Treating the Numbers: HIV/AIDS Surveillance, Subjectivity, and Risk

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Using ethnographic data, I focus on how people living with HIV/AIDS in Miami, Florida come to know and govern themselves through quantification and categories of risk, race, and ethnicity. I explore the various levels of surveillance that structure HIV/AIDS prevention programs and highlight how “numerical subjectivities” circulate, how identity and subjectivity become entangled in numerical considerations, and how particular groups of people come to be identified with certain diseases such as HIV/AIDS. By examining the deployment and interpretation of AIDS statistical data among Haitians in Miami, I illustrate how identities, through categories such as “heterosexual” and “high risk groups,” circulate, gain traction, and become meaningful for public health institutions and the people they seek to manage.

Keywords governance, HIV/AIDS, identity, risk, statistics, United States

On a hot and humid day in Miami, about 25 participants trickled into the hospital classroom for a lecture by Dr. Cruz, an HIV/AIDS specialist. A majority was African American, and a few were Kreyòl and Spanish-speaking clients. Two women led the class in an impromptu discussion of a book titled Natural Cures That They Don’t Want You to Know About (Trudeau 2004) on “self-education,” prompting a debate of the validity of the book’s claim that drug companies don’t want to find a cure because they will not be able to sell their drugs (field notes, August 26, 2005). In the middle of this discussion, Dr. Cruz came in and the participants instantly quieted down. Suddenly, as if on cue, an African American woman proclaimed with enthusiasm and pride, “I am 400 CD4 count and 250 viral load. I am the person that I am today because of this man.” Her public declaration caught everyone off guard, even Dr. Cruz, who blushed as the woman showered him with accolades. Perhaps to conceal his embarrassment, Dr. Cruz did not acknowledge her comments directly; instead he spoke about virology, antiretroviral adherence, and doctor–patient relationships. At the end of the lecture, the audience gave Dr. Cruz a standing ovation as he thanked them for their attendance.

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Many HIV/AIDS positive individuals in Miami, like this woman in Dr. Cruz’s lecture, frame and portray themselves through numbers and statistical calculations. For instance, during a 2005 World AIDS Day celebration, Jenisa Mann, an African American guest speaker, introduced herself by reciting a poem that she had written specifically for the event titled “Celebration,” which narrated her transformation from someone with a viral load of 178,000 and a 33 CD4 count to someone with a “second chance at life.” She recounted feeling “dead” when first learning of the significance of the numbers, but through self-motivation and encouragement from social and medical support networks, she made it a goal, she said, to “bring the numbers to the right place.” Like Jenisa, during county planning board meetings on HIV/AIDS, a white man named “Slim Jim” always introduced himself by his current CD4 count and viral load. He discussed how his CD4 count had decreased as a result of certain policies enacted by the board despite his objections, or expressed his sense of well-being through his CD4 count and viral load when a policy he favored passed board approval. Slim Jim was one of the few HIV/AIDS positive members on the board, and he used these numbers to embody the negative or positive effects of the board’s decisions.

NUMERICAL SUBJECTIVITY

In this article, I illustrate the growing significance of quantification in HIV/AIDS prevention, drawing on work on the role of enumeration and statistics in the overall management of nation states and their citizens (Foucault 1977, 1979, 2003; Hacking 1982, 1986; Urla 1993; Porter 1995; Bowker and Star 1999; Rose 1999, 2007; Briggs and Mantini-Briggs 2003; Lorway, Reza-Paul, and Pasha 2009). Scholars have long attended to the importance of numbers in the management of the health of populations and related practices of classification and categorization (Foucault 1979; Williams 1979). The numerical knowledge of populations has been associated with many modern state-building projects, and represents sites through which individuals, groups, and nations are rendered objects and subjects of scrutiny (Rabinow 1999). However, it is not the simple presence of numbers that defines public health discourses; rather, it is the burgeoning use of statistics, the science of collecting, analyzing, and interpreting numerical data, that plays a fundamental role in how diseases and populations come to be known and acted upon. As I argue, statistics are more than social data or techniques used to uncover veiled implications of numbers; they are a language of what I call “numerical subjectivity,” where numerical considerations play a critical role in how life is both imagined and lived. Numerical subjectivity allows certain individuals like Jenisa Mann, Slim Jim, and the woman in Dr. Cruz’s lecture, and groups, to come to know themselves and to ask that we recognize them in new and myriad ways. Through cellular statistics and hematological and virological calculations, they (and we) communicate ways of being and belonging, imagining bodies as objects of medical knowledge and numbers as markers of suffering, personal triumph, and achievement.

Using data from 15 months of ethnographic fieldwork in Haitian communities and HIV/AIDS prevention programs in Miami, Florida, United States, I concentrate on how people living with HIV/AIDS come to know themselves and become known politically, socially, and medically through enumeration, by pursuing the following questions: How do techniques of enumeration in public health shape and reconfigure numerical subjectivity? Why and how have the categories based on race, ethnicity, and risk become central to HIV/AIDS prevention discourses? In what ways do individuals and groups come to know these social and epidemiological
categories of self and other that result from enumeration? I explore these questions by tracing the circulation of HIV/AIDS statistics in its multiple forms at various levels: the national HIV/AIDS surveillance reports generated by the Centers for Disease Control (CDC), those used by local departments of health (DOH) in the training of HIV/AIDS prevention experts, and those which permeate the everyday discourses of clients in HIV/AIDS prevention programs. I argue that circulations of certain calculations and categories enable HIV/AIDS statistics and risk categories to be what Bruno Latour (1987) calls “immutable mobiles,” materials meant to flow from one site to another without change. In the field of HIV/AIDS, statistical enumerations are supposed to ideally flow “up” from individuals to local testing sites to city and state-level DOH to the CDC and global institutions, while knowledge about HIV/AIDS and resulting categories of risk moves “down” in the opposite direction. But, as I will demonstrate, contentious divides over recent transformations in HIV/AIDS surveillance systems such as PEMS (Program Evaluation and Monitoring System) and STARHS (Serological Testing Algorithm for Recent HIV Seroconversions) illustrate that these data collection technologies do not standardize data as intended. I also highlight the limitations of existing HIV/AIDS risk transmission categories. I posit that these practices and technologies of standardization enable seemingly fluid and self-evident translations of complex structural and social factors into comparable and discrete categories, while simultaneously claiming that these standardized data variables represent “real” and “factual” maps of the epidemic.

