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Once Upon A Virus

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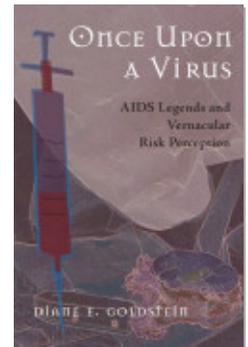
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Once Upon a Virus

Public Health and Narrative as a Proactive Form

The stories told on the pages that precede this chapter are not just entertaining tidbits of dinner conversation but rather the incredibly powerful narrative core of personal and collective action. This is not to say that we are slaves to the stories we hear, going out and enacting each narrative plot or including all narratives uncritically in the body of information we hold to be true. But the narratives we hear and tell dovetail with our cultural life, becoming slotted in holes in information, explicating unresolved issues, challenging unpopular dominant constructions, asserting the importance of cultural truths in the construction of health truths, and forming the basis of crucially important health choices.

The health-related choices that arise from the narratives are numerous and are even sometimes unquestionably positive. Rumors concerning C. J. AIDS, the writer of the letter to *Ebony* magazine who asserted that she was deliberately spreading the disease throughout Dallas, Texas (discussed in chapter 2), inspired a flurry of public health activity. Following the *Ebony* story and the interview on a local radio talk show (both of which proved to be hoaxes), there was an incredible increase in males in the area seeking AIDS tests and attending educational seminars. One local health official was quoted as saying, “I look at what happened with C.J. as a fire drill, something that has made people aware of danger and risk” (Ellis 2001:161).

Paralleling the situation with C.J., rumors of Ray Mercer infecting large numbers of women in Conception Bay North were followed by a significant acceleration in the rate of visits to local CBN AIDS clinics. The Ray Mercer stories, however, may have motivated other critical health actions, some positive and some more disturbing. One public health nurse indicated that she feared that the Mercer stories would inspire individuals to take risks, feeling safe in their knowledge that they had not slept with Ray and therefore were invulnerable and, further, that Ray would become a true scapegoat in the sense that HIV-positive individuals who wished to protect themselves or their partners from contact tracing would untruthfully assert Mercer as the source of their infection. The Mercer narratives played a role in both the closing and reopening of blood clinics, in the local understanding of and reaction to AIDS, and in partner selection. Through the stories and their tellers, we can infer the potential for other legend-inspired health choices: that some individuals might take greater care with pay phones, movie theater seats, gas pumps, cars, and fast food than they do with condom use (especially if condoms are believed to contain holes punched through them on drugstore shelves and thus are believed fallible anyway); that sex at home might be seen to require less safety than sex away or with strangers; that people who are HIV positive are perhaps understood as socially recognizable and therefore avoidable; that lack of promiscuity might equal safety; and the list goes on. But as we have said, these stories don't simply promote wrong ideas, wrong choices, and wrong behaviors, they emerge out of and articulate ideas, concerns, and attitudes that are already present and that are acceptable and viable within the culture. This chapter will explore the messages about vernacular risk perception hidden in these narratives and what they mean for public health. Before dealing with specific issues that arise out of these narratives though, a number of general areas of significance in the construction of risk and the relationship between vernacular culture and medical culture should be addressed.

The "Know Your Partner" Message

The legend material discussed in this volume underlines the possibility that the statistics on low rates of condom use despite widespread knowledge of the literature on risk activities might actually

be being misread by health educators. Continually, these statistics are taken as a sign that the general population is not protecting itself and is disregarding safe-sex messages. But a different reading, one based on Farmer's hermeneutic of generosity, is also possible. Perhaps those who are understood as demonstrating a flagrant disregard for safe-sex messages are actually hearing the messages and engaging in what they understand culturally to be a type of *safer* sex. The following quote from a teenage male, for example, demonstrates an understanding of safer sex as involving both protection from pregnancy and knowledge of the partner but not necessarily condom use.

Well, obviously, my opinion is unsafe sex is somebody who you just meet, you don't talk about things and you don't use any kind of contraception, birth control or prevention against STDs. Okay, the girl that I'm seeing right now, we practice safe sex for contraception. She's on the birth control pill and that's all we practice. Whether or not, you know, we have never been tested for HIV. (Lear 1995:1319)

As Metts and Fitzpatrick note, "Many sexually active people do not use condoms but assume they engage in safer sex because they have intercourse only with persons they believe to be safe" (1992:1). Canadian AIDS researcher Eleanor Maticka-Tynedale found in her interviews with heterosexual college students that the most popular prophylactic was the selection of a noninfected partner (variously ascertained) (1991). These findings are consistent with those of Cindy Patton, briefly mentioned in chapter 3, who found that sex workers were more likely to use condoms at work than they were in their personal relationships and that condom use would decline as the sex worker established a regular relationship with the client. Patton noted, "the better one knows a partner—paying or not—the less appropriate it seems to enforce condom use" (Patton 1994:53).

