. Thalidomide, a sedative manufactured in Germany, was used widely in Europe between 1956 and 1961, often over the counter, for the treatment of an enormous range of ailments, including morning sickness. Only after the drug's safety came under suspicion for causing nerve damage did researchers draw connections between thalidomide and the birth defects characterized most memorably by the flipper-like limbs of children whose mothers had taken the drug. The manufacturer was ultimately forced to remove the drug from the German markets in November 1961. During the years thalidomide was available in Europe; however, thousands of children were born with deformities ranging from shriveled limbs to missing organs.

While the drug was never formally approved for use in the United States, clinical trial regulations allowed pharmaceutical companies to distribute drugs directly to private physicians. Richardson-Merrell began distributing thalidomide in the United States for experimental use a year and a half before submitting their application to the FDA, expanding the trials three months later to include pregnant women despite the lack of data about the drug's effects in pregnancy. More than 2.5 million tablets were distributed to 1,267 clinicians, who prescribed them to approximately 20,000 patients; the FDA later estimated 3760 women had taken the drug, 207 of whom were known to be pregnant. Most of the doctors participating in the trial failed to keep records of patients to whom they had prescribed the drug and or note any adverse effects. Clinical trial regulations in the United States had not incorporated the provisions for informed consent outlined in the Nuremberg Code, nor had they been incorporated into the American legal code in general.[1] While fewer than 20 thalidomide babies were born in the U.S., the publicity surrounding the thousands born with severe defects in Europe and the sense of a disaster averted helped pass amendments to the Food, Drug, and Cosmetics Act requiring the FDA to maintain stringent control over the safety and efficacy of drugs released onto the market in the United States.

Despite these regulations, throughout the 1960s a series of widely-publicized cases of patients undergoing experimental therapies without having given informed consent culminated in

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the scandal surrounding the Tuskegee Syphilis study in 1972, wherein cases of syphilis in poor, African-American men were monitored, but not treated, by the U. S. Public Health Service. In response to the public outcry surrounding the Tuskegee study, a congressional panel began investigating conduct in experiments on human subjects in March 1973. In May 1974, the FDA issued regulations requiring the formation of institutional review boards (IRBs) and in July, Congress passed the National Research Act, calling for the formation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1974. The first problem the Commission took on, however, would shape the terms by which pregnant women's participation in clinical trials would be evaluated. The United States Supreme Court had handed down its decision on *Roe v. Wade* on January 22, 1973; the Commission's first task was to regulate the use of aborted fetuses in clinical research. Fetuses became the first human subjects problem. By 1977, women of childbearing age had been barred from most clinical research, either legislatively or through manufacturers' fears of litigation, and would remain so through the mid-1980s.

Thalidomide and the regulations that followed it established and reinforced the pharmacological subjectivity of the fetus. Thalidomide was not the first substance to have a teratogenic effect, but it was the first instance of a drug distributed on such a wide scale as to produce a highly visible, highly publicized link between pharmaceuticals and fetal deformities. The taking of the drug produced a kind of knowledge about the fetus, albeit of a horrifying kind, that made no demands for its immediate visibility. While there can be no doubt of the extreme degree to which the fetus became a visual subject from the 1960s onwards, thali-domide set the context for a fetus that is known through the effects of drugs and that mediates what may be known about the drugs themselves. Indeed, the fetus's relationship to the state throughout the last four decades has been mediated through the drugs its mother is prohibited from using, whether recreationally or for the potential benefit to her own health. This is not to suggest that pregnant women have been barred from drug use altogether; only that the exclusion of pregnant and potentially pregnant women from clinical drug trials implicitly recognizes the pharmacological subjectivity of the fetus. It is the protection of this pharmacological subject that the exclusion of pregnant women from clinical trials underwrote.

Tuskegee and similar events oriented the politics of clinical research around a principle of exclusion: vulnerable populations must be excluded from clinical trials for their own protection. Thalidomide, in addition to helping establish a precedent of exclusion from clinical research, also helped create a classification of subjects – fetuses – based on vulnerability. Women were largely excluded from early AIDS drug trials in part because of their epidemiological invisibility, which stemmed in part from assumptions about the nature of the disease, though others were turned away for fear of the drug's effects both on existing fetuses and on the fetuses women with childbearing potential might bear. As AIDS activists in the United States reconceptualized participation in clinical trials as a form of health care, demanding the inclusion of wider social spectrum of participants, the participation of pregnant women in AIDS trials shifted from a risk to a benefit vis-à-vis fetuses. Pregnant women's participation depended at least in part on the fetus' ability to benefit from the trial.