These practices are not only controlled by institutions like the CDC or DOH; clients who are the objects of standardization and data-making are also involved in the processes that drive the construction and circulation of data. I utilize HIV/AIDS statistics and categories resulting from standardization to demonstrate the linkages between notions of risk and concepts of identity and culture. Through ethnographic accounts of HIV/AIDS education programs and counseling sessions for Haitians, I illustrate how perceptions of external risk are transformed into internal risk, and how such changes serve to naturalize the associations between risk, race, ethnicity, and culture in official discourses and public imaginaries of HIV/AIDS. I contend that Haitian clients strategically choose, manipulate, and transform official and nonofficial discourses of HIV/AIDS risk and numerical subjectivities, even while they are bound by systems of disease surveillance that play a key role in constructing them as incompatible subjects and objects of public health and state governance.

DISEASE SURVEILLANCE AND STANDARDIZATION OF DATA

HIV/AIDS surveillance in the United States is complex, and occurs through multiple collaborations at various levels. The CDC declares:

Before we can stop the spread of disease, we need to know where infections are flaring up and who is being infected. Gathering this information in a systematic way is called surveillance—the primary way CDC tracks diseases. CDC’s HIV/AIDS surveillance system collects reports of cases of HIV and AIDS as they are diagnosed. (Centers for Disease Control and Prevention 2006)

Although the CDC portrays surveillance and resulting statistical calculations to be logical and controlled processes, the collection of numbers involve the complex coordination of various actors, organizations, and information technology systems. In the United States, local providers...
and labs report cases to local and state-level DOHs, which then report them to the CDC. However, national HIV/AIDS reporting has differed from state to state. For instance, before 1991, HIV/AIDS surveillance was not standardized, and the information prior to 1991 is considered incomplete. Since then, CDC has assisted states in conducting HIV/AIDS surveillance through the use of standardized report forms and web-based software. Although all 50 states, the District of Columbia, and dependent areas report AIDS cases to CDC by using a uniform surveillance case definition and case report form, only areas with confidential name-based HIV reporting for at least four years are included in the tabulation and presentation of HIV/AIDS data to minimize reporting delays (see Green 1998; Hall et al. 2008). During my fieldwork, from 2004–2006, HIV/AIDS data were compiled from 33 states and 5 independent areas, all of which had different surveillance practices. In 2004, the CDC began to implement changes to better standardize national HIV/AIDS statistics. PEMS (Program Evaluation and Monitoring System), a web-based national reporting system for collecting and processing standardized HIV prevention data variables and definitions, was one such technology utilized to bring about this change. The CDC purports that PEMS allows for the monitoring of behavioral outcomes, client demographics, HIV-test results, and information on partner notification, client use of services, agency indicators, and priority populations, all to allow for the systematic evaluation of HIV/AIDS prevention programs.4 At the Miami DOH, PEMS was regarded as evidence that national-level changes did not reflect local realities. Dr. Veracruz, a DOH official, explained,

People’s behaviors and the impact of prevention are hard to measure. Prevention is prescriptive. Before, the educator had a say in program development. Now, the CDC says “This is what you’re going to do!” The mentality is quality assurance. Staff goes from being trainers to being facilitators. This is a big challenge because one approach can’t fit everyone. PEMS is causing a lot of unhappiness and dissatisfaction because it requires us to ask a lot of personal information. The CDC doesn’t understand that we do outreach and education in groups and these questions have to be done on an individual basis and it isn’t translated.

Like Ms. Veracruz, many local officials felt that the quantification of behavior change and program success was complex and difficult, and that certain measurement variables such as number of unprotected sex events or referral outcomes did not adequately reflect the multiple effects of prevention programs. They felt not only burdened in asking more questions of their clients, but that the methodologies required of them did not reflect the realities on the ground (i.e., the context in which questions are asked, and the degree of cultural appropriateness of questions for certain populations). Many local officials also felt that their roles were changing with the onset of these new directives. By saying that “staff goes from being trainers to being facilitators,” Ms. Veracruz’s sentiments indicate that providers’ primary accountabilities were being forced to shift from the local public to the CDC—that the key aspect of their jobs as prevention providers is now one of “quality assurance,” acting as agents of the CDC to advance national agendas rather than to train and educate communities according to their own understandings of local issues. PEMS came to represent not only a way to standardize and evaluate HIV/AIDS-related biomedical and behavioral variables, but also to monitor local DOHs and their partnering organizations’ performances of a standard set of duties.

The restructuring of HIV/AIDS testing forms is another example of changes implemented in Miami to standardize HIV/AIDS statistical data. Florida is 1 of 33 states that adheres to confidential name-based HIV/AIDS reporting, and in 2006, health workers were informed of
a new CDC surveillance system called STARHS. STARHS is considered useful in the detection of population-level incidence of HIV/AIDS and detects if infections occurred within the past year using new blood specimen testing and additional testing questions. The new questionnaire tries to predict the time of infection by asking clients if any risk factors or sexual relations with high-risk individuals occurred during the “last 3 months.” The most noticeable changes are the inclusion of questions relating to risk exposure and the removal of “unknown” categories. For instance, in the older questionnaire, a client was asked if they self-identified as male, female, or unknown, or have had sex with a male or female; the counselor marked the responses as yes, no, or unknown. The counselor now asks whether the client self-identifies as male, female, or transgender, or has ever or in the past three months had sex with a male, female, or a transgendered person.

