Once Upon A Virus

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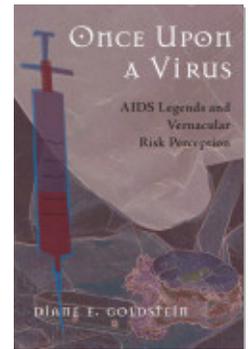
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Making Sense

Narrative and the Development of Culturally Appropriate Health Education

Lazzaro Timmo, a Tanzanian journalist, reported one day observing a thirty-five-year-old Waarusha man reading a poster explaining that to avoid infection with HIV one should "have sex with only one faithful partner." The man burst into laughter. "What am I going to do with my other wives?" he asked. Timmo noted that the man had three wives and was thinking about marrying a fourth if the harvest was good the following season. He commented, "To tell . . . [him] to relate to only one faithful partner is like telling him to get rid of his other wives, who are his source of wealth and prestige" (Timmo 1988:125–126).

Timmo's story is an example of a health education campaign gone terribly wrong. The one faithful partner recommendation makes no sense as a campaign theme in parts of Africa where polygamy is an accepted and perhaps even an expected part of traditional culture.[1] The campaign that Timmo commented on was an artifact of the mid-1980s. Since that time health educators have learned a great deal about the need for developing culturally appropriate and culturally sensitive health education. Today, most health educators would agree that educational campaigns must include unambiguous information that addresses local issues and is presented in a culturally sensitive fashion. There is general agreement that we must

1.   Other African campaigns took polygamous culture into account through themes such as "graze at home" in Kenya and "love carefully" in Uganda.

recognize cultural, political, geographic, and economic barriers to behavior change (whether generally understood or perceived) and be aware of norms and values that sanction high-risk activities and that present real risks[2] to individuals and to the community. Ultimately, most health educators would agree that health education campaigns must suggest real alternatives to high-risk behaviors, alternatives that make good cultural sense as well as good public-health sense.

Culturally sensitive health education must adapt itself to the existing beliefs, attitudes, and practices within a community rather than expect that the community will change to fit the educational program. The issue is not one of style or pedagogical philosophy but rather basic pragmatism. As Ronald Bayer notes,

> In short, AIDS prevention efforts that are not culturally sensitive will be ineffective. They will fail to promote, support and sustain the behavioral modifications that are the *sine qua non* of AIDS prevention. They will fail because they will not reach their intended audience, will not be understood by those who are reached, and will not be accepted by those who understand. They may indeed provoke outright opposition. (1995:20)

The nod toward cultural sensitivity in health education, while being emphasized with the best of intentions, has not been unproblematic. Critics of these programs note that they are often based on stereotypes of the communities in question or are dependent on overgeneralized and badly contextualized cultural information (Goldstein 2001). Critics have also been concerned about the reinforcement of heterosexism as normative in programs designed to be culturally sensitive (Patton 1996:114) and about the absence of subgroup-specific cultural materials (Stevenson, Gay, and Josar 1995). Many of the concerns about the cultural movement in health education refer to the search for linguistic equivalencies, where intimate language comes under scrutiny and sexual vernaculars are coopted and turned back on the community in the form of "folksy"

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2.   What is meant by "real risks" here is risks that actually provide a health threat for the individual or community rather than risks that are merely assumed by virtue of cultural bias or a lack of cultural knowledge. As Timmo notes, "Where no one in a polygamous sexual unit is already infected with HIV, grazing at home is every bit as safe with two or three wives (or husbands) as with one. . . . And if one or more individuals within the unit are already infected, grazing at home will at least confine the infection to that unit" (Timmo 1988:127).

explicit campaigns that have only negative impacts, both internally and externally (Patton 1996:142–147).[3] Other critics have argued that guidelines for evaluating materials designed for cultural responsiveness have been lacking (Walters, Canady, and Stein 1994).

Ultimately though, health educators and AIDS activists know that cultural concerns must form the center of any educational or intervention effort if it is to be successful. Ideally, health education programs should be community based, involving collaborative partnerships between communities, researchers, and service providers. Projects that involve such collaborations are able to redirect outsider misinterpretations, identify community subgroups and hidden or hard-to-reach populations, recognize significant issues and behavioral patterns, strategize culture-appropriate mobilization, and localize support infrastructures. Even within collaborative projects, however, the need is increasingly clear for the skills of trained ethnographers. Since community members themselves are only ever partial members of the dynamic group—never fully representing all its knowledges and concerns—the need remains for qualitative research methodologies that can be more fully representative and provide a degree of critical distance. As Joseph Kotarba, editor of a special issue of the *Journal of Contemporary Ethnography* on "Ethnography and AIDS," wrote,

> Of the major social and medical problems to appear in the past 10 years, including abortion rights, homelessness, the environment and crime, AIDS more than any other issue occasioned the application of ethnographic strategies to both policy and basic research. The study of AIDS not only demonstrates ethnography's particular ability to describe in elegant detail the ways by which people make sense of and cope with everyday life and its problems, but provides the occasion for refining ethnographic techniques and technologies. (1990:260)

From the outset of the AIDS epidemic, ethnographers have worked actively at applying their research skills to exploring settings and activities believed to be significant to the transmission of HIV