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[1] The lack of informed consent provisions in American medical regulations in startling in light of the fact that, according to Chadwick, "Unlike the 'main' Nuremberg trial of the German High Command which was conducted by representatives from all four allied nations, the judges, the prosecutors, and the expert medical witnesses in the doctors' trial were all from the United States." The trial, *United States v. Karl Brandt et al*., lasted from December 9, 1946 to August 20, 1947. Chadwick, G., Historical Perspective: Nuremberg, Tuskegee, and the radiation experiments. *Journal of the International Association of Physicians in AIDS Care*, January 1997, 27-28.

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Women and Condom Use:
An Initial Campus Survey

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In 2003, a questionnaire about women's condom use was tested at a Midwestern urban university. The questionnaire consisted of a demographic block and 67 questions pertaining to condom use by heterosexual and bisexual women with a male partner; some questions also targeted STD prevention methods of lesbian women. The average age of the 53 participants was 27 (mirroring our "typical" student) with a range from 18 to 63, but more than half were 23 or younger. Thirty-four participants identified as European American (63%), 16 as African American (30%), 6 as Asian or Pacific Islander (11%), 2 as Latina (3.7%), 4 as Native American (5.6%), and 2 as other (3.7%). This mirrors our larger student body.

The majority (50) identified as heterosexual women. Thirteen (24.5%) respondents had never had sex with a man, while 25 (47.2%) had had sex with one man in the last year. Five of the respondents indicated they had had sex with at least one woman within the last year, while two respondents (3.7%) had sex with 2 women in the last year. For pregnancy prevention, most heterosexual or bisexual respondents used condoms (40.7%), followed by the Pill (31.5%), an estrogen patch or "pulling out" (each 9.3%), while almost 30% of respondents claimed an "other" method. 'Other" methods to pregnancy prevention were abstinence and monogamy (some indicated monogamy with a male who had a vasectomy).

We created two scales to gain a greater understanding of these women's relationships with condoms in general. The first scale included questions pertaining to 'condom comfort,' which included the women's knowledge of the uses of condoms, comfort and ability to discuss condoms, and their usage of condoms. This "Condom Comfort Scale" included 12 items, with an alpha reliability level of .8683. The second scale, the "Condom Fear Scale," included questions that indicated a negative relationship, or perception, of condom usage, which included reports of discomfort with condom use, fear of violence and anger from their partner with condom use, or personal anger if their partner used a condom. The scale included nine items, with an alpha reliability level of .8341. The fact that these questions resulted in responses that were reliable in comparison with similar questions throughout the survey, added to the fact that more than 50% of the variance in each scale can be accounted for by the items they include, indicate that we have created a strong measure in understanding these women's relationships with condoms.

Significant relationships were found between several items connected to these scales:

· Between the "condom comfort scale" and whether the participants had engaged in unprotected sex, with those participants who had engaged in unprotected sex scoring higher, or indicating greater awareness and use of condoms.

· Between the "condom comfort scale" and participants' responses to methods of birth control. Those participants who scored higher on the condom comfort scale were those most likely to use condoms to prevent pregnancy.

· Between the "condom comfort scale" and whether participants 'discussed STDs with coworkers,' 'discussed STDs with professionals,' 'felt the media should talk more about ways to keep both women and men safe'. With all three of these items, those who scored higher on the "condom comfort scale" were more likely to agree with these statements.

· Between the "condom fear scale" and whether participants had engaged in unprotected sex in the last year. Those most likely to have engaged in unprotected sex scored higher on the "condom fear scale."

No relationships were found:

· Between the "condom comfort scale" and participants knowledge and use of female condoms. While no significant relationship was found, very few participants indicated even having knowledge of female condoms.

· Between the "condom comfort scale" and self-identified racial or ethnic group, household income, or employment.

· Between the "condom fear scale" and the participant's self-identified racial and ethnic group/s, income, or education level.

Our participants know about male condoms, but tend to use them mostly for birth control. While they are aware of STDs, including HIV, and know about the usefulness of condoms in STD prevention, this does not translate into increased condom use for that purpose. Our initial survey, therefore, replicates some of the results published elsewhere. Our respondents, too, indicated having unprotected sex, although they claim to know better, and are rather badly informed about female condoms.

Since this seems typical, we must understand why women would not respond better to the barrage of male-condom-use prevention efforts that have been underway lately. For the younger participants (the elsewhere "typical" student 17 to 21 years of age), the answer may lie in government-sponsored school programs that discuss abstinence only. A whole new generation may be educated having no clue about the function of one of their body parts and may feel pressured to prove that they are "good" girls by being ignorant. As Weiss et al. have shown, such ignorance only increases risk (Weiss et al. 2003).

Another answer may lie in the women-focused prevention efforts themselves, where prevention brochures and well-meant advice might be backfiring. For example, the Sexual Exposure Chart seems to promise that monogamy equals safety and proclaims that "The only safe sex is no sex until faithful married sex!" This is impressive – and completely unrealistic since even older teens who take the abstinence pledge seem to have the same number of sexual encounters as those who don't pledge. Students like this brochure – for other people, especially for their children. The senior author's own children were mildly impressed by the numbers and then dismissed them as hyperbole.

