Once Upon A Virus

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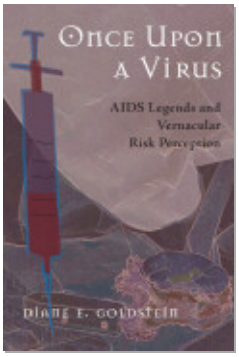

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1

"Tag, You've Got AIDS"

HIV in Folklore and Legend

One Sunday afternoon as I worked in the garden of my house in St. John's, I was distracted by five children playing tag in the neighbor's yard. The game didn't seem to be very different from the one I had played as a child. In that game, the one whom we called "it" ran around trying to catch the others, ultimately gaining on someone enough to touch them and thereby transfer "itness." This would then free up the former "it" to run and require that the new person in that role be the chaser. When the transfer happened, the chasing child would yell, "Tag, you're it, now catch me." Because I always thought it was interesting that we were such slaves to narrating what was taking place at the moment of transfer, I moved my gardening closer to the fence where I could overhear the children. To my surprise I heard the oldest child, who was around seven or eight years of age, say, "Tag, you've got AIDS." Part of me was pleased that a seven-year-old child knew what AIDS was, that public awareness had hit even the youngest sectors of society. But another part of me was terrified to see that the stigmatization of AIDS had drifted into the popular culture of one so young.

AIDS Folklore and Disease in Popular Discourse

I had never thought about "tag, you're it" as a contagion and immunity game, but the addition of the AIDS tag line reminded me

that a number of children's games are about fear of infection.[1] We played several "cooties" games as children and created a paper fortune-teller that we called a "cootie catcher." Getting "cooties" was an enormous thing to us children, although I don't think any of us had the slightest idea what a "cootie" was. We did know, however, that "cooties" was something you caught and something you didn't want to have. Children's folklorist Simon Bronner notes that cooties came into play among children in the early 1950s, the time of the polio epidemic in the United States. Bronner goes on to say,

> The polio epidemic was especially disconcerting to many Americans because the healthy and wealthy, who it was thought should be immune to such affliction because of their clean and honorable living, contracted it, and distrustful, blaming eyes turned toward lower classes. It turned out that the disease probably spread from person to person (the virus normally attaches to living tissue cells) by intimate human contact although unsanitary conditions, especially fecal and sewage contamination, could support the virus. . . . During the scare, children were pulled out of swimming pools in fear of contagion and told to avoid touching other children because of dread for the debilitating polio virus which could paralyze or kill its victims. The cooties complex became among children a way to playfully dramatize the dread of the disease while also bringing out social relations underlying the modern emphasis on cleanliness and appearance, relations important to adult ways of dealing with one another. (1990:107)

The historical emphasis in children's folklore on fears of infection, childhood obsessions with body parts, fluids, and emissions and concerns about diversity and conformity suggest that AIDS would quite naturally be a focus of children's play. Bronner reports in relation to AIDS games (1990:109) one played with three bowls filled with ketchup, mustard, and water, which are placed in a box. Players were to blindly reach over the box and put their fingers into

1. British children's folklorists Iona and Peter Opie have written extensively on the topic of contagion in children's games. The most often asserted connection of games to disease is the legendary origin of the singing game "Ring around the Rosy" as commentary on the plague. The plague-origin hypothesis argued that "rosy" referred to the rash associated with the plague, posies referred to protective herbs, and the sneezing was symptomatic. The Opies point out that this connection, while possible, has no real evidential basis (Opie 1985:220–222).

one of the three bowls. If they put their fingers in mustard, they had rabies. If they touched ketchup, they had AIDS. If they touched water, they were "immune"[2] from all diseases. Like the polio epidemic in the 1950s, AIDS affects the lives of children as well as adults, through the experience of friends and family members with the disease, through fear and prejudice expressed in and around the home, and through media coverage.