We should not be surprised by these assertions that knowledge of a partner, or what is seen as wise partner selection, provides safety from risk of infection. Public health, initially, although to some extent inadvertently, suggested that this was the case. In 1988 when the American Surgeon General's office sent its brochure, "Understanding AIDS," around to every household in the United States,

it solidified the “know your partner” public health strategy. The brochure instructed readers to ask several questions about a potential partner’s background before engaging in a sexual relationship. Among the questions were these: Did the individual experiment with drugs? Had the potential partner ever had a sexually transmitted disease? How many people had the partner slept with? The idea behind the campaign was to help individuals evaluate the risk of intercourse with each new partner. But the campaign was a mistake. It told the public that individuals infected with HIV were somehow distinguishable from “safe” partners and that rather than initiating indiscriminate condom use, one simply needed to avoid unsafe sexual liaisons.

In Canada, the campaigns contained similar messages. In 1988 the Ontario Ministry of Health created a brochure for mass mailing called “AIDS, Let’s Talk.” The brochure emphasized the importance of abstinence and monogamy and once again asserted the “know your partner” philosophy. The phrase “safe sex” was never mentioned in the brochure, and condoms were mentioned only once in a sentence that said, “If you have sexual intercourse with someone whose past you’re not sure of, use latex condoms” (cited in Kinsman 1991:50).

In many ways “know your partner” strategies form the very basis of the attitudes voiced by those interviewed for this project and found within the AIDS legend corpus. Clearly, Ray’s reported comment when his partner queried condom use (“If I had slept with any ‘sluts’ I would tell you”), the practice of showing a blood-donor card to potential partners, and the “Welcome to the World of AIDS” and “Top Forty” legends all operate on a “know your partner” principle. Later public health campaigns in both the U.S. and Canada tried to undo the damage. Health Canada subsequently issued several brochures and posters that focused on the impossibility of detecting infected partners. One poster, for example, announced, “If Mr. Right Won’t Wear a Condom, He’s Wrong.” Another used a foil mirror to indicate that even the reader could potentially have the face of an HIV-positive person. But the idea of practicing “safer” sex through “know your partner” strategies made sense to much of the heterosexual public and seemed a far less difficult option than consistent condom use.

Knowing your partner as a strategy for safety fit nicely with the negative attitudes toward condoms continually reported in North American knowledge, belief, and behavior studies (see, for example,

Kelley, St. Lawrence, Hood, and Brasfield 1989). These studies generally found that respondents reported lack of use due to reduced sensitivity, loss of spontaneity, discomfort, unpleasant odor, and messiness (Kelley, St. Lawrence, Hood, and Brasfield 1989). Further, as condoms became increasingly associated with HIV protection, they began to take on a connotation of guilt; individuals would introduce a condom into sexual activity if they had reason to believe that either they or their partners were HIV positive. The result was an association of condom use with the suggestion of promiscuity, drug use, uncleanness, and lack of care.

More abstractly, the “know your partner” strategy worked well with the natural distancing mechanism, which searches for ways to demarcate differences and boundaries between ourselves and disease. Basing his argument on physician surveys, Sander Gilman asserts that entrenched in our culture is the notion that you can *see* disease:

Young physicians often see beautiful patients as exemplary or “good” patients, patients who will follow doctor’s orders and therefore will regain health. The aged or poor patient, on the other hand, is seen even by the trained physician, as one who is a “bad” patient, a patient who will probably “make trouble” and whose health will not improve. Indeed “lower-class” patients were often diagnosed as being more gravely ill and were given poorer prognoses than those of other social classes when, in fact, they differed from the patients only in terms of the visible (or stated) criteria of class. Cultural differences concerning gender also play a major role in constructing those groups understood as being more at risk. Obesity, while statistically more frequent in males than females, was used as a criterion twice as often for women as for men. (1988:4)

If, as Gilman argues, even physicians correlate beauty, outward impressions of class, and weight with health, one can only assume that equivalent notions of health and disease as visible and easily distinguishable exist within the general population.

Added to these reasons for the cultural preference for “know your partner” strategies is a general governing natural sense that those whom you “know” (variously defined) are unlikely to hurt you, while strangers—those who exist apart from you and “out there in the world” (variously defined)—are less trustworthy. Legend scholars

call this phenomenon “stranger danger” (Conrad 1998; Whatley and Henken 2000:76), the common notion expressed in contemporary legends, including those not about AIDS, that evil lurks outside of one’s social group while known individuals provide relative safety. It is the governing ethic of “stranger danger” that places so many legends away from home, in the company of cultural “others,” and creates the foreign or culturally distant antagonist. “Know your partner” advice makes great sense within the “stranger danger” ethic. In Newfoundland, the rural and island distrust of those who “come from away” and the dependence on social networks that made so much sense in outport communities dovetail nicely with both the “stranger danger” and “know your partner” ideologies. In many ways, knowing your partner is possible in outport Newfoundland in a way that would not be possible in larger centers. One might remember in this context that news of Ray’s infection travelled quickly through the community, ultimately motivating one of the infected women to seek testing. Comments such as “if anyone I had slept with was infected I would have heard” are not uncommon in Newfoundland or for that matter throughout North America. But in Newfoundland they take on a different resonance, meshing with the common belief (and considering the isolated gene pool, the fact) that nearly everyone on the island is intimately connected.