Other messages to women stress monogamy in a relationship (heterosexual male messages, on the other hand, are rare in the U.S. and stress condom use). Here we may find the explanation for the high knowledge/low condom use paradox. Adult women know about condoms and may have a male partner who uses them for contraception, but women are still bombarded with messages that a "good" woman only does "it" with a steady partner. Suggesting the use of a condom may be appropriate for a new partner, but the dismissal of the condom becomes the ritual to indicate that a relationship has passed into the "permanent" (or assumed to be) stage. This may be especially true for women who use other methods for contraception (Pill, IUD, etc.). According to the prevention messages, a monogamous relationship will

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keep you safe – so women who are monogamous and want to think their partner is, too, dismiss the potential risk. Many health care providers and counselors seem to stress in conversations that they themselves are monogamously partnered and therefore are qualified to judge the women they work with who are not. The women targeted in prevention messages must present themselves as monogamous or at least intending to be (often ridiculed by health care providers) or be exposed to scorn as either ignorant, naïve, or uneducated.

A rarely addressed issue in prevention brochures is the coercion factor in heterosexual relationships. Most imply "just talk to him and he'll wear it" and assume that if he doesn't you can kick him out. The Red Cross pamphlet "Women and HIV" is one of the few that realized that "Talking about HIV prevention may be impossible if you are in an abusive or violent relationship" and suggests counseling. There are few pamphlets that tackle the uncomfortable problem of emotional blackmail, of threats of violence and/or abandonment, and of the economic consequences that mark for example single mothers' lives in the U.S. We do not live in a society where women can negotiate sexual relationships with as much power as men can ("Only rarely do women have direct control over the contexts, occasions and forms within which sex takes place and there is a substantial literature to indicate how difficult it is for women to persuade men to use condoms and/or reduce the number of partners in circumstances where the latter are unwilling to do so" (Rivers and Aggleton 1999:2). Women-focused prevention efforts disregard these problems and just reiterate the same facile "empowerment" messages that have no other result than to make women feel even more powerless.

This discrepancy between messages and public image on the one side, and real STD-prevention behavior on the other will be the focus of our revised questionnaire. We know that our instrument can generate valid answers and point to interesting problems. Our next step is to revise it and then, through our Student Health and Wellness Center, distribute it to all students (and maybe even staff and faculty).

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HIV Intervention on a College Campus

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Introduction

The use of anthropology to understand and solve human and cultural problems figures into HIV intervention efforts within the United States and cross-culturally. Perspectives from applied anthropology, medical anthropology, and action anthropology have coalesced over the past fifteen years in response to the AIDS epidemic.

Applied, medical, action anthropology have focused on various subcultures in industrialized societies including drug-using, ethnic and sexual subcultures in the U.S. and Europe. These diverse efforts complement each other and reinforce the concepts of holism, emic perspectives, cultural sensitivity, and grassroots involvement.

Our current project applies these concepts and methods to an HIV intervention program at a small, public, liberal arts college in a rural, isolated, economically depressed, and socially and politically conservative area of the Northeast United States. The geography, economic, political, and social isolation of this area in some ways resembles life in a tribal village: in this relatively homogeneous campus and its local population, gossip and rumor are major sources of both social control and information dispersal. Local leaders, including the mayor and campus president, are actively and visibly involved in the daily life and decision making of the local community and campus.

Background

New York State has the highest incidence of AIDS in the U.S. Since 1990, the state has mandated age and developmentally appropriate HIV education in public schools from K-postsecondary that receive state funds. The content of what constitutes "age and developmentally appropriate HIV education," however, is left to "community norms" and local school boards.

Most students attending this college come from the greater New York City area, western New York, and the North Country. They enter with varying degrees of HIV knowledge, familiarity with safer sex, and experience with people who have HIV or AIDS.

New York State has relatively clear and stringent confidentiality laws regarding HIV disclosure and discrimination in the work place, in institutions, in health care facilities, and in relation to HIV testing. The confidentiality laws pertaining to this campus are clearly stated: "We can neither confirm nor deny the presence of HIV/AIDS on the campus." This position was one of the guiding principles in developing the campus' HIV education program.

The campus reflects the conservatism and economic situation of the larger area. Most students are first generation college students whose parents are either blue collar or middle class. Most students receive financial aid in order to attend school. Non-traditional students return to school to complete an earlier interrupted college education due to military or family obligations, or as a career change move, most often to enter public school teaching. In developing comprehensive, campus-based HIV intervention programs, these economic, political, and social variables help to define the content and implementation of the program.