It should not surprise us that AIDS has entered children's popular culture, not just through games, but in songs and rhymes as well. In their book on children's subversive folklore, Sherman and Weisskopf include a rhyme sent to them by the father of a sixth-grade girl, who was overheard with her friends singing the following parody of a song from the 1988 children's television show "Barney." Barney was a stuffed purple dinosaur, who opened every show with a song that said, "I love you, you love me, we're a happy family / With a great big hug and a kiss from me to you / Won't you say you love me too?" The girls sang,

> I love you, you loved me
> Barney has got HIV
> Barney jumped on Baby Bop[3] one time
> That's called rape and that's a crime.
>
> I hate you, you hate me
> Barney died of HIV
> Tripped on a skate and fell on a whore
> No more purple dinosaur
>
> I hate you, you hate me
> Baby Bop fucked with Barney
> He gave a hop and she said to stop
> Now they have to see the DOC.[4] (Sherman and Weisskopf 1995:198)

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2. One of the things that is most interesting in children's contagion games is the extent of focus on immunity. From a biomedical point of view immunity is an incredibly complex and not well-understood process (Haraway 1991; Martin 1994). From a child's point of view one simply wins exemption from disease.
3. Baby Bop is another smaller (and younger) dinosaur that visits Barney every day on the show.
4. The father who sent in the parody commented, "It seems that AIDS awareness training does work" (Sherman and Weisskopf 1995:199).

As was the case with the AIDS games and older epidemic concerns expressed through children's play, the Barney parody takes its place next to a host of disease rhymes favored in children's folklore. Tuberculosis rhymes, for example, were common throughout the 1940s, 1950s, and 1960s and are occasionally still collected. In 1960 the following song, sung to the tune of "My Bonnie Lies over the Ocean," was collected from a twelve-year-old girl from Montana.

> My Bonnie has tuberculosis,
> My Bonnie has only one lung,
> My Bonnie coughs up slimy green stuff
> And dries it and chews it for gum.
>
> Come up, come up,
> Come up, dear dinner, come up, come up,
> Come up, come up,
> Come up, dear dinner, come up.
>
> I'm coming, I'm coming,
> Though my head is hanging low.
> I hear those gentle voices calling
> (Spoken)
> Hasten, Jason, fetch the basin,
> Oops, flop. Fetch the mop. (Sherman and Weisskopf 1995:67–68)

Interestingly, adult folklore concerning tuberculosis is not commonly found in collections and archives. Sometimes called the "unmentionable disease," the "folk" association of tuberculosis with poverty and squalor created a silence that worked against the development and preservation of adult verbal traditions concerning the epidemic.[5] Children's traditions, however, provide a special kind of insight and a special commentary on issues, which take a different

5. A few years ago I attempted to track down archived tuberculosis folklore for comparative purposes as the current TB epidemic affected more and more of the population. At that time, I was told by three different archivists that such material was scant, because of the secrecy surrounding the disease. TB had a devastating effect on the Newfoundland population in the previous epidemic, and yet neither the Memorial University Folklore and Language Archives nor the Center for Newfoundland Studies Archives had any significant holdings related to community experiences of the disease.

form (or which are absent altogether) in adult culture. Children have license to speak the unspeakable. Furthermore, the fact that something is spoken in children's folklore suggests that an issue has truly taken hold in society. In many ways, what makes children's folklore so interesting to adults is that we recognize children as a wildly original, too loud, too truthful version of us. As children's popular culture expert Kathleen McDonnell observes, "Children don't recognize the distinction between high and low culture, they embrace it all equally" (1994:18). In this sense, children's folklore articulates attitudes and understandings internally censored by their more mature adult counterparts. In the play, in the games, and in the rhymes are expressions of health beliefs and attitudes held on some level by the children and perhaps also, despite the internal censorship of maturity, held by their parents. Complex themes of the "infecting Other," morality and illness, blaming victims, stereotypes of the correlation of economic class with illness, concerns about contagion and sanitation, and health fatalism pervade the games and rhymes of children, who in some cases aren't old enough even to have lost their first tooth.