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3. In earlier publications I myself have argued for the cooptation of sexual vernaculars (Goldstein 1991, 1993). I since regret taking this stand. As Patton notes, "mere imitation or reproduction of a vernacular will not suffice; it may even be a dangerously subtle cultural imperialism. . . . If comprehended at all, most sexual vernaculars are offensive or embarrassing to those for whom it is not a native tongue" (Patton 1996:146).

but about which little was known. Ethnographers explored everything from the culture of intravenous drug use and "shooting galleries," where knowledge of the culture could illuminate possible solutions to the development of safer injection practices (see, for example, Des Jarlais, Friedman and Strug 1986; Fox 1991; Broadhead, Heckathorn, Grund, Stern, and Anthony 1995), to ethnographies of sexual choices and motivations used to explore unsafe sexual practices (see, for example, Sobo, Zimet, Zimmerman, and Cecil 1997; Lear 1995; Sobo 1993; Parker and Carballo 1990; Tarr and Aggleton 1999; Adam, Sears, and Schellenberg 2000).

Ethnography clearly went beyond more typical knowledge, attitude, belief, and behavior studies (KABB[4] studies), which were largely quantitative in nature and which, while supplying useful statistical data, left great gaps in our understandings of deeper symbolic meanings and the reasons behind practices related to HIV/AIDS. KABB studies were aimed at producing scientifically valid data that would explore social determinants and variables serving as predictors of condom use, needle sharing, sex with multiple partners, and such, or that would illuminate target areas for AIDS education. Most of these studies were heavily dependent on questionnaires, continually refined and modified according to the results of complex pilot studies and presurvey focus groups. The studies would survey, for example, sources of HIV information, accurate and inaccurate belief in forms of transmission, beliefs about condom use, awareness of personal risks, and so forth. Many KABB studies were refined to be context and culture specific, creating regional and subgroup versions of international questionnaires and resulting in statistical data on knowledge, beliefs, and behaviors among, for example, Chinese adolescents in Hong Kong (Davis, Noel, Chan, and Wing 1998), female Mexican migrant farmworkers (Organista, Organista, and Soloff 1998), university students in Delhi, India (Sachdev 1998), and medical school students in the urban midwestern United States (Chavis and Norman 1995).

Fact vs. Behavior

Quantitative studies told us repeatedly that AIDS education, per se, was working–at least in the sense of developing widespread high

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4.   Also known as KAB (without behaviors) and KAP (using practices instead of behaviors).

levels of AIDS knowledge. Questionnaire data and public informa-
tion polls administered in a variety of countries and among a variety
of subgroups appeared to reveal relatively consistently that surpris-
ingly high numbers of respondents were knowledgeable about the
major modes of human immunodeficiency virus transmission (see,
for example, Organista, Organista, and Soloff 1998; Sachdev 1998;
Davis, Noel, Chan, and Wing 1998).[5] But knowledge, attitude, be-
lief, and behavior surveys also indicated that, as the AIDS epidemic
entered its second decade, AIDS-related behaviors continued much
as they had before the epidemic.

The Bureau of HIV/AIDS Health Canada (1999) and the 1992
American National Health Interview Survey (Schoenborn, Marsh,
and Hardy 1994) found that 94 percent to 96 percent of Canadian
and American adults know that HIV can be transmitted through
sexual intercourse with an infected partner, from pregnant women
to their babies perinatally, and by needle sharing with an infected in-
dividual. Similar statistics indicate that a vast majority of Canadians
and Americans possess reasonably accurate information on risk re-
duction, particularly in relation to the practice of safe sex and blood
precautions. Nevertheless, only 13 percent of Canadians report that
they have changed their behavior because of AIDS, and Bureau of
HIV statistics indicate that among Canadian sexually active fifteen-
to nineteen-year-olds, 51 percent of females and 29 percent of males
reported never using a condom in the past year (Bureau 1999). And
as Sobo notes concerning the American situation,

> most studies conclude that no significant relationship exists be-
> tween safer sex and the degree of AIDS or HIV knowledge people
> have . . . ; behavioral changes made by homosexual men . . . living
> in areas with firmly established gay social and political structures

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5. Demographic and Health Survey reports from UNICEF for 1994 through 1999
    show an enormous information gap in parts of Africa, Asia, and Central America.
    Their data indicate, for example, that 96 percent of females and 88 percent of males
    in the fifteen to nineteen age group in Bangladesh reported that they did *not* know
    any way to protect themselves against HIV/AIDS. In Mozambique, 74 percent of
    females and 62 percent of males reported the same lack of information. Several of
    the countries reported in the UNICEF data have been surveyed with very different
    results than those found in the KABB studies. Proper analysis of these differences
    would require a close look at the type of questions posed, how those questions were
    articulated, how they might have been interpreted, and so forth. Nevertheless, the
    UNICEF study should serve to remind us that availability of information and rights
    to information do differ significantly from group to group and country to country.

are the exception. But even among this group patterns of relapse have been documented. Factual information is necessary, but it is certainly not sufficient to drive and sustain behavioral change. (Sobo 1995:25)