The Program

The AIDS Education Group is in its 17th year. It is interdisciplinary, involving the academic, administrative, student, and student services sectors of the campus. It includes:

- An upper division, Anthropology, research-focused course in HIV/AIDS
- A website that received approval from a campus board and SUNY central for "appropriateness of content"
- Safer sex kits, safer sex and safer needle brochures posters
- Trained peer educators
- Confidential HIV testing at student health
- Involvement with local and regional HIV CBOs
- Participation in widely held AIDS awareness events such as World AIDS Day.

The group also works with other organizations on campus to hold wellness fairs and informational programming. The group developed and is revising the campus's and faculty union's official HIV/AIDS policies.

The program adapts to the "changing face of the epidemic." In 1988, outside experts were brought in to stress the importance of having such a program. In 1989, the peer AIDS educator program began. The Anthropology of AIDS, first taught in 1988, is taught every fall. The syllabus reflects the changing nature of the epidemic to include sections on drugs, women, and the global nature of the problem. The Anthropology of AIDS provides an academic component to the program, and a relatively non-controversial, cognitive, intellectual, and theoretical approach.

The program is funded from the student health budget. As such, it is relatively protected from the vagaries in the state budget. Student health funding also lends legitimacy to the program as a preventive health effort.

Between 1990 and 1993, safer sex kits and confidential HIV testing at student health centers were added to the program. World AIDS Day was recognized by bringing in nationally and locally known speakers. During this time we began working with local and regional CBOs that address HIV concerns.

These programs have continued and been updated from 1993 to the present.

Anthropological Concepts

Core anthropological concepts provide a foundation for the program. Local campus and community leaders have been involved from the beginning. They continue to be part of the program. The mayor, whose son died of AIDS, speaks in the Anthropology of AIDS class every fall, and has participated in World AIDS Day events. She and the president of the college were opening speakers when we brought the Names Quilt to campus for World AIDS Day in 2000. The president signs the Peer AIDS Educator Training certificates. Previous presidents were involved in creating the website and making the safer sex kits available. Their involvement adds credibility, legitimacy, and support to the program. In 1996, the campus was recognized by the state for its comprehensive HIV efforts based on a survey of all SUNY campuses.

The group respects and works within campus and larger community norms. We discreetly "push the envelope." While peer educators are flexible in what they present in the residence halls, their more public talks reflect the larger social norms. Safer sex kits are given only to our students, and are not available to children in the campus's day care center or to visitors to campus. Safer sex kits are only available from Student Health, during residence life talks, or on an as-needed basis for classroom demonstration. Their packaging is discreet, a brown paper bag, and their contents follow recommendations by the CDC, American College Health Association, GMHC, and the SFAF. Safer sex kits contain informational brochures as well as condoms, vaginal dams, finger cots, gloves, and lubricants.

The program is comprehensive and holistic, focusing on prevention and testing. All innovations such as the website and HIV testing comply with larger medical and state mandates about HIV education in a college setting.

Peer Educators conduct the bulk of the non-academic, non-HIV testing work of the program. Their efforts are grass roots and peer based. They speak in the language of their target audience. Peer Educators are making an HIV informational video for college students. They presented a poster session on the global nature of the pandemic at a campus-wide diversity festival in the spring.

The program is delivered in a variety of formats: pedagogical, peer educator training, safer sex kits, and posters and brochures. It addresses the social, sexual, and drug usage realities of the students through these various mechanisms. It respects community norms and uses its resources in a way that compliments the campus and larger community's values, and adapts to the changing face of AIDS through its various components.

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Latinas, Sexual Communication & HIV/AIDS Education: Notes from the Field

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Outside of academia, community organizations are working with Latinas of diverse ages and acculturation levels to influence positive sexual health practices. *La Casa de Esperanza Inc.(La Casa)*, a non-profit serving Waukesha, Wisconsin, conducts programs focusing on sexual health using the Risk Reduction Program, an AIDS/HIV prevention education program. *La Casa* is centrally located in the city of Waukesha, within Waukesha County. The city's proximity to metropolitan Milwaukee has contributed to Waukesha County's rank as fifth in HIV/AIDS case reports for the state. Despite the fact that Latina clients at *La Casa* are not naïve to the realities of sexual health, cultural norms regarding sexual communication leave some Latinas silent. This lack of communication with steady and/or casual partners can put women at considerable sexual risk. Using case notes and participant risk information, we discuss sexual communication strategies and barriers among Latina clients at *La Casa*, as well as their responses to HIV/AIDS education.

Field staff address two key questions of interest: 1) What communication barriers hinder Latina women from successfully negotiating prevention strategies within their primary relationships?; and 2) What negotiation strategies work well with the Latina women who participate in *La Casa*'s Risk Reduction Program?