As mentioned above, an unfortunate consequence of the “know your partner” strategy is a resulting notion of discernable innocence and guilt associated with HIV. The strategy provided questions that are easily construed as a quiz or test for innocence—the right answers cleared one enough to allow sexual interaction. The flip side of the strategy’s “low vs. high risk” / “innocence vs. guilt” message was a prevailing notion of an identifiable HIV-positive bad guy, an AIDS outlaw. In some sense the “know your partner” brand of “safer sex” could be taken as the ability to find the bad guys and avoid them. C. J. AIDS, the “Irish Angel of Death,” “Welcome to the World of AIDS,” Ray Mercer, “Top Forty,” and numerous other AIDS legends all depict the knowable, distinguishable, AIDS bad guy. While that notion is devastating when considered in relation to the treatment of persons with HIV/AIDS, it also, of course, conveys the message that if one stays away from the AIDS bad guy, safety is assured. The public’s job then is to devise increasingly sophisticated ways of assessing guilt or innocence (Patton 1994:83), new and better ways of spotting the bad guys. The legends and legend tellers do exactly that. After all, public health told them to.

Lay Risk Assessment and the Problem of Perceived Susceptibility

The rationalistic models of risk-related behavior discussed in chapter 3 (the Health Belief Model, the Theory of Reasoned Action, and the AIDS Risk Reduction Model) all contain an inherent assumption that knowledge of risk factors will relate directly to the informed estimation of one's own risk. As we have argued, where the models have not been successful is in their lack of allowance for the cultural associations and meanings that feed individuals' abilities to internalize and apply notions of risk to themselves. The various knowledge, belief, and behavior studies suggest that the correlation of knowledge of risk factors, perception of susceptibility, and risk-reducing behavior is not a simple one. The problematic part of these models is our lack of understanding of the components of perceived susceptibility. Separate studies by Landesman (Nichols 1990) and Lindsay (with others, 1989) of large samples of seropositive women, for example, found that over 70 percent of those who tested positive for HIV did not acknowledge *any* participation in risk activities. As discussed in the previous chapter, Weinstein addresses the issue of unacknowledged risk by asserting that most individuals engage in what he calls "an optimistic comparison bias," which preserves self-esteem by asserting that others are at higher risk (1989). As a result, the more stigmatized the condition, the more likely one is to underestimate personal risk. Sobo's subsequent analysis (1995) puts both a cultural and narrative spin on Weinstein's findings by asserting that women continually tell stories to the outside world and to themselves concerning their participation in what they see to be the ideals of heterosexual relationships, particularly wisdom in partner choice and the monogamous nature of their actions and those of their partners. To suggest risk then, Sobo argues, is to suggest that one or one's partner has at some point not chosen wisely. Likewise, to suggest condom use implies that either the individual has not been monogamous or accuses the partner of infidelity (Sobo 1995). According to both Sobo and Weinstein, the need for preserving self-esteem makes it highly unlikely that one will recognize potential participation of either partner in risk activities or take protective action. Deeply entrenched in our cultural response to the "know your partner" advice is the belief that a partner who has been chosen wisely will not hurt us, and that is the very stuff of the optimistic bias.

The diminishment of one's own risk, inherent in the optimistic bias and the wisdom and monogamy narratives, corresponds natu-

rally, however, to the *exaggeration* of risk outside of one's primary relationship, home, or community. AIDS crime legends and panics reinforce notions of diminished risk at home by constructing the image of the "foreign" or "named" deliberate infector with murderous intent who is responsible for high rates of infection. The scapegoated deliberate infector creates sharp contrasts of guilt and innocence that feed directly into optimistic bias and pinpoint risk as existing primarily with identified externalized individuals. Legal cases of nondisclosure of HIV-positive status fan the flames of externalized risk belief, appearing (especially through the media's handling of such cases) to suggest that once specific individuals are incarcerated (or dead) the public will be safe from disease. Risk is "out there," not in one's home or personal relationships. The needle and pinprick stories discussed in the last chapter convey a similar message, making the external world and the behavior of others the "real" location of risk. Stories of garbage collectors handling bags and receiving needle pricks, individuals finding discarded needles on a lawn, and other more mundane pin-prick stories combine with the legendary needle narratives to externalize risk by collecting unusual risk factors and making them appear usual. As noted, the effect is to make the external world riskier than any risks that might obtain in personal behavior.