AIDS facts appear to be well known in North America and easily repeated in response to survey questions but not so easily acted upon. A number of explanations have been suggested for this apparent inconsistency, but none is intended to represent the entire spectrum of behavioral motivations. Numerous studies have demonstrated that while respondents are able to accurately repeat facts related to transmission risk factors and protective actions, they simultaneously report inaccurate lay beliefs, sometimes referred to as "older" health beliefs (Kimmel and Keefer 1991; Sobo 1993; Sobo, Zimet, Zimmerman, and Cecil 1997; Herek and Capitanio 1994). Fear of public toilets, shared drinking glasses, giving blood, mosquitoes, and door handles appear to coexist comfortably with more accurate knowledge of transmission factors. Social scientists tend to favor a survivalist notion of why these beliefs continue to be held, arguing that they involve "primitive" thinking involving ideas of "magical contagion" and that individuals will hold beliefs concerning magical contagion despite the fact that these beliefs make no logical sense even to the individual in question (Nemeroff, Brinkman, and Woodward 1994).[6] Some authors have suggested that these "older beliefs" support risky action, even when they are held simultaneously with accurate information about AIDS (Sobo, Zimet, Zimmerman, and Cecil 1997; Nicoll et al. 1993). Without further support, however, this argument is untenable. Fears of public toilets, shared drinking glasses, giving blood, mosquitoes, and door handles, while incorrect and problematic in terms of understanding the virus and treatment of people with AIDS, are not in and of themselves beliefs that contradict the need for safer sex or blood precautions.[7] It is hard

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6. The assumption that beliefs that are illogical to AIDS educators are therefore also illogical to those who hold those beliefs is ethnocentric at best. Analysts should always begin with the assumption that such beliefs are logical and rational in terms of the larger belief system of the individual involved. While it is possible that individuals will hold illogical beliefs, it is more likely that the investigator simply does not understand the believer's context and system of reasoning. See O'Connor (1995) and Hufford (1982; 1984; 1991) for discussions of this issue.

7. This is not to say that beliefs that threaten protective practices don't exist. The belief, for example, that condoms are deliberately impregnated with HIV during

to see, without further ethnographic information, how any of these beliefs support risky action if they truly are accompanied by accurate knowledge of the main transmission factors and protective practices. It is important, if we are to understand lay health belief, that it not be interpreted a priori as a threat to health safety, unless it presents a real obstacle. Of course, the problem is that clearly *something* is presenting that obstacle, and that *something* seems to elude the grasp of AIDS educators. The real concern about the coexistence of inaccurate lay health beliefs with high levels of reportable correct knowledge should be that it suggests a larger health worldview that educators are not understanding.

Many AIDS educators suspect that the resilience of certain inaccurate lay beliefs about transmission vectors is a result of early epidemiological confusion that associated risk factors with risky populations (Patton 1996); that publically identified mistaken sources for the disease, which then had to be recanted (such as the use of "poppers"); and that failed to clarify why some modes of body fluid exchange were riskier than other modes (Sobo 1995:27).[8] Many of the erroneous beliefs retained together with accurate knowledge of transmission factors would appear nearly counterintuitive to discount. Anyone, for example, who has crushed a mosquito and detected how much blood the small insect can contain would wonder about its potential as an effective transmitter (Nicoll et al. 1993:231). Common sense would argue that if small amounts of HIV are detectable in mosquito blood or saliva, the insect should also be able to transmit the virus. Similar commonsense arguments could be made for beliefs about the retention of saliva on drinking glasses and toothbrushes. Issues of quantity and magnitude of the detectable

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manufacture would dissuade the believer from condom use and thus provide a real basis for concern. My point here is that some beliefs present more of a problem than others. Of course, beliefs that result in negative attitudes toward people with AIDS, blood donation, and so forth present a different problem but *not* one that (on the surface) explains nonprotective choices.

8. The absence of information from official sources creates a risk-information vacuum. As Powell and Leiss note, "Society as well as nature abhors a vacuum, and so it is filled from other sources. For example, events reported in the media (some of them alarming) become the substantial basis of the public framing of these risks; or an interest group takes up the challenge and fills the vacuum with its own information and perspectives; or the intuitively based fears and concerns of individuals simply grow and spread until they become a substantial consensus in the area of public opinion; or the vacuum is filled by the soothing expressions beloved of politicians: "There is no risk of . . . . [fill in the blank]." (1997:31)

virus needed for efficient transmission have presented continuous problems with alternate vector beliefs.

A significant number of AIDS studies, particularly concerning African American and Hispanic communities, suggest that the survival of "older" AIDS beliefs may be tied to mistrust of health experts (Thomas and Quinn 1991; Herek and Capitanio 1994; Smith 1996; and others). Conspiracy theories about government targeting of specific communities for annihilation, holding back of existing drugs and vaccines, dishonesty about the dangers of casual contact, information kept from the public, and policing of sexuality and drug practices appear to be common—particularly in communities that are disenfranchised. Numerous superb ethnographies have demonstrated the centrality of conspiracy beliefs to understandings of AIDS in subaltern communities (Farmer 1992; Turner 1993; Sobo 1995). Quantitative studies suggest that distrust of AIDS experts is widespread, with one survey (conducted by the Southern Christian Leadership Conference of 1,056 church members in five cities in the United States) finding that 35 percent of the respondents believed that AIDS is a form of genocide, 37 were unsure whether AIDS was genocide or not, 44 percent believed the government is not telling the truth about AIDS, and 34 percent believed that AIDS is a man-made virus (Thomas and Quinn 1991).[9] Other studies revealed similar numbers with nearly all who surveyed this issue indicating that their findings demonstrate considerable mistrust related to HIV/AIDS, particularly among youth and minority communities.[10]

The preponderance of AIDS conspiracy theories and expressions of mistrust has a direct relationship to safe sex and safe injection practices. Where there is a lack of trust in experts linked to the epidemic, there will be a lack of compliance. But the expressions of mistrust, the reporting of nonuse of protective measures despite accurate knowledge of transmission vehicles, and on some level, the continued signs of externalizing health beliefs point to

9.   The legacy of the Tuskegee syphilis study is evident here. From 1932 until 1972, 400 southern African Americans infected with syphilis were deliberately left untreated to allow scientists to monitor the progression of the illness. This study stands out as a horrific example of inhumanity and racism for the sake of "research" (see also Stevenson 1994:72).