Adult folklore contains the same themes and concerns but chooses slightly different means of expression. Our jokes, sayings, songs, stories, and even our material ways of expressing ourselves[6] can become what illness-narrativity theorists call "illness representations." Beyond obvious referential statements, traces of explanatory models for illness are embedded in our multiple forms of discourse. To create distance from disease and illness, we "construct boundaries between ourselves and those categories of individuals whom we believe (or hope) to be more at risk than ourselves" (Gilman 1988:4). The means of distancing, the boundaries we create, the risks we construct and destruct can be read in our expressive choices.

While games and rhymes appear to be the genres of choice for such articulations from children and adolescents, adult illness

6. We express our concepts of health and illness through the construction and use of buildings, objects, costume, and art. The so-called care-cottages associated with the treatment of tuberculosis are a good example of architectural expressions of attitudes toward health and illness. The cottages had large porches built so that patients could spend long hours taking "the fresh-air cure." Material culture related to AIDS is a vast and relatively untapped resource for exploring disease understandings and constructions. A number of interesting and important studies of representations of AIDS in artistic renderings have been published, however (see, for example, Gilman 1988, Crimp and Rolston 1990, and Miller 1992).

representations make use of what are understood in our culture as more mature vehicles of expression. AIDS beliefs and commentary certainly appear in adult games (including risk-taking games) and rhymes (particularly in graffiti, Xerox lore, and slogan making), but by far the most vital adult forms for AIDS-related expressions are jokes and narratives.[7] Furthermore, since tradition is dynamic, these expressive forms reflect the changes in beliefs and attitudes that come in response to new scientific developments, new understandings of transmission patterns, public health education programs, media coverage, current events, and so forth. The traditions, however, do not simply follow a specific trajectory chosen by public health or other officials but rather reflect the processing of a vast quantity of different and sometimes competing messages, all affecting disease understandings.

Jokes about AIDS followed slowly after the documentation of the first cases in 1981, but became gradually more popular as the disease entered public consciousness. As epidemiologists continually refined notions of who was most vulnerable to the new disease, jokes followed suit, always distancing the teller from the population currently understood as "at risk." Early jokes focused on the gay population and the association of AIDS with drugs, eventually incorporating other notions of risk groups. These initial jokes focused on what came to be known as the 4 Hs: Homosexuals, Heroin users, Hemophiliacs, and Haitians. Like most health folklore, they assigned the disease to a group understood as distant from the teller.

> Question: Do you know what the hardest thing about having AIDS is?
> Answer: Convincing your mother that you are Haitian.[8]
> Question: Do you know what gay stands for?
> Answer: Got AIDS yet?

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7. Genre choice for the expression of specific topics is, of course, extremely culture bound. Wallman has noted that AIDS expressions in Uganda show preference for proverbial forms (see Goldstein 1993). Clearly, within a culture, specific peer groups may demonstrate a preference for other forms (for example, professional musicians may choose musical expressions). My assertion of a Western adult preference for jokes and narratives as AIDS expressions is meant only as a general observation based on years of following AIDS popular culture.
8. This joke was told in gay and straight communities. Joe Goodwin, writing on gay folklore, observed that its popularity in the gay community reflected concerns about being "outed" by the disease (Goodwin 1989). In this case, the joke is self-consciously about assigning "otherness."

As AIDS affected more and more of the population, the jokes became increasingly homophobic and racist, with many focusing on famous figures known to be infected with the disease. Liberace and Magic Johnson jokes affirmed stereotypes of risk and deviance, collapsing notions of risky behaviors with notions of risky people. Like all folklore, the jokes changed as public health and public education became more refined, evolving in response to emerging understandings of the disease. By the mid-1980s it became clear to health educators that the general public was concerned about issues of casual transmission, generating fears of social contact[9] with members of groups dubbed as "high risk." In 1988, in response to these concerns, the United States issued the Surgeon General's Report on AIDS,[10] which, as Cindy Patton notes, "assumed that while risk reduction knowledge was nice, the general population, never imagined to be at risk, should be educated about the impossibility of contracting HIV through casual or social contact" (Patton 1994:15). Jokes again followed suit. Goodwin reports one joke involving a little boy telling his mother about the AIDS discussion in his sex-education class.