At Sante` Ayisyen, a small Haitian clinic in Miami, these questionnaires were introduced in March 2006. Jerome, the HIV/AIDS counselor, confided that he was too overworked and underpaid to translate additional questions without training. The first client tested with the new questionnaire was an older woman. Jerome explained the testing process and confidentiality measures. As he was filling out standard administrative questions, the woman asked, “If one were to get AIDS, what would happen?” Jerome looked up in surprise and explained HIV/AIDS transmission and the procedures following a HIV-positive test. The client nodded quietly, staring off into space. After obtaining her previous testing history, Jerome asked whether she was male, female, or both, and she said, “Comment? [Come again?]”. She giggled nervously but Jerome did not crack a smile; instead, he explained dryly, “There are people who change from one sex to another.” She responded quietly, “Female.” Jerome often looked confused as to what to mark and the session took longer to complete because he was simultaneously translating in Kreyòl without instructions or training. He then asked if she slept “with men, women, or both,” again translating “transgender” as “both.” The client answered “man and woman,” meaning that her sexual relationships include a man and a woman. Jerome looked up suddenly and uttered “What? You sleep with men and women?” focusing on his own newly created third category of “both.” The woman looked confused, and then giggled nervously saying, “No. No. What? I sleep with men only! What kind of question is this?” Perhaps to conceal his own confusion, Jerome ignored her by silently marking “men.” He then interpreted the question “Are you a sex worker?” as “Are you someone who has sex for money or other things?” The woman responded by saying again, “What? No!” Her reactions suddenly stopped, and she answered the remaining questions without further comment.

The new questionnaire, in the context of this Haitian clinic, exemplifies the difficult translations (literal and otherwise) that are often negotiated between counselors and clients. Jerome is forced to translate, without any training, the questions to accommodate new categories in another language, and in the process, different ways of understanding sexuality, gender, and risk categories. The clients he interviewed often seemed confused and, at times, outraged about the survey’s recent integration of complex categories of sexuality and identity. This interaction, centered on the questionnaire, highlights the ambiguous nature of standardized variables that often do not circulate as they are intended.

**MORAL CARTOGRAPHY OF HIV/AIDS**

PEMS and STARHS exemplify what many researchers call “triangulation”—the processes of incorporating data from multiple domains to support a particular theory or hypothesis in order
to reduce the accompanying uncertainty from the use of only one specific data set. Sociologist Janet Shim states that triangulation has “several unintended yet important consequences: obscuring local uncertainties while emphasizing the ultimate ‘truth’ of a multifaceted model, and minimizing individual differences in favor of generalized, simplified findings” (2002:138). As illustrated through the examples, PEMS and STARHS, through triangulation, allow for the obscuring of complex structural factors and social dynamics such as poverty, immigration policy, and racism that contribute to the social context of disease vulnerability in Miami, translate broader identities such as gender and sexuality into discrete biomedical categories and calculable standardized variables, and accept as true that these processes of standardization and resulting categories represent a “real” map estimate of the epidemic.

Triangulation, on a broader level, facilitates the “black-boxing” of the processes that seek to normalize health surveillance systems (i.e., HIV testing through prenatal visits, routine physicals) and simultaneously increases their potency and invisibility (cf. Bowker and Star 1999). By erasing and, at the same time, transforming the multiple interconnecting social and material histories from which they emerge, the final products of HIV/AIDS surveillance data (i.e., reports, graphs, charts, policies, funding priorities) appear flawless. For instance, compulsory training workshops for HIV/AIDS providers in Miami start with worldwide, national, and local HIV/AIDS statistics. In one such workshop that I attended, we were told that “there are 65 million infected worldwide, with 38 million living with AIDS, and new infections happen at the rate of nine per minute, 14,000 per day, and five million per year. Half of all new infections are amongst ages 15–24 and 67% of all infections are in sub-Saharan Africa.” We then viewed an HIV/AIDS world map which indicated “40,000 new infections” as occurring in the United States, with 10% located in Florida. We were told that “25% of new HIV/AIDS infections were in people under 22 years of age and half in women.” The instructor informed us that these statistics were rising because of “unprotected sex, peer pressure, and a lack of education” and that “HIV/AIDS is the leading cause of death in Florida in African Americans ages 25–44.”

HIV/AIDS statistics are part of broader processes of HIV/AIDS surveillance and prevention, and as such, carry moral weight, represent various constituents, and contain invisible and visible mechanisms of categorization (cf. Bowker and Star 1999). In the DOH workshops described, instructors teach providers to read HIV/AIDS statistics as indicative of the amount and the types of people who are infected and the speed at which these infections occur. By formulating a so-called portrait of the epidemic and by forecasting future trajectories of HIV/AIDS (cf. Porter 1995), these statistics prompt providers (and the general public) to infer that numbers are rising because certain kinds of people have inadequate education and unprotected sex. The numbers plotted on the world map convey the spatial extension of the existence and movement of HIV/AIDS, with a kind of ground zero radiating from sub-Saharan Africa. The comparison of global and local statistics works to reveal the pronounced gaps and similarities between the two and simultaneously distances and connects the US and non-US epidemics. In this manner, the numbers allow for moral readings of people and places.

This morass of numbers has the effect of telling a holistic story of global and local HIV/AIDS. Such statistical discourses no longer need to outline their sources. The only connection between them is that they all relate to HIV/AIDS. For instance, the “40,000 new infections” in the United States may or may not represent the same “65 million infected” worldwide. Age, gender, and racial groupings do not need to be similarly exhibited for global statistics as they are for national and local ones. What is emphasized, however, is that a majority of global
HIV/AIDS cases are located in sub-Saharan Africa and HIV/AIDS is the leading killer of African Americans in Florida, implying an inherent relationship between certain groups of people and the disease. Through triangulation, HIV/AIDS statistics of sub-Saharan Africa and Florida are able to construct scales that both distance and connect imaginaries of global and local epidemics by compressing and conflating diverse forms of knowledge about HIV/AIDS collected from various sources representing different constituents.

CRITICAL FRAMINGS OF RISK AND CLASSIFICATION

Numerical subjectivity as imbued by the woman declaring her CD4 and T-cell counts in the opening vignette is inherently associated with surveillance systems, standardization procedures, and resulting classification structures. Ian Hacking (1982) stated that an unexpected aspect of enumeration is the way it subversively creates and maintains classificatory labels. Classifications permeate everyday practices and symbolic and material interactions and help to create the social reality of individuals and collectives (Hacking 1986). For instance, since the beginning of the pandemic, the CDC has been classifying modes of exposure to HIV/AIDS, linking them to behaviors and groups deemed “high-risk.” With the advent of the AIDS pandemic in the 1980s, for instance, the CDC designated Haitians as one of the official high-risk categories for HIV/AIDS, and in 1990, the US Food and Drug Administration prohibited anyone of Haitian descent from donating blood. Currently, even though an individual can be exposed to multiple risks for HIV/AIDS, surveillance records allow for only a single categorization except-for the male-to-male sexual contact (MSM)/injection drug use (IDU) category. The CDC has employed a hierarchy of these risk factors since 1986 (McDavid and McKenna 2006), with MSM contact at the top, and IDU, MSM and IDU, heterosexual contact with an individual with HIV/AIDS or at high-risk for HIV/AIDS, and “other/non-identified risk” (NIR) following in that order. Thus, if a person is noted as an IDU who has heterosexual sex with an HIV-positive partner, the person is classified as an IDU. A majority of cases in the NIR category are either reassigned to existing risk categories or remain without a risk category after health department surveillance follow-ups, while others are reclassified using a standard reporting delay adjustment weight “according to the distribution appropriate for the sex and race/ethnicity of the case” (Green 1998:146). Increasingly, the procedures for investigating NIR cases have moved from ascertaining a risk factor for each reported case to estimating risk factor distributions from statistical models and population-based samples.

In Miami, growing numbers of the high-risk heterosexual and NIR categories are considered a “problem” by DOH surveillance managers and reassigning cases to other standard high-risk categories like MSM or IDU is deemed a “success” (Florida DOH 2006). A high percentage of Haitians in Florida fall into these “problem” categories. DOH surveillance managers, when facing high numbers of cases that are deemed NIR, use various statistical methods to reassign cases to more traditional high-risk categories such as MSM or IDU (Florida DOH 2005a). According to the Florida DOH, with the NIR cases redistributed:

The major mode of transmission for cumulative adult HIV/AIDS cases in Haitians was through heterosexual contact (78%) while men who have sex with men accounted for 17% and injecting drug users 4%. Other risks, such as transfusions, hemophilia and mother with HIV+ status, accounted for 1% of the cases reported in Haitians. (Florida DOH 2004:1)
The redistribution of Haitian NIR cases has resulted in very similar outcomes: an increase in numbers under the ‘high risk heterosexual’ category. Many advocates call for the reformulation of risk factors to better understand the impact on women and minority populations who often are designated as having “heterosexual” or “non-identified” risk (Espinoza et al. 2007; Hader 2001; Mokotoff et al. 2006; National Women and AIDS Collective [NWAD] 2007). Some assert that the surveillance system is flawed and argue that the presumed heterosexual transmission category only captures those who can report specific heterosexual contact with a partner who has or is at increased risk for HIV infection (e.g., IDU or MSM in the case of women). Often individuals will not be certain about their partners’ HIV status or risk (Smith and Payne 1998; NWAD 2007). Others argue that the addition of an official heterosexual category will only recreate singular conceptions of risk rather than allow for a better understanding of how individuals and groups are left vulnerable through a variety of economical, political, and social positions (Zierler and Krieger 1997; Dworkin 2005).

Although those born in Haiti represent the highest percentage of foreign-born Blacks living with HIV/AIDS and the second highest percentage of the overall Black population living with HIV/AIDS in Florida (Florida DOH 2005b), there is currently no active HIV/AIDS prevention or intervention program that specifically focuses on the Haitian population in Florida. Many Haitian community advocates often negotiate between using surveillance statistics to point out the enormous need for HIV/AIDS resources in the Haitian community and highlighting the ineffective impact of those same statistics in garnering them financial and programmatic benefits. In doing so, these advocates underscore that official conceptions of surveillance data as “bible,” as divine and inerrant text, is nothing more than political posturing without any substantive action, reflecting broader undercurrents of social and economic injustices that impact Haitians in Miami.

Despite these growing criticisms, the CDC and numerous public health researchers continue to present the rising rates of NIRs as a problem of “poor risk factor ascertainment” and are currently working toward improving these methods through “scientifically designed projects” (McDavid and McKenna 2006:289–291). Stark deviations from the supposed numerical accuracy of HIV/AIDS surveillance and transmission determination in the case of increasing NIRs seem to signify that the problem lies with the collection, analysis, and presentation of data. In other words, officials continue to conceive of the rising numbers of Haitians who fail to fit neatly within existing risk categories as a result of inadequate data collection and disclosure. As a result, they seek to resolve these issues through more efficient surveillance and data redistribution (as in the cases of NIR and high-risk heterosexual categories mentioned previously) rather than to reconceptualize the methods through which enumeration takes place and the resulting categories that it produces (Zierler and Krieger 1997; Dworkin 2005; McDavid and McKenna 2006). In this way, focusing attention on methods (i.e., how to count and classify) shifts the onus from concentrating on broader questions of the uncertainties of knowledge production (i.e., why count and classify) and in the process, enables different sets of data to be coordinated without insurmountable barriers (Star 1989; Star and Griesemer 1989; Shim 2004).