10.   Some studies have suggested that mistrust of experts related to AIDS exists at the same rate throughout the entire population. Herek and Capitanio found, for example, that 44.5 percent of the white population in their survey also expressed distrust.

problems in risk perception and an inability to internalize personal vulnerability.

Risk Perception

Over the last sixty years health educators and social psychologists have designed a number of different models in the hope of explaining or predicting how health choices are made by members of the lay community. Models designed to predict health-related behaviors, such as the Health Belief Model, the Theory of Reasoned Action, and the AIDS Risk Reduction Model, all emphasize that perceived susceptibility is a key variable in health decision making. Each of these models posits a process by which behavior change is thought to occur in the cognition and lives of "normal" individuals.

The Health Belief Model was developed in the 1950s by social psychologists involved in the U.S. Public Health Service to explain the lack of public participation in tuberculosis-screening projects. The model attempts to predict health behaviors by focusing on the beliefs of individuals faced with a series of health choices. The model suggests six[11] variables that come into play as health choices are contemplated: perceived susceptibility to health threats, perceived severity of the health condition, perceived benefits of strategies to reduce the threat, perceived barriers to taking action, cues that motivate individuals to take action, and demographic and structural variables that affect decision making. Application of the Health Belief Model in a number of studies identified perceived barriers to taking health action as the most significant variable, with perceived severity of the health condition identified as the least significant motivator in health-related behaviors (Janz and Becker 1984). The Health Belief Model—although rife with limitations—was, in many ways, quite forward thinking for its time, particularly in its recognition of the importance of individual beliefs and perceptions as crucial to health choices and actions. The model does not, however, provide guidance in identifying the reasons for variety in the ways that individuals evaluate the potential consequences of their behavior.

The Theory of Reasoned Action, developed by Ajzen and Fishbein in 1980 as a general theory of behavior, is predicated on the

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11. Some assess the model as consisting of five variables by collapsing the final two into perceived ability to perform the task. (See, for example, Vanlandingham et al. 1995:196.)

notion that humans are rational and that their behaviors are under volitional control. According to the Theory of Reasoned Action, behaviors arise from intention, and intention is influenced by a set of attitudes along with a set of perceptions about group norms concerning the behavior. The theory links beliefs, attitudes, intentions, behaviors, and norms in a linear process that essentially argues that changes in an individual's behavioral beliefs (beliefs regarding outcomes) and normative beliefs (beliefs regarding other people's views of a behavior) will ultimately affect the individual's behavior change. The model is praised for its inclusion of peer influences on behavior, previously left out of the Health Belief Model (Vanlandingham et al. 1995:198). The Theory of Reasoned Action, however, is frequently criticized for its intentionality and for its linearity, which insists that changes in beliefs and attitudes must precede changes in behavior. Critics of the theory have pointed out, for example, that studies of seatbelt behaviors found that negative attitudes about seatbelts changed as individuals grew accustomed to using them (Kippax and Crawford 1993).

The AIDS Risk Reduction Model was first introduced in 1990 as a framework for predicting individual behavior change regarding sexual transmission of HIV/AIDS (Catina, Kegeles, and Coates 1990). The Risk Reduction Model incorporates variables from the other two behavior-change theories into a three-stage model. The three stages include (1) recognition of one's behavior as high risk; (2) making a commitment to reduce high-risk sexual contacts and to increase low-risk activities; and (3) taking action, including information seeking, obtaining remedies, and enacting solutions. In addition to the three stages, the model suggests influences that move the individual through each stage (for example, stage one includes knowledge of sexual activities associated with AIDS, belief that one is personally susceptible, belief that AIDS is undesirable, and social norms and networking). The AIDS Risk Reduction Model, while generally understood as a useful framework for designing interventions to reduce sexual behavior, is also criticized for not taking adequate account of the social influences that limit individual behavior choices (Denison 1999; McGrath et al. 1993).