The prevention sessions consist of 2 one-hour sessions that include a sexual risk assessment, HIV pre-test/post-test, transfer of sexual health information, skills development and referrals for HIV testing. All sessions are conducted in Spanish by bilingual staff. The risk assessment addresses risk behaviors that occur at two time periods: Previous 3 months, and previous 6 months. The pre-test/post-test focuses on basic HIV information, including transmission routes and prevention strategies.

Of the 28 participants who initially enrolled, 14 completed the sessions. Among these 14 participants, the average age was 30 years old. Fifty-seven percent had at least one child, and 82% were monolingual Spanish speakers. Ninety-three percent of participants reported being an immigrant or migrant, 42% were employed, and 15% indicated that they held at least two jobs.

Seventy-nine percent of participants indicated that they had a steady partner, and the average number of sexual partners in the past 3 months was one. The majority of participants became sexually active by 17 years of age. Fifty percent were referred for HIV testing and obtained their test results. Fourteen percent reported that they had used condoms in the past. Interestingly, the 6% of women who reported a past sexually transmitted infection (STI) also reported past participation in compensated sexual exchanges and that their current steady partner was a man who engaged in sex with other men (MSM).

Participants expressed difficulty discussing sexual risk when it brought up issues of partner infidelity, a finding supported by previous research. We found that the emotional stress connected to perceived or actual partner infidelity inhibited participants from discussing HIV prevention with their steady partners.

The topic of HIV and sex is taboo within some Latino communities. According to the women participants, they did not feel empowered to facilitate sexual health communication in many areas, including both disease prevention and conception prevention. Due to some cultural norms, they indicated a greater degree of discomfort in discussing sexual risk and HIV risk in specific detail or within mixed gender groups. Coupled with the reality that the majority of the participants lived with their partner's family, participants did not have many opportunities to discuss prevention in private.

During session discussions where the possibility of risk associated with partner infidelity arose, participants expressed condemnation of their partner's behavior but felt that it was their duty to remain within the relationship. Women's devotion to maintaining the family structure in situations of partner infidelity was related to women's inability to discuss prevention strategies with partners. In addition to maintaining family order and structure, participants indicated that it was difficult to access information and resources about condoms because it was against their cultural belief system and gender norms, (i.e. it was 'unfeminine').

Some of the women expressed concern over the issue of sexual silence within the family and with partners. The American Red Cross (1997) discusses the concept of sexual silence as a hindrance to HIV/AIDS prevention. Sexual silence refers to the concept that people avoid speaking about matters of sexuality and/or sexual health as a mechanism to avoid embarrassment. Sexual silence results in a lack of information about HIV and AIDS that can put people at risk. Consistent with prior research, the participants in the present study perceived the embarrassing nature associated with sexual matters sufficient enough to hinder prevention discussions from taking place.

Many participants claimed that because their steady partner controlled sexual decisions, he most likely would not use condoms even after he learned how to use them correctly. Such participants felt that this was due to the fact that the partner continued to feel that he was in control of sexual decisions, including condom use. According to Lifshitz (1990)

Latina women identified a ‘good’ woman as one who is uneducated about sexual matters and will readily defer sexual decision-making to her partner. Nearly fifteen years later, the comments from many participants in the present study support this claim.

The women taught us the importance of using cultural norms as a way to promote prevention messages. We found that changing the dynamics of ‘caregiver’ within the family to include caring for themselves was a successful strategy when discussed in relation to family welfare. Although participants expressed that it was difficult to balance sexual power and gender norms, many felt they had a stronger voice with regards to family dynamics. Participants expressed the desire to use the concept of family welfare to promote knowledge of HIV/AIDS prevention among immediate family members, including their steady partners. Many women were also receptive to other quality of life resources and/or services and indicated that HIV prevention should be included with other resource venues.

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Lesbian Sex Behind Bars: Identity and Function

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Sexuality is an important aspect of all women’s lives and self-identity; however, incarcerated women’s sexuality and sexual expression can be very fluid, and is found to serve many functions such as employment, companionship, dominance, or just to get off. Sexual practices in jail may be an important aspect of jail lives, and when women refuse to engage in these practices, they may face isolation. “Women do experience love and sex with other women while in prison [and jail]…up to 80% of incarcerated women are sexually active with each other” (Maeve 1999:48). In fact Morgan stated that prisons and jails “may be one of the few places in America today where lesbianism is commonplace” (Morgan 1998:76). Sexual practices prior to being arrested may often emphasize heterosexual practices, yet during incarceration women may engage in homosexual acts with fellow inmates. HIV and STD prevention programs must be developed for these populations, even though lesbian sex is still considered a low risk sex act. Those who engage in same sex acts in jail may maintain a lesbian identity; however, when released they may practice high-risk heterosexual activities for money or social conformity. In addition, other STD’s (such as syphilis and herpes), which is common in the jails, can increase the HIV risk of women who have sex with women, since open wounds and sores can transmit the virus.