Also present in the AIDS legends is a message concerning the *futility of risk management*. Primary among the arguments related to futility assessments are narratives concerning the fallibility of risk-reduction measures. Stories of condoms that break or that are reported to have holes deliberately placed in them and narratives of lack of care with body fluids by HIV-positive individuals outside of the bedroom provide the data for futility assessments by suggesting that no matter what one does to reduce risk, efforts of self-protection will be rendered insignificant or useless. Futility assessments also take the narrative form of conspiracy and fatalistic beliefs, suggesting release from personal responsibility for self-protection by placing viral control in the hands of corrupt government or medical bureaucrats or in the hands of a higher power.

While Weinstein and Sobo tend to take a sociopsychological view of the optimistic bias, monogamy, and wisdom arguments, their findings are parallel to the concerns and attitudes expressed continually in AIDS legendary forms. For Weinstein and Sobo, however, these are mechanisms of denial: a refusal to grant the truth of one's

risk. The denial argument is indeed one way of understanding lack of perceived susceptibility, but it moves toward a line of argument that reflects perspectives focused on “real risks” as a nondialogic form, that is, as a singular one-way communication of messages. Similar to the cultural understanding of “safer sex” as careful *partner choice* despite lack of condom protection, optimistic forms of risk denial can also be understood as the weighing of cultural truths over public health truths. In this understanding, risks are not denied, they are ultimately weighed as less significant than the risks to self, partner, and relationship implied in a perception of personal susceptibility.

Despite my small quibble with Weinstein and Sobo on the framing of these narratives and attitudes as “denial,” they address the issue of diminished internal risk assessment in a way that provides clarity for understanding a series of risk-assessment mechanisms expressed in the legend corpus, including the expanded external risk and futility arguments discussed above. Through diminished internal risk assessment, exaggerated external risk assessment, and an assessment of the futility of risk prevention, the narratives reinforce the decision not to comply with condom-use advice. These mechanisms and their corresponding narrative forms are portrayed in the following table.

Mechanisms for Risk Assessments

Diminished Internal Risk Assessments	Expanded External Risk Assessments	The Futility of Risk-Prevention Assessment
Optimistic Comparison-Bias narratives (Weinstein 1989)	Deliberate Infection Narratives	The Fallibility of Risk-Reduction Measures Narratives
Monogamy Narratives (Sobo 1995)	The Collection of Multiple-Unusual-Risk-Factor Narratives	The Fatalistic/God’s Will Risk-Assessment Narratives
Wisdom Narratives (Sobo 1995)	AIDS Crime Narratives	The AIDS Conspiracy Narratives
“Know Your Partner” Advice	Nondisclosure Legal Cases in the Media	

The diminished internal risk, expanded external risk, and futility mechanisms continually feed into and out of the narrative tradition, affecting health choices and asserting the importance of cultural values in the construction of risk.

The Question of Authority

The tellers of these stories and their audience are actors in a world that combines the traditional reliance on narrative for life's instruction and news with a new kind of medical consumerism, lay activism, and questioning of medical authority. More than any other disease, AIDS has challenged the construction of health expertise, questioned the credibility and claims of scientists, physicians, and others in positions of power, and brought to the forefront the view of a thinking, researching, credible, political, and active layperson. As Steven Epstein has argued, "the interventions of lay people in the proclamation and evaluation of scientific claims have helped shape what is believed to be known about AIDS—just as they have made problematic our understanding of who is a 'layperson' and who is an 'expert'" (1996:3). The reasons for the incredible impact of AIDS in the promotion of lay expertise are complex but arise largely from the populations first associated with the disease and the moment in history at which it arrived. As Epstein notes, the disease affected young people in their twenties and thirties, who were disinclined to "lie down and wait to die" (10), and it initially appeared in the gay community among people who had become used to identity management and knew how to mobilize and to challenge social norms, organizations, and institutions. It is also not insignificant that the gay community was comprised in part of white, middle-class men with political clout, education, money, and fund-raising abilities. But AIDS also benefited from what Epstein calls "social movement spillover" (12), coming as it did after the feminist health movement of the 1970s, which critiqued patriarchal medical institutions, argued for women to take back their bodies, and promoted the creation of self-help and support groups. It also followed the activism of the antinuclear and "green" movements, which actively challenged scientific authority, and the New Age movement, which rejected much of the scientific way of knowing and argued for the importance of other kinds of epistemological structures (Epstein 1996). While lay activism is generally discussed in relation to the control of treatment and clinical trial issues, it can also be seen in less obvious and perhaps less political ways in resistance to medical authority and moral regulation, defiant reactions to constructions of safety, distrust of and noncompliance with public health information and expertise,

and an overall assertion of cultural ideologies rather than scientific/medicalizing ideologies.