Ramos, Shain, and Johnson (1995:499) argue, concerning the AIDS Risk Reduction Model, that "although this model makes intuitive sense, it does not provide an understanding of how to accomplish its goals." This comment is easily applicable to all three

behavioral-change models and captures the commonly held feel-ing that all three are more appropriately described as conceptual frameworks for thinking about illness behaviors rather than as ac-tual "models" (Fitzpatrick et al. 1984). While the models give us a means to begin to think about the variables involved in decision making and change, they serve only as templates for information that we know is elusive, and they do not give us any idea of how much weight to attach to each of the variables. The problem is, as Byron Good notes, that the health behavior models don't really re-flect "real world decision processes" (1994). The models ultimately are too synthetic in their view of "the value maximizing individual, responding adaptively to disease, selecting among a stable set of choices, and motivated by a set of meanings external to the subject" (Good 1994:44). Behavior change models construct the individual as, in Good's terms, "a universal economic man, proceeding . . . toward the goal of positive health, a preference only slightly modi-fied by health beliefs" (1994:42). The fundamental rationality of be-havior depicted in the Health Belief Model has been attractive to folklorists, who have long argued that vernacular health choices are not ipso facto irrational (see Hufford 1984; O'Connor 1995). But the models appear to work better in this regard and not as they have been applied to behavioral change. In the behavioral-change appli-cation, all three models become mechanical descriptors of what are considered "normative" decision-making processes.[12] As normative, rather than descriptive, models, they depict us all as autonomous health seekers—free to make what are seen as the "right" choices and needing just a bit of a shove to be oriented like any "rational" person toward the obvious steps leading to the obvious goals. So what, then, of the woman who dares not suggest her partner use a condom because she knows that he will interpret her request as a comment on his (or her) sexual history and the discussion will end in physical violence? In the risk-benefit ratio that is so central to

12.   Folklorists have read the Health Belief Model as an open model that "can be applied within any health belief framework and set into any cultural background, to assess how a given individual understands health or illness circumstances and how health behaviors follow from this understanding" (O'Connor 1995:31). The inclusion of perceived benefits and barriers and other aspects related to perception does suggest cultural openness. In behavioral-change psychology, however, the model is applied as a closed model, oriented toward moving the individual from one set of choices to another set of choices in as economic a means as possible. In this latter sense, the three models offer little guidance and continually frustrate health educators. In some sense, the models are both too open and too closed for this endeavor.

behavioral models, it is unlikely that protection against AIDS will ever weigh in as a benefit, when the perceived barrier is a black eye and a couple of broken bones. The problem with these models when used as behavior change models is that they are compliance models, oriented toward correcting wrongness—wrong beliefs and wrong behaviors—but they treat those "wrongnesses" as though they are singular and self-evident and as though they exist in isolation. Such an orientation destroys the notion of choice and yet simultaneously raises it to an unachievable stature.

In the behavior change calculation, risk is seen as having a consistent shape and a limited set of meanings, and "risk perception" is understood as concerned with a single "objective" form of risk. But, as the woman described above will tell us, the world is full of risks that have to be assessed, not only in relation to themselves, but also in relation to a multitude of other events and issues.[13] In part, the problem with risk-reduction models is a problem with the erosion of the term "risk" over time. As Mary Douglas notes,

> 'Risk' is the probability of an event combined with the magnitude of the losses and gains that it will entail. However, our political discourse debases the word. From a complex attempt to reduce uncertainty it has become a decorative flourish on the word 'danger.' (1992:40)

The sense of risk activities as associated with danger distances the notion from issues of cultural understanding involved in the weighing of gains and losses used in personal risk assessments. Risk activities (translated in Douglas's terms as "danger") tend to be seen in institutional terms as generalized, predetermined, and unquestionable. Richard Stoffle and his colleagues, in writing about environmental risks, discuss this institutional imposition of definition:

> Often, the specialists who conduct these assessments believe their estimates reflect the "real risks" of a technology or project because the estimates derive from scientific calculations. These "real risks" typically are presented through formal processes, such as public meetings, in which information flows one way, from risk

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13.   Stephanie Kane argues that one of the four central characteristics of risk is that risks are linked to each other and to non-health-related phenomena (1993:227).

communicator to the public with little or no exchange of infor-
mation between the two groups. (1991:612)

The emphasis on "real risk activities" as predetermined ar-
eas of danger frames risk assessment in externally defined values
and concerns, leaving locally defined concerns out of the picture.
Risk assessments, on the other hand, that are based on local crite-
ria focus on risk as it is perceived and evaluated by the lay public.
The tendency to ignore perceived risk as a valid component in the
assessment of risk is based on the notion that perceived risks are
neither objective nor scientifically derived—a position that hardly
matters if the party one is trying to motivate does not care about
or trust either of those criteria. While it is clear that the Health
Belief Model and other predictors of behavior change have tried to
account for risk perception by focusing on perceived susceptibility,
perceived severity, perceived benefits and barriers, they still assume
that the object of those variables is a single constellation of factors
that represents an objective thing (self-evident and devoid of ideo-
logical content) that we can call "risk." But understanding attitudes
toward susceptibility is dependent on understanding the variety of
cultural issues and influences that constitute risk *for the communities
and individuals in question*. The following observation concerning
sex-workers' risk behaviors should immediately tell us not only that
generalized risk categories can themselves be culture bound, politi-
cal, and moralistic but also that risk perception is multifaceted and
complex.

> Evaluation of sex worker risk reduction projects suggest that wom-
> en who sell sex are more likely to adopt prevention measures (es-
> pecially condom use or avoidance of intercourse) than are women
> who simply have sex in the context of recreation, love, or other
> socially condoned sexual arrangements. But the strong separation
> between sex for hire and sex for 'love' also results in a bifurcation
> of sex workers' risk reduction strategies. Women who sell sex are
> more likely to engage in prevention behaviors while having sex in
> the context of 'work' than in their domestic relationships. Several
> studies also show that condom use tapers off as a sex worker estab-
> lishes a regular relationship with a client. Sex has a range of sym-
> bolic meanings and use of preventative measures also has symbolic
> meanings: apparently, the better one knows a partner—paying or

not—the less appropriate it seems to enforce condom use. (Patton 1994:53)

The real problem is in trying to understand what risks look like to those who take them and in trying to understand the criteria that communities and individuals use to assess susceptibility. As Sobo notes, research on risk perception suggests that the meanings associated with a given risk affect how individuals "personalize, internalize and apply to themselves the information they receive about that risk" (1995:33).