The categorization of risk in HIV/AIDS, therefore, is highly prolific but contested. Social science scholars have come to understand the concept of risk through three dominant frameworks (Lupton 1999). The first is a cultural symbolic approach, originated by Mary Douglas (1966, 1968; Douglas and Wildavsky 1982), in which notions of risk circulate through cultural
mediums and serve to uphold existing social structures. The second, elaborated by Beck (1992) and Giddens (1999), is informed by the concept of “risk society,” where government, science, and industry, institutions integral to the functioning of late modernity, are understood to produce the notions of danger and risk. The final perspective builds on Foucault’s (1979) notion of governmentality, in which risk is one of the myriad governmental strategies of disciplinary power utilized to administer populations and individuals, where the onus is on the self-management of risk and the increasing privatization of risk (Lupton 1999).

Although all three frameworks are important to understanding risk, the third perspective is often used to frame recent shifts in the ways that we come to conceive of health and illness: from the diagnosis and treatment of illness to the focus on risks and the commodification of health. Adele Clarke and colleagues state:

The focus is no longer on illness, disability, and disease as matters of fate, but on health as a matter of ongoing moral self-transformation. . . . Terms such as “health maintenance,” “health promotion,” and “healthy living” highlight the mandate for work and attention toward attaining and maintaining health. (2003:172)

Risk ultimately becomes controllable through expert management and self-governance, and the maintenance of optimal health constitutes an individual responsibility.

The notion of risk is durable enough to circulate between public health institutions such as the CDC, experts such as researchers, clinicians, and HIV/AIDS counselors, and patient consumers. But it is also ambiguous enough to be the object of diverse, and at times, conflicting meanings. For instance, in a recent CDC report on national estimates of risk, the concept of risk is perceived as self-evident (Anderson, Mosher, and Chandra 2006). In a discussion of the methodologies utilized in the measurement of risk, the authors state:

The risk categories used in this report are based on known HIV transmission routes and epidemiologic studies. The behaviors used here to define increased risk are based on the HIV/AIDS Reporting System (HARS), which defines a route of transmission for each case of HIV and AIDS. HARS defines transmission in terms of broad categories (male-to-male sexual contact, injection drug use, heterosexual contact) and not specific acts; the HARS procedure has been followed in this report. (Anderson et al. 2006:4)

Without a clear definition of the concept of risk, the authors assume that risk, like transmission, can be categorized. Second, they stated that behaviors used to define risk are “based on” presumed transmission categories assessed by HARS and previous studies of HIV/AIDS. But the underlying presumption is that the concept of risk comes to stand in for behaviors that increase an individual’s chances of contracting HIV/AIDS (i.e., male-to male sexual contact, injection drug use, heterosexual contact). Thus, even though the assumption is that heterosexual contact is a behavior practiced by many and is only considered a risk for exposure to HIV/AIDS in certain circumstances such as having multiple concurrent sex partners, the behavior itself becomes indistinguishable from risk. The notion of risk is highly ambiguous. At times, it is a group of behaviors that contribute to increased exposure to HIV/AIDS; in other instances, it stands in for the behaviors themselves; while in others, it can be conceptualized as something else entirely.
There is also a high level of uncertainty as to whether it is individuals or their behavior that constitute risk. In the methodology section of the same report, the authors continue to explain the ways in which risk is measured:

In 2003, 45 percent of new cases of HIV and AIDS reported to CDC were to men who had sex with men (MSM), 19 percent to injecting drug users, and 34 percent were accounted for by heterosexual contact. Based on this, injecting drug use and male-to-male sex in the previous year have been used to define respondents as being at increased HIV risk. (Anderson et al. 2006:2)

Reportable cases to the CDC are categorized as clusters of individuals, grouped together on the basis of what they do or what they have done at one point in their lives. The authors take a category composed of a group of people that have been labeled as “MSM,” extract the sole behavioral factor (male-to-male sexual contact) that is used to construct, and therefore, define its existence in the first place, and use it to classify those in the study as being “at increased HIV risk.” Again, grouping individuals based on one characteristic behavior and moving fluidly between groups of people and behaviors in defining risk makes more evident the indefinite nature of how risk is conceptualized and utilized. These instances exemplify that risk is both fluid and situationally grounded in HIV/AIDS prevention.

**RISK, RACE, AND CULTURE**

The characteristics of flexibility and invariability serve to naturalize associations between risk, race, ethnicity, and culture, which are grounded in official narratives of HIV/AIDS and taking root in popular imaginaries. For instance, the CDC states:

Race and ethnicity, by themselves, are not risk factors for HIV infection. ... Blacks are also more likely to face challenges associated with risk factors for HIV infection, including ... sexual risk factors, substance abuse, lack of awareness of HIV serostatus, sexually transmitted disease, homophobia and concealment of homosexual behavior, and socioeconomic issues. (2007:3)

The official stance, therefore, is that race and ethnicity “by themselves” are not related to HIV/AIDS but serve as proxies for HIV/AIDS risk in combination with social and structural factors such as substance abuse and homophobia. However, national and local-level surveillance collect and report information only on the racial demographics of HIV/AIDS (and not on other social and structural factors mentioned earlier). Although many argue that such collection methods aid in the determination of funding and in the implementation of programs to improve health inequities, routine discussions of race- and ethnic-specific rates of disease serve to naturalize connections between groups of people and HIV/AIDS.

Such linkages become firmly rooted through the production and validation of expertise in HIV/AIDS. Providers often asserted that everyone is at risk. Dr. Peters, a DOH official, for instance, declared “HIV/AIDS is about individual behaviors and so anyone can get it,” but later stated:

I think that saying certain races are more at risk is purely political. Lifestyle has a lot to do with it. I think African Americans get it because of risk behaviors like drugs and alcohol. They need to satisfy
their great desire for addiction and drugs, so they are willing to do whatever. Haitians are housewives who become positive because their men are having sex with different women.

Like this official, many providers simultaneously divorced notions of risk from race and ethnicity while associating behaviors considered as high-risk with racial and ethnic groups. Many claimed, like the CDC, that risk was not related to race or ethnicity, but to “social environments,” “culture,” or “predispositions.” Briggs and Mantini-Briggs (2003) argue that such discourses of characteristics stemming from cultural influences are often indistinguishable from racial and ethnic rationalities of risk. They state:

When the concept of culture is used to characterize racialized populations, its capacity to essentialize, exoticize, totalize, and dehistoricize is powerfully unleashed, reducing complex social phenomena to timeless sets of premodern traits that purport to provide a self-evident and exhaustive interpretation applicable to all “bearers.” Because cultural and overtly racial discourses are both capable of achieving these effects, even invocations of culture that are anti-racist can racialize populations effectively, and they wield their power without enabling target populations to make the sorts of appeals to liberal sentiment that would be prompted by overt public attributions of biological or intellectual inferiority. (2003:313–314)

Concepts of culture, like those of race and ethnicity, function not only as proxy risk factors for HIV/AIDS transmission but also implicitly connect ideas of race and disease. Cultural reasonings allow issues of risk and prevention to become problematized through characteristics of communities and their cultures (cf. Rose 1999, 2007), obscuring the ideological constructions of race and ethnicity on which they are based.

For many non-Haitians in Miami, articulations of targeted surveillance and testing based exclusively on biomedical and social categories of race, ethnicity, and culture serve to connect behavioral risk and high-risk groups and determine self-management practices of risk such as numerical subjectivity. So when Karrie, an African American prevention manager, declared, “It’s just the way it is. Maybe it’s due to some biological or cultural predisposition that we have” when discussing why African Americans were disproportionately affected by HIV/AIDS in a training workshop for providers, no one questioned or disagreed with her comments. For Karrie and her audience, not only do African Americans have a natural tendency to be at higher risk for HIV/AIDS due to a combination of biological or behavioral factors, but this predisposition itself is immutable (i.e., “It’s just the way it is”). Here, the relations between risk, race, and ethnicity have lost what Bowker and Star call their “anthropological strangeness” (1999:299). They state, “The more naturalized an object becomes, the more unquestioning the relationship of the community to it; the more invisible the contingent and historical circumstances of its birth, the more it sinks into the community’s routinely forgotten memory” (299). As exemplified by the perspectives from providers, the relationship between risk, race, ethnicity, and culture is not only grounded in official narratives of HIV/AIDS but is also rooted in popular imaginaries.

RISK AND SUBJECTIVITY

The kind of flexibility that risk embodies in official statistics is obscured, however, in local settings, where the notion of risk becomes a dynamic means through which HIV/AIDS experts construct clients and clients construct themselves. In DOH training workshops for HIV/AIDS
counselors, for instance, the goal of prevention is “to support individuals in making behavior changes that will reduce their risk of acquiring or transmitting HIV” (Florida DOH 2005b: II-A-21). Although risk is never defined, counselors are taught that in order to “influence” clients to “change their behavior,” they must induce their clients to “personalize the risk.” The training manual states:

A person who has multiple sex partners may not be aware that he/she is at risk of infection because of the common view that primarily homosexual men and injection drug users get HIV. Some who are at risk may even deny that risk. They may not believe information they hear regarding their risk or may ignore it. (Florida DOH 2005b:IIA-23)

Risk, in both the DOH statement and in general, is treated as an inherent part of the individual, alluding to an internal state of vulnerability. It is also suggestive of individual exposure to an external danger or hazard. In order to be effective, counselors are told to persuade clients to personalize their risk by helping them take “ownership” of their risks. They are asked to transform clients’ conceptualizations of viewing risk as outside the self (i.e., social risk) and outside the purview of one’s own actions to recognizing risk as part of the self and under “self-control.” HIV/AIDS counselors are trained to be experts in the mediation of disease-specific risk, transforming individual client’s perceptions of external risk into internal risk and obscuring other non-HIV/AIDS threats to well-being.

Clients, as a result, are consistently inundated not only with statistics which relay HIV/AIDS rates of prevalence and incidence but also those which represent the state of their health or risk of infection. Like many consumers of health care, they are encouraged and expected through various prevention programs and providers to have an understanding of key enumerations and risk classifications so that they are able to achieve numerical subjectivity and manage their own health and well-being. In many ways, statistical data are used “as the necessary foundation for other knowledge” (Treichler 1999:110), and they underpin ways of understanding self and other in the discourses and practices surrounding HIV/AIDS in Miami.

In clinical and nonclinical settings, however, Haitian clients act to divorce risk from cultural and biological rationalities. One way that Haitians actively negotiate the associations made by HIV/AIDS prevention programs between risk, culture, and biology is by not participating. In Miami, Haitians are a scarcity in clinical and nonclinical HIV/AIDS prevention programs as compared to other ethnic groups. The largest clinical HIV/AIDS prevention program in Miami, for example, hosts only two–four regular clients in bi-monthly Kreyòl classes, as compared to the English and Spanish classes, each of which hosted 30–40 regular clients weekly. Other clinics also expressed the futility in having prevention programs in Kreyòl because of a lack of attendance. Even the DOH has continually cancelled HIV/AIDS classes in Haitian Kreyòl for providers because of a lack of participation.8 Both Haitian clients and their providers framed the lack of participation as stemming from fear of being associated with HIV/AIDS and an aversion to programs with a sole focus on disease. Dr. Paul, an HIV/AIDS specialist, told me, “When I tell my Haitian patients to come to the Kreyòl classes, they say ‘No, I don’t want to be mixed up with HIV/AIDS and Haitians.’ The Haitians, they don’t want to be identified as Haitian and having HIV.” Similarly, an HIV-positive Haitian woman explained, “I’m just too tired of talking about HIV over and over again. I’m not HIV.” By rarely participating in programs that target them specifically, many Haitians refrain from associating themselves with HIV/AIDS and away from embracing numerical subjectivity.
Another way that Haitians act to transform discourses of risk is to claim, with official rhetoric, that risk is a perpetual state of being, that one is always in a state of risk, and that risk is intimately linked to representations of moral, self-efficacious individuals, contingent on individual choice. However, unlike official narratives of risk, Haitian clients refute the distinction between personal and social risk, and do not divorce the concepts of internal and external risk. For example, Lissette reiterated that risk for young Haitians like her was in personal values such as “making money fast” and “low self-esteem.” She reasoned, People who don’t want to work—they don’t respect their bodies. Instead of working for money, they want fast money easily. But other people have more respect for themselves, their bodies, and they have only one woman. They won’t catch AIDS. People right now, they’re looking at how to have a good world. They think they need to have good things, so they choose sex because they don’t want to work. If everybody works, it would not be easy to catch.