The spectacular successes of AIDS activism also came at a time when the economic structures of health care were shifting in ways that were seen as threatening to patient-practitioner relationships and the continued quality of health care. The corporatization of the American health-care system, continual threats of privatization in Canada, and the growing power of third-party hospitalization and care payment systems to define treatment strategies were increasingly creating lay dissatisfaction with medicine and a heightened sense of alienation. As O'Connor states,

The shift in perspective from medicine-as-service to medicine-as-business transforms patients into "consumers" of health care. The business model embodies a fundamental change in moral view: while the classical patient-physician relationship was based on an ethic of trust and service, the consumer-provider relationship is based on savvy, skepticism, self-protection (on both sides) and the directives of the "bottom line." Ironically, it has also placed patients in a relatively more powerful position ideologically with respect to the system, for it has heightened their sense of their right to choose. Consumerism is based on choice. Consumers compare and critique, and they bring their own standards and preferences to bear in evaluating their purchase options. They continue to patronize (and help to advertise) only those providers of goods and services who satisfy their needs within the framework of an adequate cost-to-quality ratio. Consumers decide both what they perceive their needs to be and how well they feel those needs are met by specific products and services. (1995:167–168)

The new medical consumer no longer "bought" what physicians said "on spec." Medicine was a new ball game from the lay perspective and one that required greater public accountability and less arrogance and authoritarianism on the part of health care systems.

In addition to the activism created by lay reactions to the epidemic and the business model of health care, the Worldwide Web and Internet were also busy creating a new kind of medical consumer in North America—one who had access to a proliferation of information and ideas. Researching your own syndromes and treatments on

the Web, becoming knowledgeable about ever more sophisticated ways to protect yourself,¹ communicating with others through Internet health-support groups, passing on warnings about products, conspiracies, and misinformation are all part of the rise of lay uses of computer technology. Not long ago such a statement might have been true only of privileged populations, and to some extent this is still the case; but increasingly Internet accessibility has worked its way out into the community, available in public locations such as free libraries and through schools, community centers, and other social services.² The new, technologically assisted health consumer was no longer forced to be a passive receptor of physician's advice. The result is a (generally) more-educated lay consumer but also one who processes information and ideas from a variety of sources, including those that medical professionals might not wish to encourage or support. Conspiracy sites, hoax sites, alternative-science sites, as well as natural communication in chat rooms, e-mail, and discussion lists—all are seen as potential purveyors of misinformation. As a result, Health Canada and the Center for Disease Control have both created medical rumor and hoax Web sites dedicated to dispelling popular information which they see as inaccurate and risky. The United States Information Agency (USIA) also employs a Program Officer for Countering Misinformation and Disinformation, charged with responding to false stories considered to pose a risk to the United States and its citizens, many of which are health related (Castañeda 2000:137).

Despite official stereotypical views to the contrary, lay readers of Internet health materials have not, however, been passive receptors of the information they contain. In fact, many Internet health-support groups and discussion lists exist, in part, as a mechanism

1. This is not to say that lay people have not always asserted considerable knowledge about their health and treatment. Certainly vernacular health practices and beliefs have always coexisted with the use of more-official medical resources. The new activism, consumerism, and access to information through the Internet, however, represents a higher degree of interaction between systems than has been previously the case in Western cultures.
2. When I once asserted too strongly to an American colleague that ready access to computer communication was class based, she took me to the public library in her city to witness the number of homeless individuals "surfing the Web." While I admit that access may be more widespread than I had once thought, it is worth noting (with caution) that literacy in general is still, to some extent, an artifact of privilege. Nevertheless, the increased access for some means, in a sense, increased access for many, due to the speed with which lay health information is shared by word of mouth.

for sifting through the proliferation of studies and information now available to both health care workers and the lay population (see Goldstein 2000). The cooptation of the C.D.C. voice, and therefore C.D.C. authority, in the circulated “needles in movie theater seats” warning indicates that lay users of the health Internet do not only sift through and carefully process the content they find there but also react to the legitimization structures encountered on the Web. In other words, they are cognizant of the source and the relative hierarchy of authority. While they may not agree with that source or agree with its place in authoritative structures, they are aware of its officialness, and one would assume they are equally aware of official hierarchical attitudes toward less-legitimated sites. As is the case with all forms of health information, lay users of the Internet may weigh subjective experience and vernacular knowledge over education, training, and professional status in their own concept of what creates an authority. Lay health Internet users, in other words, are not indiscriminate readers.

Access to the Internet, proactive medical consumerism, and epidemic activism have, in the eyes of some public health practitioners, created a lay health monster. Lay knowledge is considered to be dangerous, creating innumerable obstacles to the management of the health of the population. Irving Zola provides a classic example of this attitude in the anecdote recounted below.