In discussing risk management in relation to a series of case studies including E. coli, mad cow disease, silicone breast implants, and other high-profile risk-management controversies, Powell and Leiss note that good risk communication, focused on public perception of risk, seeks to

> 1. Understand the public's "framing" of the risk issue, especially in qualitative dimensions; 2. Acknowledge the specific questions that arise in this domain (which may be, and often are, quite different from those posed by experts); [and] 3. Analyze the conditions needed for allowing the public to acquire needed information, skills and participatory opportunities. (1997:30)

Management and marketing efforts focusing on purely persuasive techniques of risk reduction must be replaced with new ways of listening and responding to lay perceptions of the situation, if they are to be at all effective.[14]

Health Belief, Vernacular Theory, and Behavior Change

One of the issues that is most problematic in the behavior change paradigm of risk management is an underlying attitude that the concern with lay or public health belief and risk perception can

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14.   The risk-perception model presumes a high degree of agency in the practice of AIDS risk reduction. Some AIDS scholars have favored a model closer to that of the universal precautions used in health care because that model was not dependent on identifying and persuading specific individuals or groups that they are at risk in specific situations. Compliance with universal precautions tends to be extremely high (80 percent is reported in surveys of nurses) regardless of perceived risk. At the beginning of the AIDS epidemic, however, health educators favored a risk-based strategy over a population-wide strategy, emphasizing risk groups and "choose carefully" campaigns (Patton 1996:160). The result is our current struggle with risk perception.

go only so far before it will be incumbent on health experts to *correct* public perception, assert the *real* dangers associated with specific activities, and *manage* behavior change. This assumption is linked to the equation of risk assessment with scientific and technological "truth" and risk perception with "false" understanding. As David Hufford notes in connection to academic treatment of folk belief, the implicit attitude is "what I know, I know; what you know, you only believe" (Hufford 1982:47). This "arrogance of technical expertise," as Powell and Leiss call it (1997:35), varies in its expression from open articulation of contempt for the lay public to the zealous and sincere defense of passionately felt concerns about public danger. While the latter is at least backed by an overwhelming concern for the public good, both perspectives demonstrate an impatience with a public seen as noncompliant and, by definition, unsophisticated in its evaluation of risk realities. Like other compliance models, attitudes of risk experts toward public risk perception and lay decision making arrange themselves along an authoritarian/democratic continuum with ideological concerns expressed as the need for, at one end, obedience and adherence and, at the other end, cooperation and collaboration. But, as Bonnie O'Connor comments concerning patient education,

> Patients to be educated are often assumed to be "empty vessels" who, in the absence of medically accepted knowledge about health and illness, are assumed to have *no* knowledge about them as a basis for making choices or taking action. . . . The conception of patient education thus frequently operates on the basis of an extremely simplistic view of its mission: "communicate successfully with people so they will understand their health problems (usually as we, not they, define them) and they will want to change their behavior. . . ." When the proposed changes do not occur, or when they come about very slowly, the cause is generally interpreted as "resistance to change" and defined as a "problem" which is located in the "target population." (1995:177)

O'Connor continues by noting that this model omits the "actualities of patients: their circumstances, experiences, worldview, knowledge, values, self-perceived needs, and their agency in responding to these" (177). Assumptions made by risk theorists have tended to mirror those noted by O'Connor in relation to patient education, treating

the members of an educational target population as though past and present sexual, social, and health experiences, cultural associations, social contexts, influences, and knowledge have no significant bearing on health decision making. The notion that individuals have "expert knowledge" in their own cultural milieu is not a comfortable notion for health educators trained in a compliance, information-dissemination model. Nevertheless, most individuals, if asked, can provide clear, and sometimes quite sensible, "explanatory models" (Kleinman 1975) for how they arrived at health choices.

The task of risk-perception theorists is to uncover the cultural assumptions that dominate both within health education and within individual cultural contexts. For example, as Calnan (1987) and others have shown, lay health-belief systems tend to place high value on subjective experience and focus heavily on ability to function and social well-being as evidenced by physical fitness, energy, vitality, absence of pain, feeling healthy, and the ability to maintain social relationships. This contrasts with the biomedical valuing of objective experience over the subjective and the emphasis placed in Western biomedical paradigms on health as the absence of disease and the appropriate functioning of biological and psychophysiological process. These contrasting characteristics of health belief systems are reflected in risk perception in terms of the following: issues of immediate and ultimate causes of illness and the identification of risk; what counts as evidence of risk and standards of credibility for risk managers; what degree of risk is acceptable, normative, or even desirable; whether or not one combats risk once located and how; what type of information is needed and how information is appropriately obtained; and what are seen as acceptable alternatives to activities internally identified as risky.