During a case study conducted in a Florida county jail, twenty-nine female inmates were interviewed regarding HIV/AIDS services, perceptions of transmission and risk. In addition, the participants were questioned about their sexual experiences and preferences, specifically, their perceptions of HIV risk while in jail and during lesbian sexual contact. The open-ended questions provided a lot of information on their sexuality, and this paper will discuss the initial analysis of the data resulting from the inmate interviews, along with discussing some of the common US cultural perceptions of women’s sexual identity and function, and how they affect the assessment of risk behavior.

In the U.S., women’s sexuality is still constructed as serving men’s uncontrollable sex drive. Homosexual acts between women are eroticized for the pleasure of men and are commonly requested when a client purchases sex from a sex worker. This ideology influences the lives of women who are incarcerated. Additionally, many of the women found in jail have other factors that increase their risks for HIV infection and loss of power when negotiating safe sexual practices, such as a history of abuse and drug addiction.

One of the factors influencing the sexuality of women in jail is abuse: In the U.S., forty-eight percent of jailed women reported having been physically or sexually abused prior to admission; 27% reported being raped (U.S. Department of Justice 2001). Additionally, studies have shown that those women involved in street prostitution reveal a high occurrence of physical battering. During my interviews, I encountered a significant number of the women disclosing their history of abuse.

Ilene, a self-identified lesbian, described self-abuse that is a result of repeated exposure to violence. “Since I was little I would hurt myself rather than expressing anger; I cut myself 5 times last time - really bad - and got put in ‘C’ [isolation housing unit]. My brother is 16 and wanted for rape and my sister is missing. We think she is dead. My boyfriend is wanted for attempting murder. It started with my father, he abused everyone. I was with a girlfriend and we went to Kansas, she beat me up and left me for dead in 15 degree weather.”

During my interviews, many women admitted and at times

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even bragged that they were very sexually active in jail. These women emphasized the need for affection. Deputies confirmed these stories, and also added that it is illegal to engage in homosexual activities in jail, and inmates who are found having sex are put in isolation for a period of time as a punishment. However, deputies stated that they were aware of sexual activity among inmates, and they only need to see it happening to charge the inmate with the infraction.

Eleven percent of the women I interviewed reported being gay (some disclosing they “perform heterosexuality as a prostitute”), 14% disclose they are bisexual, 21% reported being straight, but then went on to discuss lesbian experiences they had, and 53% reported being totally straight, but of those, many disclosed they had played with girls for their man. One woman stated: “in here it is all going on… I don’t do it, but damn you see it and get curious”.

Exchanging sex for drugs or commissary goods while in jail is a common occurrence. Women who have adopted coping mechanisms of using their body for survival, could easily find themselves exchanging sex with women, just as frequently as with men, for goods which otherwise would be restricted or limited. It costs money to be incarcerated. Inmates who enter the jail with no money, and who receive no money during their stay, run a tab for urgent medical services while in jail, and they lack access to the comforts of the commissary such as supplementary food and daily medical needs such as mild pain medications. In this event, women will turn to the reciprocal behaviors they came to learn on the outside: sex work.

Additional research must be completed in this area in order to provide effective prevention campaigns for women in jail. Incarcerated women lack HIV prevention services, and in addition, researchers lack effective language when talking with incarcerated women about sexuality. By defining these women’s lifestyles and identity, researchers are boxing the women in an identity which might leave them at high risk for HIV infection.

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Research note: “To live is worse than to die” - Discrimination against Female Drug Users Creating Danger to All

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When I did a field survey to know the HIV-related high risk behaviors in 4 Detoxification Centers in the Gansu Province in Western China in 2002, I was astonished by the evidence I found. It revealed that the lives of the surveyed female drug users were extremely miserable, owing to the very strong social discrimination towards them. Below, I present several examples of this.

1. Selling sex for drugs

A policeman: “More than 80 percent of drug using women sell sex. That is their way to earn money for drugs.”

Woman # 2: “It is impossible for a woman not to sell herself… I was sentenced to reform through labor when I was 20, for taking and selling drugs. Later, selling myself became the only way to get money.”

All discussions I held with both male and female drug users and interviews with policemen indicate that commercial sexual activity among female drug users was common. It shows that a bridge connecting these groups at high risk for spreading HIV emerged in the surveyed areas between populations of IDUs and sex workers and their clients. This is a dangerous signal, since condom use is not consistent, as the next section indicates.

2. Condom use

Woman # 2: “When my client agrees, I would use [a condom]. But, sometimes, you cannot care about using it, at the time when withdrawal comes.”

Woman # 6: “When I work, I buy condoms in drug stores or on streets.”