Recently, in a European country, I overheard the following conversation in a kidney dialysis unit. The chief was being questioned about whether or not there were self-help groups among his patients. “No,” he almost shouted, “that is the last thing we want. Already the patients are sharing too much knowledge while they sit in the waiting room, thus making our task increasingly difficult. We are working now on a procedure to prevent them from ever meeting one another.” (1972:501)

Concerns about patients knowing too much reflect the philosophical premise that the public should submit uncritically to the claims of experts who know better and who can act on behalf of the common good. These experts in part gain and preserve their authority through claims of dispassionate objectivity, which allows them to weigh information and make decisions without psychological, social, or cultural issues clouding their judgement (Hufford 1991).

The patient population and the educational target groups are seen in this formulation as too subjective, too “in the moment,” and too self-interested to process health information and address larger medical needs. Within this framework, situated or vernacular knowledges are seen as unacceptable, trivial, chaotic, misleading, and fragmented.

In this essentially positivist construction, all information and all knowledges concerning health require mediation by experts, who translate the relativistic and probabilistic logic of science into statements of certainty and fact (Adam and Loon 2000:4). While these statements of fact appear to be objective and authoritative, they are all too often ridden with value judgements dressed up as expert knowledge. In a process that David Hufford calls the “bloating of cultural authority,” scientists move beyond the boundaries of their expertise, presenting authoritative statements that are actually intensely moralistic and doctrinal but that are nonetheless presented *as expertise*. Hufford explains,

Our professional authorities have set the boundaries of their expertise far beyond the limits that can be rationally defended. When experts in radiation and health tell us what increase in cases of leukemia is likely as a result from a given release of radiation, they are within the legitimate boundaries of their expertise. They may be wrong; they may even be biased in their calculations. But this is their territory. Ordinary citizens do not expect to be able to do such calculations. However, when those same experts state how many such cases of leukemia constitute an acceptable risk given the value of nuclear power, they have no grounds for claiming authority. The people around the power plant are not obliged to suspend their personal judgement about this issue, and the experts have no special knowledge that is pertinent. The same is true when a physician goes beyond telling you how painful a procedure may be and how likely it is to be successful, to telling you how much pain you should be willing to bear or how desirable such a success may be to you or what one chance in ten is worth. The physician has no more grounds for telling you these things *than you have for making that determination yourself*. The physician may disagree with your decision, but the physician cannot show such a decision to be wrong. (1991:13–14)

A number of the legends and narrative motifs discussed in this volume demonstrate vernacular response to both the rise of the educated lay person and the bloating of medical authority. The resistant redefining of risk, fears of medicine's role in the manufacture of disease, belief in the withholding of drugs and treatment, concerns about government health conspiracies, and distrust of both the giving and receiving of public health information all point to a crisis in confidence concerning the social institution of medicine. The primary concerns arise out of a very particular set of authority issues: a perception of a *lack of accountability* on the part of medicine and suspicions about the medicopolitical power of government and special interests groups (clearly articulated in the origin narratives); *the extension of medicine into areas of life seen as outside of medical jurisdiction*, including intervention into areas of personal intimacy and moral regulation (articulated in the origin and needle narratives, stories of mandatory house-to-house testing, contact list narratives); and *the excessive control over access to and withholding of information* (seen in relation to narratives about withheld treatments, suspicions about noninfectious and infectious body fluids, healthy carrier narratives, condom fallibility, and a number of other motifs).

Concerns about medical authority expressed in the narratives also demonstrate a consciousness of the expert dismissal of lay knowledge and expertise. Even when vernacular knowledges are taken into consideration by health experts, it is generally with a sense of "we must know what it is that we are combatting" and rarely with a sense that disembodied information can be understood only as incomplete. Numerous narratives, such as the "Holes in Condoms," "Needles in Movie Theater Seats," and "Top Forty," assert the strength and power of subjective experience and local observations over medical cautions. In these narrative constructions, medical authority is diminished through an assertion of the superiority of vernacular reasoning.

What the Tale-tellers Know That Public Health Does Not

The very strength of vernacular knowledge is in its understanding of the individual context of health information and in the subjective experience of disease constructions. In other words the greatest asset of lay expertise is in precisely those areas of thinking and relating to information most criticized by medical authorities.

Scott Rushforth, in his work on Athapaskan knowledge and authority, distinguishes between primary and secondary ways of knowing:

Primary knowledge denotes fully justified beliefs that an individual acquires through his or her experiences, including social interactions. Primary epistemic evidence is the foundation of primary knowledge. People employ the former as warrant for the latter. Secondary knowledge is based only indirectly on primary evidence. Non-epistemic factors such as a speaker's credentials can provide the salient reasons for believing in secondary knowledge. (1994:336)

The existence of health legends and health narratives should indicate to those who are concerned about public health and who are listening to lay responses that all information requires placement in cultural context. Narratives provide just that. Through narration, health information comes to life, exploring, affirming, rejecting, and sometimes replacing information that is offered by powerful outsiders without true cultural contextualization. Narratives take truth claims and hegemonic constructions and make them a culture's own (or not), twisting them and turning them in ways that force them to make cultural sense. Sometimes that sense is consistent with what the claim's makers wish, sometimes it is discordant and risky, and other times it improves on those claims in remarkably positive ways. But while health educators might recognize some responses to information as positive and others as negative based on results in terms of changed risk behaviors, this formula is in and of itself based on cultural misunderstanding. Responses that imply negative "uptake" of health messages are gifts of cultural insight, moments to understand health truths that may not be compatible with cultural truths. The accommodation of that new information about lack of "fit" has the potential to result in not only greater cultural understanding but also potentially greater medical understanding.