While it is tempting to create a dichotomy in which all medical researchers, scientists, and health educators understand the world through biomedical paradigms and all nonmedical and nonacademic individuals become the "folk," understanding the world through lay health paradigms, the formula is misleading. Although lay models of health and illness tend to differ from biomedical models, this does not necessarily mean that physicians, medical researchers, or health educators hold strictly to medical models. As Lock (1982) has shown in an examination of gynecologists' approaches to menopause, practicing physicians' views are based on a melding of folk, as well as textbook, concepts. According to Lock, the combining of views assists

physicians in dealing with the practical interactive aspects of their clinical work. A similar combination of lay and medical concepts can be found in explorations of risk assessment among physicians. Numerous studies have highlighted pervasive fears of HIV exposure and transmission among health-care workers, associated with stated intentions to leave the medical field. Heath, Acklin, and Wiley note that these fears are "often bordering on hysteria, exist[ing] despite the reportedly low percentage of patients who are seropositive (three percent . . .) and the even lower incidence of seroconversion following a single exposure (estimated by the Center for Disease Control at one percent upper confidence boundary following needle puncture exposure)" (1991:1860). Heath and her coauthors argue, based on these observations, that "although such fears are understandable given the horror of the disease, biases and distortions in the risk assessment process might be leading those at comparatively low risk to be excessively fearful" (1991:1860). It is likely that in most areas of health, both patients and physicians hold a variety of lay and conventional ideas, ideas that can play a significant role in risk assessment and response. For this reason, understanding lay risk models is crucial, not just to the ability of health educators to reduce risk-taking behavior in the general population, but also to understanding attitudes toward risk at the very core of health care.

The ability of analysts to gain access to lay risk models is dependent on their ability to sacrifice the mind-set that "theories" can be held only by a certain intellectual elite. Useful in this regard, both for social science perspectives and for changing paradigms in health education, is the notion of "vernacular theory," initially coined by Houston Baker in his book *Blues, Ideology, and African American Literature: A Vernacular Theory* and elaborated by Thomas McLaughlin in *Street Smarts and Critical Theory: Listening to the Vernacular*. The term "vernacular" has been used for some time to refer to community-based forms of cultural expression, such as vernacular architecture, vernacular design, and vernacular language. The sense in which vernacular is meant here, however, goes a little bit further than community-based expression, following on McLaughlin's contrast of "vernacular theory" with "critical theory." McLaughlin defines vernacular theory in this way:

> It refers to the practices of those who lack cultural power and who speak a critical language grounded in social concerns, not

the language spoken by academic knowledge elites. They do not make use of the language of analytical strategies of academic theory: they devise a language and strategy appropriate to their own concerns. And they arise out of intensely local issues that lead to fundamental theoretical questions. (McLaughlin 1996:5–6)

Vernacular theory can be seen as parallel to Michel Foucault's notion of "subjugated knowledges." Foucault notes, "A subjugated knowledge is an autonomous, non-centralized kind of theoretical production, one . . . whose validity is not dependent on the approval of established regimes of thought" (1980:81). These knowledges, according to Foucault, "have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity" (1980:81). Foucault contrasts these knowledges with what he calls "the tyranny of globalizing discourses" (1980:83). Popular culture theorist John Fiske contrasts a similar notion, which he calls "localizing knowledges," to the "imperializing knowledges" of dominant culture (1993:19). He argues that localizing knowledges

> function not to extend a great vision over the world but to produce a localized social, ethnic, communal sense of identity. They create cultures of practice, ones that develop ways of living in the world and which seek to control only those ways of living rather than the world in which they live. (1993:19)

While Fiske's comments appear to sell short the potential for proactive vernacular response, he nevertheless stresses the immediate and quotidian nature of local knowledge in a way that mirrors McLaughlin's sense of vernacular theory.

Vernacular theory is useful to the understanding of risk perception in that, like ethnoscience, ethnomethodology,[15] standpoint feminism, and a number of other social-scientific frameworks, it accepts local voices and native expertise as the starting point of analysis. Vernacular theory as applied to risk perception reminds us that

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15. Ramos, Shain, and Johnson apply ethnomethodology to risk perception in their study "Men I Mess With Don't Have Anything to Do with AIDS: Using Ethnotheory to Understand Sexual Risk Perception" (1995).

1. the authority of experience is frequently weighed as superior to "objective" information in individual and cultural analysis defining risk;

2. shared experience creates observable *patterns* identified by community members as a basis for risk theory (in a process clearly identifiable as a kind of folk surveillance or folk epidemiology);

3. vernacular theory provides an experientially based, alternative construction of risk, which, while subjugated in terms of medical authority, is likely to address the daily concerns, experiences, and worldviews of those coping with health, illness, sexuality, and other risk-related issues;

4. vernacular theory raises questions about dominant cultural assumptions, and like all theory, it begins in specific interpretive complexities, proceeds by local rules, uses local forms of discourse, and makes its fullest sense in the cultural context out of which it arises.