For Lissette, “working” is a notion that insinuates a way of being. She uses the concept of work to imply not using one’s body to get material or social benefits and to represent a self-respecting responsible individual. According to Lissette, risk exists as a danger that is simultaneously internal and external to the self and flourishes in the practices of not working hard and in the bodies of those who want to have a rich easy lifestyle.

Similarly Rita, an HIV-positive counselor, was adamant that everyone was at equal risk for HIV/AIDS but stated that “the level is not the same.” She elaborated:

I have to do what [hospital administrators] want me to do but when I am talking to Haitian people, I tell them “Do not resist what is.” If you are poor, you are poor; if you are short, you are short. We resist so much about who we are and we blame our spouse, our friends, the government, and we don’t go to the cause of our problems. We are trying to address symptoms and leave the cause behind. If we want to adjust the symptoms, resolve the cause and then you will have no symptoms.

Rita also alludes to the inseparability of internal and external risk, as well as individual and social risk. For her, the level of risk is independent of age, gender, or race; rather risk is reliant on whether an individual is able to address the “causes” of unhappiness, desire, and necessity that exist internally, rooted in notions of self-worth and self-awareness, and externally as substantive and social goods.

Although these discourses align with the official rhetoric that compels clients to be the mediators of their own risk, they give way to divergent conceptualizations of the self-management of risk. Managing risk, for many Haitians, translates into practices that are not restricted to disease prevention imperatives (i.e., safe sex, clean needles, living positively). Haitians who are HIV-positive do not necessarily interpellate themselves to their condition through numerical subjectivity in the same ways that non-Haitians in the opening vignette do. Instead, many Haitians approach their HIV/AIDS status not through disease-specific enumeration and numerical subjectivity, but as broader representations of risk that is part and parcel of everyday life where HIV/AIDS is not central to their identity:

I read books that say HIV causes AIDS and that say HIV doesn’t cause AIDS; I get with the doctors, I go alternative ways, change my diet, exercise, read all the books that contradict each other. HIV is the last thing on my mind to think. (Veronique, HIV-positive Haitian woman)
My doctor says “I don’t see that you need medication. What did you do?” I say I drank my herb tea every morning. I don’t have any problems. That’s not a reason for me not to come to see my doctor. I always come to the hospital, I go to all the groups and I learn. . . . I am not thinking that I’m sick; I don’t have any problems being sick at all. (Sissie, HIV-positive Haitian woman)

Both women’s interpretations of an HIV-positive status derive from having multiple choices in the care of the self. Haitian narratives pinpoint sex as the primary way that people are able to get HIV/AIDS, and many reasoned that because of this, everyone was equally vulnerable to transmission. Many Haitian women spoke of “taking precautions” but these did not always translate to traditional “safe sex” practices such as condom use. For instance, Claudette, a woman who brought her husband to get tested for HIV/AIDS, reasoned that the only way to ensure not contracting HIV/AIDS was to threaten her husband with abstinence until he proved via testing that he did not have HIV/AIDS. For her, safe sex was validated only through testing; it did not consist of using condoms in the face of uncertainty, as is currently taught by HIV/AIDS prevention programs.

These conceptualizations of risk and safeguard practices signal broader contrasts with official norms of risk education and HIV/AIDS prevention. For instance, many Haitians frequently questioned or rebuked the epistemological foundations of HIV/AIDS risk reduction, of ascertaining and ultimately controlling one’s personal risk of HIV/AIDS. They cited that one can never truly know about the actions or statuses of intimate partners, hence the futility of official discourses of “being careful.” When I asked Florence about how she and her friends viewed sex education and HIV/AIDS prevention, she wryly exclaimed,

How can you be careful when you don’t know anybody? You can have a husband or wife and they can give it to you. My dad says all the time, “You don’t know anybody! Don’t talk to people!” And I asked him one day, “Daddy, do you really know everybody? You could never know anybody. I’m your daughter but you don’t know me. You’re my dad but I don’t know you. When you go to work, how do I know you go to work, that you’re not a criminal when you go outside? How do you know if I don’t go and prostitute myself? I don’t know you and you don’t know me. We don’t know anybody.”

Florence’s comments lay bare the very foundation of HIV/AIDS prevention—that one can reduce risk of HIV/AIDS by recognizing one’s personal risk. This framing presumes the transparency of self-knowledge; that is, individuals can discover knowledge of risk merely through self-reflection because this knowledge is true, real, and waiting to be realized. It also takes for granted that individuals “know” the sexual and drug-using practices of others. Florence challenges this presupposition by asking “How can you know anybody?” questioning the very foundation of HIV/AIDS prevention and risk reduction by bringing into focus whether we indisputably know what and who we think we know. Florence contests these otherwise unquestioned assumptions of HIV/AIDS prevention, and in the process, renders visible the multiple obscured forms of social organization, labor, and discourses that produce and veil such modes of knowledge making. Florence, like many Haitian clients, challenges the very ideas of knowledge production in HIV/AIDS prevention by reframing certain “facts” about HIV/AIDS, risk, community, and subjectivity as socially constructed and as highly dependent on the social relations of knowers themselves (cf. Shapin and Schaffer 1985). These practices that shun participation around HIV/AIDS and other diseases indicate not so much a fierce resistance to biomedical
expertise and claims but rather a way of divorcing associations between risk, race, culture, and disease, especially in the face of complex historical, political, and economic conditions that render Haitians as unequal global citizens.

CONCLUSION

There are many, like the non-Haitians in the opening vignette, who fervently interpellate themselves to HIV/AIDS prevention rationalities through numerical subjectivity, by positioning themselves as active ethical citizens who formulate and transform their own health destinies. But there are just as many, like the Haitian clients mentioned in this article, who conceptualize risk not through numerical subjectivity but as co-constitutive of everyday practices, adamantly refusing individual or expert management of risk. Haitian clients are acutely aware of notions of risk and individual responsibility, despite expert discourses that circulate notions of their unsuitability as both statistical data and as ideal subjects and objects of HIV/AIDS prevention. For many Haitians, HIV/AIDS represents a continuing legacy of unequal citizenship, power, and privilege based on the very notions of racial hygiene and biomedical and social primitivism. Due to existing biopolitical and public imaginaries of Haitians as natural carriers of disease (see Gilbert et al. 2007), many Haitians have and continue to understand and describe themselves away from numerical subjectivity.

Continuing transformations in HIV/AIDS surveillance such as PEMS and STARHS illustrate that enumerative practices are highly dynamic phenomena. Standardization techniques enable seemingly unambiguous translations of structural and social inequalities into comparable and distinct categories, while claiming the products of these translations and categories represent actual and accurate maps of the epidemic. Such practices involve institutions like the CDC and DOH; they also require the participation of clients who are the objects of standardization. Notions of risk in HIV/AIDS prevention and treatment present productive spaces through which clients are able to exhibit numerical subjectivities while HIV/AIDS institutions and experts construct them as “risky” subjects. Moreover, accounts of clinical education programs and counseling sessions demonstrate how perceptions of external risk are transformed into internal risk, and how such changes serve to naturalize the associations between risk, race, and ethnicity in official discourses and public imaginaries of HIV/AIDS. Although the transformation of HIV/AIDS risk from social insurance to that which is self-managed continues to occur, formulations of risk are co-constitutive of articulations of targeted surveillance informed by biomedical constructs of race and ethnicity. Haitian clients, however, continually negotiate official and nonofficial discourses of HIV/AIDS risk and numerical subjectivities, enlist enumerative products to make subjectivities, and reject expert mediation in the management of risk, and in the process, become constructed as incompatible subjects and objects of governance through systems of enumeration.

NOTES

1. Following Paula Treichler (1999), I utilize HIV/AIDS to refer to both (1) an epidemic representing a wider social and cultural crisis and (2) the broad clinical range of HIV-related conditions from asymptomatic infection to diseases used to define AIDS.
2. Although commonly referred to as Haitian Creole in English, Kreyòl or Kreyòl Ayisyen is how it is pronounced and spelled in Haiti; this version is increasingly being used among speakers and teachers of the language in the United States. I use Kreyòl instead of Creole because it indicates the official language of Haiti and a language in its own right rather than pidginized French.

3. I conducted research in July 2004, and from July 2005 until August 2006. My data collection comes from (1) observations of social and health service agencies, (2) 53 in-depth interviews with providers and patients, and (3) epidemiological and surveillance data.

4. PEMS data allow the CDC to monitor the adoption of evidence-based interventions and to identify details of the agencies implementing these interventions, characteristics of the populations targeted, and the locations and settings in which targeted populations are served.

5. Multiple imputation, a statistical approach in which each missing risk factor is replaced with a set of plausible values that represent the uncertainty about the true, but missing, value, is used to assign a risk factor for HIV/AIDS cases, which are reported as NIR. For further information, see Green (1998).

6. Haitians born in Haiti are classified as Haitian, and those born in the United States are categorized as Black/African American.

7. Multiple imputation, a statistical approach in which each missing risk factor is replaced with a set of plausible values that represent the uncertainty about the true, but missing, value, is used to assign a risk factor for HIV/AIDS cases, which are reported as NIR. For further information, see Green (1998). I did not have access to the data before redistribution was done.

8. Haitians who attend often participate in classes offered in English and sometimes in Spanish, rather than those offered specifically in Haitian Kreyòl. The small number of HIV/AIDS prevention classes in Kreyòl and low rates of engagement by Haitians in clinical prevention programs could mirror the number of Haitians living with HIV/AIDS. For instance, in February 2011, the latest monthly HIV/AIDS surveillance report available for Miami-Dade County, the total number of cases of adults living with HIV/AIDS comprised of 11,868 Blacks/African Americans (including Haitians and Caribbean Islanders), 9966 Hispanics, and 5257 Whites, while adults born in Haiti represented 2625 cases (Miami-Dade County Health Department 2011). Although HIV/AIDS cases in Miami-Dade county for adults born in Haiti are lower than those for Hispanics, African Americans, and Whites, Haitians comprise 9% of HIV incident cases and 16% of AIDS prevalent cases, while only comprising about 5% of the County population. This number could be higher given that only those born in Haiti (as opposed to Haitians born in the United States or elsewhere) are captured in these Haitian-specific estimates. In addition, the Miami-Dade Partnership, the entity responsible for planning the delivery of HIV/AIDS care, treatment, and services in Miami-Dade County, has designated Haitians as a high-risk group requiring special focus in terms of service delivery due to high rates of poverty, lack of insurance, and cultural barriers to engaging health care services (Miami-Dade Partnership 2009).

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