> So she said, "Well, what did you learn about AIDS?" He said, "well, you can't get it from a toilet seat, and you can't get it from kissing, and you really have to watch those intersections"[11] (Goodwin 1989: 84).

The emphasis in the Surgeon General's Report on the "facts" as they were known and constructed at the time began to move AIDS jokes into new areas of focus on risk behaviors and safety.

> Did you hear about the two junkies? They were sharing needles. A friend said, "Don't you know you could get AIDS?" The junkies replied, "It's OK, we're wearing condoms."

AIDS jokes of the early 1990s (in addition to the ever-present

9. Casual contact includes fears of viral transmission through toilet seats, drinking glasses, shaking hands, hairbrushes, and other means that do not involve any real exchange of body fluids.
10. The U.S. Surgeon General's Report had an impact in Canada as well as in the United States, in part because the resulting educational campaigns in the American media were broadcast continually in Canada.
11. Goodwin notes that the joke is an apparent conflation of "homosexuals," "injections," and "intercourse" and a seeming play on the standard parental warning to look both ways (Goodwin 1989:84).

themes of racism and homophobia) asserted fool figures, like those in the joke just cited, who were too stupid to understand safe-sex messages. The jokes were, in their own way, educational.[12]

As Patton argues, however, health educators and education projects showed little agreement on whether to decrease risk by modifying the behavior of an entire population or by targeting only those (subgroups) believed to be at the highest risk. For the most part, public health chose the targeted approach, focusing educational campaigns on "at risk" subcultures (Patton 1996). Even as the global AIDS picture began to make it clear that whole populations were at risk, public health accommodated information on the potential for heterosexual transmission through "Choose Your Partner Wisely" campaigns. These campaigns continually underscored notions of AIDS "otherness" even in attempts to be inclusive. As AIDS became more and more an issue through increasing numbers of infections and deaths, moving beyond subcultural boundaries, AIDS jokes began to drop off,[13] becoming fewer in number and tending to flare up only in reaction to specific media events, such as new-treatment news or celebrities announcing that they tested HIV positive.

Where AIDS jokes began to drop off, narrative took over. This is not to say that AIDS rumors and legend only began to circulate in the late 1990s as the disease took hold in staggering epidemic numbers. To the contrary, stories were circulating from the beginning. But over time legends and rumors flourished, producing more than the nervous laughter or outrageous biting social commentary associated with humor. Instead, rumor and legend revealed a deep-seated sense of concern, fear, distrust, and even resistance. In some sense, while AIDS jokes focused on what was known about the disease (or believed to be known at that moment regarding, for example, risk groups and safe sex),[14] AIDS legends focused on what was still unknown, unproven, unspoken, and, most of all, uncomfortable.

Legends were the perfect tool for dialogue. They were not personal since they tend to be stories about what happened to someone else. The risk of telling was minimal because the narratives take a

12. See Goldstein 1991 on the responsible folklore of AIDS.
13. As one of my students noted, "It's hard to think it's funny once you know someone who's died—and we all know someone who's died from AIDS."
14. Jokes tend to follow public familiarity with an issue. If there is not a degree of shared understanding, the joke will not work. For this reason, jokes often appear after issues have become mundane. See Goldstein 2001.

"believe it or not" position, opening up discussion but not really requiring that one reveal one's own stance in relation to the narrative's truth or falsity. But the stories were not completely distanced either; they brought the issue closely into the teller's sphere through the legend's characteristic "friend of a friend" protagonist. These stories did not happen to the teller or even to anyone the teller knows. Rather, they happened to the friend of someone with whom the teller was familiar—close enough for concern, distanced enough for comfort. Legends put the issue out there, created dialogue, but allowed the teller to mask personal fear or curiosity.

AIDS Folklore in Newfoundland

In 1986, as it became clear that AIDS was not only not going to go away but was beginning to have a devastating global affect, I began to collect AIDS folklore in Newfoundland. At that time, Newfoundland had not yet reported its first cases.[15] Nevertheless, AIDS folklore was everywhere. Jokes, slogans, cartoons, graffiti, and even songs were circulating about the disease; but, by far, the most interesting material was in the form of contemporary legend. I began with a questionnaire distributed to the students in my classes at Memorial University. I included very general questions about jokes, stories, and other kinds of expressive lore concerning AIDS, asking that the respondents write down their recollections of what they had heard. This information was accompanied by a series of bare-bones biographical questions and a couple of questions asking the respondent to reflect on the material they reported and on the AIDS epidemic in general. Each questionnaire was anonymous[16] but included a tear-off sheet, which the respondents could fill out if they were interested in a follow-up interview. At around the same time as I began to administer the questionnaire, I also started a survey of local newspaper, radio, television, and health brochures to enable complementary study of media and public health information coverage. I began the survey initially to point out to my students the contemporary nature of folklore and the manner in which folklore responds to current events. But my longtime interest in the relationship between health folklore and health information soon

15. Later in 1986 the first two cases were reported to public health.
16. Because of the sensitivity of much of this material, both the questionnaires and follow-up interviews are presented anonymously, unless otherwise stipulated.

took over, and the project began to grow. Interviews led to other interviews, and once AIDS cases entered the local scene, I began to focus on specific events reported in the media and specific rumors that were making the rounds. As the Internet became an increasing part of my students' lives,[17] I also began to include AIDS folklore communicated through e-mail and the Web.

As the largest university in Newfoundland, Memorial's student population of between sixteen thousand and eighteen thousand clearly represented a huge sample of the age group seen at the time as most potentially "at risk" in the province (ages eighteen to twenty-nine). Further, the cohort came from all over Newfoundland and Labrador, since the University serves the entire province. It was not long before students began to come back to me with things they had heard at home on semester breaks or from friends in other places, further widening the research sample. Over the years, numerous graduate and undergraduate students voluntarily initiated and conducted their own interviews on my behalf, turning over tapes, transcripts, e-mails, Xerox lore, and a great variety of other materials to the project. I am indebted to them for their enthusiasm and hard work. What their generous additions to the research did, in addition to seizing the "ethnographic moment," was to provide additional access to other age and educational groups, other networks and cohorts, and a wider scope of the provincial population. In that sense, this study is based on material that began with the university population but ultimately evolved to include a portion of the larger body of non-university-related Newfoundlanders.

The People and the Place

Newfoundland and Labrador is located in the most northeastern corner of North America. After a long period as an autonomous colony of Great Britain, Newfoundland joined Canada in 1949, becoming one of the ten provinces and three territories[18] that make up the country. The vote to join Canada was won by an incredibly narrow margin of 51 percent, a result that is still the

17. Regular use of the Internet came relatively late to Newfoundland due to the province's disadvantaged economic situation. Consultation with the Computer Help Center at the University confirmed that full e-mail and Internet access for every student occurred sometime around 1994.
18. The country added the third territory of Nunavut in April 1999.

subject of controversy and of a fledgling separatist movement. The province officially carried the name of Newfoundland until 2001, when an amendment to Canada's federal Constitution Act changed the name to Newfoundland and Labrador, in recognition of Labrador's[19] status as a full provincial partner (Rosenberg 2003). Even with its two geographical parts, Labrador and the island of Newfoundland, the population is small (estimated by Statistics Canada in July 2002 at 531,600)[20] and is spread over an extremely large land mass (405,720 square kilometers).[21] Despite the fact that well over half of the land mass belongs to Labrador, the vast majority of the provincial population lives on the island portion of the province; only about 30,000 of the total population reside in Labrador. This book is based primarily on research from the island portion of the province.

The majority of Newfoundlanders live along the picturesque coastline. Referred to fondly as "the rock," Newfoundland is extremely rugged, featuring jagged cliffs and rocky beaches along the coast and a largely unpopulated interior, thickly covered in forest and brush, bog land and ponds. The approximately one thousand communities along the coast and small islands around its edges are referred to locally as "outports." Many of these communities were traditionally accessible only by sea until the middle to late twentieth century when the provincial government began campaigns to centralize and resettle isolated communities and to expand the roads.[22] As part of the resettlement program, the Newfoundland government offered one thousand dollars per household to families from isolated communities who agreed to move to larger growth centers. In some communities, the government also restricted access to ferries, teachers, and other essential services, in attempts to force

19. Labrador had traditionally been considered a part of Newfoundland, a relationship that was solidified in 1927 when the British Privy Council defined Newfoundland's "territorial jurisdiction" over the coast of Labrador (Baker and Cuff 1993).
20. Statistics are from Statistics Canada, Population, 2003. (Online at http://www.statcan.ca/english/Pgdb/demo30a.htm/.)
21. Newfoundland and Labrador has an area more than three times the total land mass of the maritime provinces of Nova Scotia, New Brunswick, and Prince Edward Island. Compared to land size in the United States, Newfoundland and Labrador ranks fourth in size behind Alaska, Texas, and California. It is nearly two times the size of Great Britain. (See Government of Newfoundland and Labrador, 2003, Provincial Economy. Online at http://www.gov.nf.ca/nfld&lab/economy.htm/.)
22. Donna Davis writes about "the Road" in Newfoundland communities as a metaphor for the comparative merits of traditional versus modern ways of life (1995).

the population to relocate. Promises of "two jobs for every person," "the good life," and modernity in these new homes didn't, however, pan out for the large numbers of fishermen, with no formal education, who found it impossible to compete for employment. Feelings of betrayal by the government resulting from the resettlement initiative continue to this day and are the topic of a wealth of songs, poetry, short stories, plays, novels, and artwork.

The population of the island sprang mostly from English and Irish migrants who came in the late eighteenth and early nineteenth centuries hoping to make their fortunes or at least sustain their families through the traditional cod fishery. Some have estimated that 95 percent of Newfoundlanders are of Irish or British stock (Hanrahan 1993). Early cultural influences were also provided by Scottish immigrants who settled on the West coast and the French, who maintain a culturally strong Francophone community. The province is also home to three native groups: the Innu and Inuit in Labrador and the Mi'kmaq on the island (see Dettmer 2001). In the early part of the twentieth century small Chinese, Lebanese, and Eastern European Jewish communities sprang up in and around St. John's. While the population has been, for the most part, remarkably homogeneous, there is a small and growing ethnic diversity in the province. The university, industry, mineral resource development (particularly oil and gas), and a series of refugee waves to Canada in the 1980s and 1990s have created a degree of pluralism. In contrast, however, to other parts of North America, Newfoundland's diversity is extremely limited.

The province's religious makeup is similarly lacking in heterogeneity. Approximately 37 percent of the population are Roman Catholic. Of the remainder of the population, all but 2 percent are Protestant, primarily Anglican, United Church, and Pentecostal.[23] The beginnings of ethnic diversity in the province in this century are reflected in the establishment of Jewish, Muslim, and Hindu places of worship; but numbers of adherents are small, and those communities continually struggle to retain their buildings and organizations. Newfoundland has traditionally been religiously conservative, boasting a denominational school system, which was only abolished (by referendum) in 1998.

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23. Statistics are from the 1991 census, published by Statistics Canada, Population by Religion. (Online at www.statcan.ca/english/Pgdb/demo30a.htm/.)

Resources and Their Management

Traditionally, it was the fishery that drew residents to Newfoundland, considered at one time to be among the greatest fishing grounds in the world. Cod was, for centuries, the sole basis of the Newfoundland economy. Everything about Newfoundland was organized around the sea and the fishery. As one historian of Newfoundland wrote, "With the Greeks, ocean was a synonym for barrenness, land alone being life-giving. To the Newfoundlander the land is a forest or a 'barren,' the ocean a mine or harvest field" (Rogers 1911:190). Rogers, along with numerous more contemporary historians, argued that the land, for Newfoundlanders, was simply a platform for access to the sea (Baker 2001:9). The land in Newfoundland is rough, boasting little in the way of soil, flora, or fauna. The growing season is short, and the climate is challenging, with a reputation for the most rain, fog, wind, and snow in Canada. For a long time, the sea made up for the seemingly scarce resources of the land—but that was to change.

The cod fishery remained the central feature of the Newfoundland economy until 1992, when, in hopes of rebuilding dwindling fish stocks, the federal government imposed a moratorium on the cod fishery off Newfoundland's east coast. The decision put thirty thousand Newfoundland fisher people out of work (Baker 2001:9) and created enormous spinoff unemployment.[24] In 1995, all commercial ground stocks around Newfoundland were closed to fishing indefinitely. The government created a compensation package for displaced fisher people, with funding tied to enrollment in counseling and retraining programs (Sinclair 2001). Nevertheless, in a culture so strongly oriented toward the sea, the effects of the collapse of the fishery were devastating. Out-migration escalated and numerous fishing communities, traditionally thriving with activity, began to resemble ghost towns.

Despite the continued devastating effects of the collapse of the fishery on Newfoundland society and culture, economic forecasters argue that due to new growth sectors, the financial outlook for the province has never been brighter. Government statistics indicate that in the period between 1997 and 2001, the Newfoundland economy

24. Primary among the spinoff effects was the closure of a large number of fish plants. The collapse of the fishery, however, could be felt in virtually every sector of the economy, from transportation to real estate.

expanded by more than 24 percent.[25] The fishing industry has diversified, focusing more on crab and shrimp, and secondary processing in the province has increased. Non-resource-based manufacturing and service industries are constantly being developed and expanded. By far, however, the brightness of Newfoundland's economic future is seen to rest on oil and gas offshore developments.

While the advent of the oil industry has meant new wealth, jobs, and opportunities for the province, many Newfoundlanders are not convinced that they will benefit from the industry. The province's take in royalties has been seemingly small compared to the profits of oil companies; and the benefits have not appeared to spread to rural Newfoundland, where unemployment is most significant. Newfoundlanders are concerned about the resources being exported to be processed elsewhere, about the employment of the local labor force on oil projects, about the impact on the environment, and, more than all else, about the impact on local culture (House 2001). Traditionally referred to as a "have not" province in Canada, Newfoundland now leads the other provinces in predictions for financial growth. Ironically, however, Newfoundland still maintains the highest unemployment rate in the country (over 16 percent)[26] and one of the lowest income rates per capita (McGrath 2001).

Newfoundlanders are not strangers to concerns about receiving minimum benefit from the sale of their rich resources. Numerous deals made by successive governments on everything from hydropower to forestry to fishery have been decried by the public, historians, and economists alike as primarily benefitting outside interests (McGrath 2001). The themes addressed repeatedly in the narratives discussed in this book—themes of government distrust and "otherness"—are perhaps resulting from, or exacerbated by, decades of feeling "ripped off" by leaders who claimed to be working on behalf of the population.

The issue of the exploitation of the province's natural resources took on an even more dramatic and bizarre twist recently through the discovery of the desirability and profitability of Newfoundland's genetic legacy. Due to geographic isolation and the fact that early

25. Taken from Government of Newfoundland and Labrador, Provincial Economy, 2003. (Online at http://www.gov.nf.ca/nfld&lab/economy.htm/.)

26. This figure does not include the "hidden unemployed," such as those who have enrolled in school or have entered retraining programs for the purpose of receiving loans and grants to sustain themselves and their families.

immigrants came from a limited number of British and Irish communities, Newfoundland has been called "a gold mine for the study of human genetics" (Staples 2000:117). The province has an isolated gene pool, meaning that 95 percent of the population can be traced to the first twenty thousand people who settled the province. This so-called founder effect is of enormous interest to genetics researchers, pharmaceutical manufacturers, and biotechnology companies who invest heavily in genetic research. For several years, