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Once Upon A Virus

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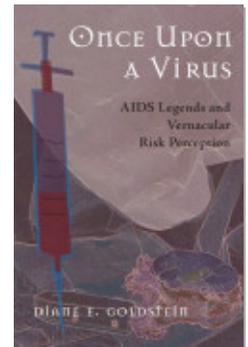
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Introduction

Philosophizing in a War Zone

AIDS activist and cultural theorist Paula Treichler once commented that speaking of AIDS as a symbolic and linguistic construction “may seem politically and pragmatically dubious, like philosophizing in the middle of a war zone” (1999:4). She continued,

But . . . making sense of AIDS compels us to address questions of signification and representation. . . . Language is not a substitute for reality; it is one of the most significant ways we know reality, experience it, and articulate it; indeed language plays a powerful role in producing experience.” (1999:4)

Once Upon a Virus is a book about how AIDS discourse, in the form of narrative, shapes and creates vernacular responses to the disease. But like Treichler, I wish to go further, to argue that AIDS narratives don’t just create responses to illness but in fact come to constitute the disease itself. In the pages that follow, I shall demonstrate that narrative both provides compelling insight into cultural concepts of risk and also socially constructs and reconstructs those risks, making them powerful disease realities.

By titling my book *Once Upon A Virus*, I had hoped to capture exactly the dilemma of the philosopher in the war zone mentioned by Treichler. The kinds of stories addressed here rarely use the “once upon a time” opening suggested by the title, but the image of story worlds conjured up by the familiarity of that opening, juxtaposed with the hard realities of the scientific term virus, provided me with a microcosm of exactly the relationships I wished to highlight. Story and science are interrelated, interactive, and ultimately constitute each other. This is not to say that T cells, test tubes, and retroviruses don’t exist but, rather, that the natural world and the cultural world share the burden of creating disease realities.

As I write this introduction, another deadly disease, SARS (Severe Acute Respiratory Syndrome) has hit the world stage. In these initial weeks of the outbreak of the disease, one cannot help but notice that epidemiologists and the general public alike have become obsessed with story making. While members of the public engage in rumors about who has the disease, places and people to avoid, mandatory quarantines, and government health conspiracies, epidemiologists create and recreate plots that they hope will establish links of transmission. Both sets of stories mirror the narratives discussed in this volume. They explore notions of animal origins, superinfectors, hidden carriers, and numerous other themes entrenched in our stories about AIDS but also seen in reaction to virtually any devastating disease we have experienced historically. Already, only a few weeks into the SARS outbreak, we can see how story comes to define risk. And therein lies the subject of this volume.

Once Upon a Virus is organized as a series of case studies, each centered around a cluster of contemporary legends about AIDS and each exploring a different constellation of issues concerning official and vernacular notions of risk. In the first chapter, I will introduce disease folklore and its relationship to the cultural construction of illness through a general discussion of various types of popular expression concerning epidemics. I begin with children's folklore to highlight how early our folkloric constructions of risk take hold in our thinking. "Tag, you've got AIDS," the phrase I have chosen for the title of the chapter and the name of a game I describe at the onset, is in many ways a representative anecdote (to borrow from Kenneth Burke), a story that sets the tone for everything else to come (Burke 1945:60). The second part of this introductory chapter locates my study in its ethnographic context, the Canadian province of Newfoundland and Labrador. While most of the narratives discussed in this volume appear elsewhere in the international reaction to AIDS, they are best understood in situ, as responses to real world situations taking place in local cultures. The understanding of legend as an index to risk perception requires contextualization among a people, within a place and set in time. Proper contextualization, however, requires that we not simply match bits of social information with bits of narrative but rather that we try to understand those narratives, those perceptions, and those aspects of health as having meaning only in relation to cultural worlds.

Chapter 2 introduces the reader to the genre of contemporary legend and traces the use of narrative as a means of understanding health worldviews. As a type of narrative that captures the extraordinary in the ordinary, the unbelievable twists in daily life, legends provide an index to what intrigues us, concerns us, frightens us, and puzzles us about quotidian reality. They capture our thoughts and understandings of health, illness, risk, life, and death and turn those thoughts outward in ways that are not otherwise easily seen. Perhaps most importantly, this chapter begins to establish the relationship between narrative and emergent action, setting the stage for exploring the role of legend in personal health decision making.

Chapter 3 examines approaches to the development of culturally appropriate and culturally sensitive health education and introduces some of the crucial differences between expert and vernacular constructions of risk. Primary among the goals of this chapter is to convey the commonsense basis of vernacular perceptions of risk and the means by which risk perception evolves in response to cultural as well as health realities.

Chapter 4 is the first of four narrative case studies. This first study focuses on AIDS-origin narratives as they are found in both official discourse and vernacular culture. Science and folklore seem to have a common obsession with establishing origins, a shared sense that knowing where something began is to understand it. This chapter explores the means by which such narratives establish concepts of cultural otherness, control, and distrust.

The second case study, in chapter 5, traces localized variations of one AIDS legend, examining how the narrative adapts to and comes to reflect regional, social, and cultural understandings. Tied to notions of geographic vulnerability, the protection of community social networks, and local cultural taboos, the legend becomes a powerful means of articulating risk perceptions unlikely to be captured through standard knowledge, belief, and behavior studies.

Case study number three follows in chapter 6, demonstrating the central role of legend in official responses to the disease and examining relationships between legend and reality. This chapter explores a legal case of HIV-status nondisclosure, which became intertwined with legendary tradition in a rural community devastated by a high incidence of infection. The chapter shows how legend moves from being told as narrative to being enacted.

Chapter 7 provides the final case study, focusing on legends of HIV-infected needles encountered in public venues. This chapter explores the evolution of deliberate-infecter narratives and the creation of nameless, faceless infectors, which move risk out into the public and away from personal responsibility. Ultimately, this chapter addresses vernacular concerns about the increasing medicalization of our lives and the intrusion of medicine into our homes and personal relationships.

The final chapter in this volume provides a more general discussion of vernacular risk perception in this particular ethnographic context based on the narrative articulation of AIDS beliefs and worldview. Chapter 8 primarily provides some thoughts about the relationship of vernacular theory to public health education, exploring the methods and pragmatic use of narrative in combating disease.

And so, having established a general map for what follows, the time has come to explain what a folklorist, and a narrative specialist at that, is doing in the dubious place of this particular war zone. As is appropriate for a folklorist, I will begin with a story.