Illness and Narrativity

While research in the social sciences has increasingly stressed the cultural construction of health and illness and the critical importance of an adequate understanding of lay health decision making, researchers continually struggle with the means to access vernacular health belief. Attitudes toward health and illness are often out of awareness and are not easily articulated in response to standard survey methods (such as questionnaires, polls, or directed and semi-directed interviews). The struggle to access vernacular health belief has prompted, among both medical researchers and social scientists, an exploration of the use of illness narratives as a natural form for articulating the meanings and values associated with health, illness, and suffering, within specific individual and cultural contexts. The growing literature on narrative dimensions of illness, care-seeking, and therapeutic process asserts that experience is organized in narrative form and that cultural knowledge and scripts for health decisions are encoded in illness narratives. Cheryl Mattingly makes the case for the study of illness narratives:

> If narrative is based, as Jerome Bruner (1986, 1996) notices, on a "breach" of the commonplace, then profound physical and mental suffering constitutes one breach that seems to demand a narrative

shape. It is one liminal place within the human condition that calls for sense-making and this often takes narrative form.

Speaking of the need for narrative among the very sick, the literary critic Anatole Broyard, dying of cancer, writes: "my initial experience of illness was a series of disconnected shocks, and my first instinct was to try to bring it under control by turning it into a narrative. Always in emergencies we invent narratives." (1998:19)

Illness narrativity research focuses on narrative as a means of experiencing, representing, and negotiating illness, highlighting the interface of experience with cultural models of thought and action. The theory behind narrativity research is that attitudes toward illness and health are better apprehended through narrative than through abstract or formal discourse and that a wealth of vernacular health information is revealed in the telling of narratives and their interpretation by others within the same culture.

Illness narratives are most often culled through a process that expands on the clinical history model used by physicians by focusing on the interpretive significance of fuller illness-related life histories. Good, Brodwin, Good, and Kleinman (1992), Good (1994), Mattingly (1998), and others assert that experience has a fundamental narrative quality and that illness stories both represent the past and provide a frame for organizing and understanding the present and the future. In this sense, illness narratives serve as statements of cultural knowledge and understandings and also provide scripts for future care seeking and health decision making. Byron Good argues that much of what we do in daily life, and much of what happens to us, is not worth narrativizing (or, in William Labov's terms, is not "tellable" [Labov and Waletsky 1967]); therefore, what does become a narrative indicates some level of significance for the teller or the audience[16] (Good 1994:139). In this sense, illness-narrativity scholars see narrative as a means of marking the impact and importance of a narrated health event or incident on the individual, thereby articulating complex symbolic meanings and cultural values. As Farmer notes, "illness meanings emerge in situated discourse" (1994:806).

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16. This is not understood by illness-narrativity scholars in quite the situated and emergent way that performances are understood by folklorists. Nevertheless, the notion that the creation of a narrative indicates significance (at some point, in some way) for the teller or audience (or both) is not, all in all, a notion with which folklorists would disagree.

Evelyn Early's work on therapeutic narratives among women in Cairo was among the first studies to focus on illness narratives. Early focused on everyday stories of illness that, she argued, operated as a "middle level system between experience and theory," allowing the women to develop an interpretation of illness in relation to "local explanatory logic" and biographic context and to negotiate reasonable action (1982), thus, as Good notes, "embedding the illness and therapeutic efforts within local moral norms" (1994:143). Early's work demonstrates the use of illness narratives as a means of gaining access to health worldview. Later studies in illness and narrativity have experimented with the benefits of applying methods of literary analysis and structural analysis to stories of personal illness experiences. Scholars such as Garro (1992) and Mattingly (1998) have focused on the relationship between the chronological structure of illness narratives and the parallel structure of illness and have explored the usefulness of literary concepts such as temporality and enplotment in illness narratives. While these studies are interesting and potentially very useful for our understandings of illness experience, it is primarily the use of narrative as a tool for uncovering vernacular health belief and explanatory models that has potential implications for accessing risk perception.

The following study will not focus on the narratives of those currently experiencing illness through the eyes of a patient; nor will it focus on illness history narratives, although AIDS research would certainly benefit from both perspectives.[17] Because this volume is primarily concerned with risk prevention rather than the experience of those who are already ill, the focus will be on illness encounter narratives. While illness narrative theorists have generally recognized the existence and importance of nonpersonal, shared, or "prototypical" (Good 1994:133) narratives, they have tended toward the construction of such narration as rare and located primarily in the past, while casting contemporary North American health narratives solely as reports of personal experience.[18] Nearly all of the more extensive works on illness narratives discuss the search for meaning in older exotic "myths," "magical stories," and "ritual

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17. And has benefitted from such studies. See, for example, Chandler (1991) on narratives from AIDS support groups and Dean (1995) on AIDS in autobiography.
18. A significant exception concerning the role of collective narratives in understanding cultural models of AIDS is Paul Farmer's article "AIDS-Talk and the Constitution of Cultural Models" (1994).

performances" (Mattingly 1998; Good 1994), but contemporary collective or fictional narratives are somehow not seen as relevant to the contemporary scene.[19] As Cheryl Mattingly notes, "current analysis of narratives, especially within medical anthropology, focuses increasingly on personal stories of individual experience rather than collective stories" (1998:9). Such a construction ignores the vast body of *shared* nonpersonal narratives about health that encode associative meanings linking illness and health to fundamental cultural values, explanatory models, and social relations. In the pages that follow, these stories—the ones that we use to explore AIDS, the ones that we share with others who share our cultural outlook, the stories we use to understand and discuss risk—will help us try to make sense in *and of* health education.

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19.   This treatment of shared narrative as primitive betrays the lack of folklorists' writing in the field of illness narrativity. Generally, this literature cites only the work of Vladimir Propp and one or two other scholars in the field.