Woman # 2: “I dare not take condoms with me. I fear that they could be found by the police or by my boyfriend when I come back home. Sometimes my clients buy them. Usually, if they request, I would use them.”

These examples show the uncertainty of condom use, owing to:

1. Carelessness when in the grip of drug cravings;
2. The fact that it is the client who makes the decision regarding condom use;
3. The woman fearing being in possession of a condom, since it may be regarded as evidence of prostitution, either by a regular partner (boyfriend) or by a policeman, who may then arrest her, because prostitution is illegal.

In sum, biological factors [with respect to drug addiction], social factors (gender inequality that makes it difficult for women to insist on condom use), and institutional factors (prostitution is illegal) all make female sex workers vulnerable to HIV infection.

3. Life philosophy: "to live is worse than to die"

Woman # 2: "Taking drugs, is somehow like smashing a pot to pieces because it's cracked."[1] "I do not fear death. Because of the drug, I do everything against my own conscience. In society, just to look for a bare living. I have no money. I have to think out a way. We girls cannot steal… Those drunkards with a bad smell of alcohol; who likes them? We just want the money in his pocket. Who knows whether he has sexual diseases, or AIDS? You just now asked, is AIDS dreadful? Of course it is."

Woman # 1: "I say that it is not. I don't mind death. When I have no drugs, I feel terribly bad. To live is worse than to die. Everyone will die. I take drugs, and I feel hollow. It is senseless to live on."

These comments by drug using women show the degree to which they are trapped in a miserable life that is beyond the imagination of people living in mainstream society. The danger they face lies in their vulnerability, in lacking the willingness and ability to protect themselves from sexually transmitted diseases.

Woman # 1 in the discussion group is a college graduate of Han nationality, 29 years old: "AIDS patients are discriminated against. But, we drug users [have been] discriminated against for a long time. The discrimination against our female drug users is even more severe than that against men. Society regards us as "fellows selling out themselves"… We don't care whether we live or die. What I said is true, from the heart." She emphasizes that they suffer twofold forms of oppression: the discrimination towards drug users and the one towards women. No similar expressions were found when talking with male drug users.

Woman # 2: "…you can find all kinds of people among my clients. Many of them are officials."

Investigator: "How do you know that they are officials?"

Woman # 2: "Those living in hotels, at least are clerks above the level of subdivision. Businessmen are generous. They only earn a salary, so [they are] always bargaining. Officials love to preserve face. So, getting their address, name and work unit, then harass them everyday! The other day, I encountered those from the Bureau of Energy. I called them from downstairs, and they ran to me immediately! College graduates, the more they've learnt, the more like hooligans they would become! He did not pay his own money, but finds a method to defraud you of your money… Men, clients, I hate them to the marrow of their bones!" The profound hatred implies a danger towards all: if she were HIV infected, she would not think of protecting her clients.

4. HIV positive sex workers

A nurse working in the detoxification center: "In Lanzhou, every nine out of ten Tai Sisters[2] take drugs. We have a student[3] from Xinjiang, a beautiful girl. After she tested HIV positive by the Provincial CDC, she was released for treatment. However, only a few days later she was brought back by the police. CDC people have talked with her. She was very clear about her HIV status. Even so, she still wandered about in society. We still have no method to deal with her." This is a concrete example of danger to the general population.

Commentary:

The evidence I found in the detoxification centers in the Gansu province indicate that there are drug-using female sex workers in our society who are suffering very severe discrimination and abuse silently. Without improvement of their extremely marginalized position, it would be impossible to change their high risk behaviors. Eventually, the nation as a whole will pay grievous losses for this discriminatory attitude, which is rooted in almost everyone's mind, through thousands of years of Confucian tradition. In an extremely hierarchically organized society like China, it was the basic means for the feudal ruling class to socialize and inculcate in its people the value of strict hierarchy to control deviant behaviors. That is the historical origin of the strong HIV/AIDS related stigma and discrimination. In the past two decades, China has made very rapid social and economic development, but has not undergone a transformation of gender relations and attitudes toward sexuality, which remain ideologically puritanical, while in practice it is women who are blamed for "disorderly" sex and drug use. We need anthropology to rethink the practices of our society with our people. We need to conduct action-research with women in China, like Prof. Brooke Grundfest Schoepf and her colleagues did in Kinshasa, Zaire/DRC, to form a body of knowledge of culturally constructed gender relations, to develop prevention strategies and to reduce the impact of AIDS.

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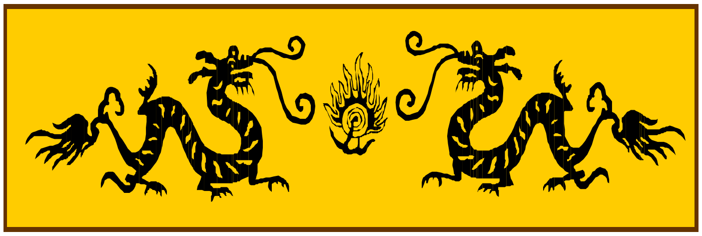

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[1] *A Chinese saying, meaning: to write off one's situation as hopeless and act recklessly.*

[2] Tai sister: local slang for prostitute.

[3] In Yuzhong Detoxification Center of Gansu Province, all drug users were called "students", a neutral label to avoid discrimination.

From the Memebership Officer: The Status of the Membership

Since I took over management of the AARG Membership Directory in January 2004 I have entered 14 new memberships and updated 13 renewals. This brings the AARG membership total to 224 members (111 of whom who are part of the listserv). The current breakdown of members is as follows:

14 Honorary Members (all residing in the United States)
74 International/Non-United States Residence Members
(35 countries represented) United Kingdom 9, South Africa 9, Canada 6, Germany 4, Australia 4, India 5, China, France, Argentina, Jamaica, Pakistan, and Switzerland 2, Austria, Bangladesh, Belgium, Botswana, Brazil, Cameroon, Costa Rica, Denmark, Ethiopia, French Guiana, Ireland, Israel, Japan, Kenya, Mauritius, Mexico, Nepal, Nigeria, Philippines, Rwanda, Sweden, Tanzania, and Thailand 1.

There are 93 Regular Members and
43 Student Members.

My records indicate the following preferences for email vs. print version of the newsletter:
42 members prefer an email version of the newsletter,
19 members prefer an email version of the newsletter; however I have no email address, and 163 members prefer a printed version of the newsletter or have yet to indicate a preference.

Susan Pietrzyk

Can be reached at: spietrz1@binghamton.edu

AARG Paper Prize Committee

During the recent AARG business meeting held at the SfAA/SMA/SOPHE meeting in Dallas our paper prize committee gained new life, very like a Phoenix rising from the ashes. The Steering Committee wishes to thank the members who volunteered to be on the AARG Paper Prize Committee. In order to establish communication to begin the work, would the new members of the paper prize committee please e-mail or telephone each-other, and also contact the Chair at doug_goldsmith@hotmail.com and the Newsletter editor at annamarien@hispanichealth.com Then we can take heart when we meet next in San Francisco. (High on a hill it calls to mind).

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 annamarien@hispanichealth.com
Please keep references to a minimum, preferably just with direct quotations.
We have edited the articles in this issue according to this policy.
The deadlines for the coming issues are August 30 for the fall issue, and November 30 for the winter issue.

AIDS and Anthropology Research Group 2004 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.

As an AARG member, your benefits include:

… access to the AARG listserv, which allows you to send and receive email messages about conferences, job announcements, calls for papers, publications, etc.;
… access to the AARG website, which contains valuable information including course syllabi, important links, upcoming conferences, and publications like the AIDS and Anthropology bibliography;
… the quarterly AARG Bulletin, distributed to national and international scholars, including social scientists and medical professionals;
… AND the AARG Membership Directory, including names, institutional affiliations, addresses and research interests for all AARG members, available in both paper and electronic formats.

Membership is open to all interested persons. Persons do not have to be members of either the American Anthropological Association or the Society for Medical Anthropology to join AARG. Regular membership is $20, and student membership is $5 per year (January 1-Decmber 31). Free membership is available to non-U.S. based researchers.

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.

✂ -

Please Print or Type **New Member** **Renewing member**

Name:________________________________**Affiliation:**____

Mailing Address:____

____

Office Phone:__________________________**FAX:**__________________________**E-Mail:**____________________________

Website:____

Regular Member - $20.00, Student Member - $5.00, Free Membership (available to non-U.S.-based members, or financial hardship)

Please provide up to five key words about your research interests:

1. ________________ 2. _________________ 3. _____________________ 4. ___________________ 5. _________________

Please briefly describe your current project/s:

____

If given the option in the future, would like to receive the AARG BULLETIN by e-mail? Yes ____ No ____

Would you like your email address to be added to the AARG listserve? Yes ____ No ____

Please send this form and a check or money order (made out to AARG in U.S. funds only) to:
Susan Pietrzyk, 126 Chapin Street #122, Binghamton NY 13905, (607) 723-2256, Email: spietrz1@binghamton.edu

NOTE: FOR OVERSEAS MEMBERS, ELECTRONIC APPLICATIONS ARE AVAILABLE ONLINE
(see http://puffin.creighton.edu/aarg/form_new_membership.html).
SAVE YOUR POSTAGE -- FILL OUT THE APPLICATION AND EMAIL TO: spietrz1@binghamton.edu

AIDS & Anthropology Bulletin
C/O Hispanic Health Council, Inc.
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Hartford, CT, 06106