So what do the tale tellers know that public health might have missed, forgotten, or been unable to see based on lack of primary knowledge?

1. Public health messages must get more sophisticated as the target audience itself becomes more sophisticated in its processing of the problem. Much of the legend material, particularly with regard to origin and contamination legends, is based on vernacular

understandings of the nature of body fluids and viral shelf life. Insect transmission, semen in food products, and car or home contamination narratives are not unreasonable or lacking in logic, and the stories create the opportunity for dialogue on the nature of various apparent inconsistencies in the role of types of contact. Participation in that dialogue is missing at the official levels. Public health has failed to clarify the reasons why some modes of bodily fluid exchange are riskier than others and the quantity and magnitude of the detectable virus needed for efficient transmission. Legal regulations further complicate this situation, enforcing in some jurisdictions laws against the importation of used clothing, real estate regulations that require disclosure of the HIV status of previous homeowners, and criminal prosecution for spitting by HIV-positive individuals. Information from official sources is in this sense inconsistent and contradictory. The public wants the information necessary to assess situations for themselves—not simply announcements of the safety of casual contact, which are then thrown into question through the punitive actions of other official sectors of society.

2. The inconsistent and contradictory nature of AIDS information has fueled a preexisting fire of North American distrust in medicine. Public announcements of mistaken sources for the disease, such as the use of “poppers” in the gay community or speculation about the role of Haitian voodoo, create an environment that casts into question the competence of medical authority and the role of cultural bias. While conspiracy narratives provide the most direct evidence of medical distrust, other legends demonstrate sharp discomfort with the handling of information coming from and going to medical and institutional sources. Narrative concerns about the withholding of drugs and AIDS-related genocide sit side by side with narratives about contact tracing, naming of HIV-positive individuals, testing anonymity, and the management of private information. One of the most interesting differences between the 1988 (King) survey of attitudes toward AIDS found among Newfoundland Youth and the 1991 (Cregheur, Casey, and Banfield) follow-up study, which focused on the same questions, was a significant decline in reported trust in AIDS information from public health and government sources and a rise in trust in parental information about AIDS. As noted earlier, it is both a sociolinguistic and a public health dictum that the effectiveness of a message depends on the credibility recipients attach to its source. Public health and medicine are in dire

need of both restructuring and public relations focused on gaining the trust of the population.

3. While public health is losing trust, it is simultaneously asking that communities reverse their trust in local information networks. The insistence on a single (official) source for information is not a workable prospect, particularly in closely knit communities. If forced to make a choice between local information sources and hegemonic sources, community members will most often choose "their own people," those who through primary experience are known to be trustworthy." Top Forty," "Pinholes in Condoms," needle narratives, and deliberate infection stories all suggest a strong attachment to local information sources. It is foolish for any organization to operate on the principle that individuals will trust outsiders over those they know, particularly in the context of eroding medical authority. Peer-education programs recognize the importance of local community members but still tend to work on a nondialogic, one-way, risk-relating basis that upholds the hierarchal nature of medicine and negates the discursive nature of primary knowledge.

4. AIDS theorists have written about concerns of moral regulation (Kinsman 1996) and the policing of desire (Watney 1987) in relation to gay activist responses to AIDS messages, but the issue has received less attention in relation to heterosexuality. Abstinence messages and health constructions of HIV-positive and gay bodies as deviant continue to suggest that sex itself is problematic or that specific types of sex are responsible for transmission of the virus rather than the practice of unprotected sex. This context of apparent condemnation creates a perception of medicine and public health as keepers of the moral good. Gay activist efforts to create erotic guides to safer sex have tried to remedy these negative sexual messages by AIDS educators, but less has been done in addressing heterosexual sexuality in a way that recognizes intimacy and eroticism. Reactions to the punitive infiltration of medicine and public health into areas of sexuality and intimacy are, however, addressed by the legends. Numerous conspiracy narratives refer to government creation of AIDS to control teenage sexuality or to limit procreation through condom use. The concern with privacy expressed through legend also indicates a sensitivity to public health's role in moral regulation. Narratives of mandatory house-to-house testing and contact lists, while not specifically about sexual policing, certainly suggest a fear of intrusion. This perception of medical intrusion and sexual

policing makes it impossible for individuals to discuss their actual sexual behaviors (such as the heterosexual practice of anal sex to avoid pregnancy—see chapter 5), thus further burying those areas of post-safe-sex education that might warrant further dialogue. Resistance readings of much of the legend material push not only risk but also regulation out of the bedroom.

5. The legends point out the continued promotion by public health of risk as related to groups and individuals, despite the lip service paid to the movement away from notions of risky people to the concept of risky behaviors. In a sort of tag-team demonization, the vernacular tradition and the actions of official sectors in Conception Bay North continually constructed a location for risk—a person, a people, a place. Despite motives of concern, the legal trial and the removal of area blood clinics pointed to the isolation of individuals as a solution to the spread of the virus rather than highlighting the need for universal precautions. The result is a stigmatized community, a stigmatized individual, and a public-health message that is both unclear and contradictory.

6. The narratives recognize the boundary-making activities that are a natural part of dealing with an imposing threat. Association of safety and risk fall predictably along the lines of “home” and “away,” “familiar” and “foreign,” “moral” and “immoral.” “Know your partner” advice espoused the same ideal, creating an identifiable risk, which simply required knowledge of the boundary and avoidance. The narratives create an AIDS bad guy so that it will be easier to see the AIDS good guy. But the narrative tradition also recognizes that not all people who are HIV positive are bad or foreign or immoral. The narratives of high numbers of HIV tests at high school blood drives and the stories of long lists of contact partners submitted to public health also suggest a realization that the virus can affect anyone. The narratives are not strictly about externalizing risk but also about fears of having to own those risks. While the AIDS bad guy is scary, the AIDS good guy is an even scarier prospect—for both the community and official sectors.

Once Upon a Virus

The aim of this volume has been to use the rich tradition of AIDS legends, as they are situated in cultural context, to explore vernacular perspectives on risk. While many of the narratives discussed

here are reported all over the world, they *mean* at home—finding, in their telling, the nuances that give them local life and import. Few of the issues discussed here are significant only in this culture. The relationship between AIDS messages and cultural life, the concerns of rural communities, and the sense of distrust of medical officials are all issues likely to be expressed in many places—but not as they relate to this particular past, this culture, this moment in history. The little and large nuances of a tradition of outsider doctors renaming families to tell them apart (in chapter 5), badly managed resources and genetic mining (chapter 1), poverty and the collapse of the fishery (chapter 1), a health care system that struggles with rural access (chapter 1), a dependence on the mainland for everything from refrigerators to bone-marrow transplants—all of these issues and many more make these stories what they are, give them meaning and depth. Indeed, the Newfoundland world of AIDS is unlike any other. As is the Haitian world of AIDS or the Chicago world of AIDS.

I believe that it behooves public health officials to be aware of these narratives—not just as an indication of the rumors they need to combat, but also as a resource for understanding risk, local perspectives on public health efforts, and areas for improvement. But being able to interpret what the narratives are saying requires a degree of respect for the narratives and their tellers, a willingness to relinquish sole expert status, and a recognition of lay authority. It requires moving on from thinking about communities as target groups and narratives as ephemeral quaint stories.

It is not uncommon in the current intellectual climate to read studies directed at strengthening risk communication that argue, as does Dana Lear, “We have proceeded with assumptions about the way people behave and with whom they identify that have too often proved incorrect” (1995:1312). And yet, a few sentences earlier in the same article, Lear writes, “Public reaction toward AIDS has moved universally through stages of denial, scapegoating and blame before any constructive response to the epidemic has occurred” (1312). The simultaneous concern for understanding lay communication and condemnation of that communication for what it contains are both extremely common and problematic. Understanding the cultural conception of risk requires being prepared for its divergence from the understandings of public health while recognizing that that very divergence is instructive. Denial, scapegoating, and blame are not

dismissible, and neither are the narratives that express those ideas. The very fact that the ideas and the narratives affect health choices and decision making means that they, at the very least, must be taken seriously as expressions of cultural values and health worldviews. These narratives produce and support assertions of truth and claims about the nature of reality, sometimes literally, but more often as a way to test that reality, to find out more about it, to shake it up. As Bill Ellis says, “Legend telling is often fundamentally a political act” (2001:xiv). The coherency and logic of the legend discourses are keys to frames of local awareness, to the ways that reasonable and intelligent people make use of information—how they selectively assign importance to issues and how they turn health truths into cultural truths and cultural truths into health truths.

In the best of all worlds, in the land of fairytales and not legends, the story would go like this: Once there was a virus. No one got sick. No one was stigmatized. They all lived happily ever after. Unfortunately, the world of fairytales is not the world of legends. People are getting sick and getting stigmatized and dying, and it is time to listen to what the storytellers have to say about that.



Editorial cartoon by Kevin Tobin from *The Evening Telegram*, St. John's, Newfoundland, April 7, 1995.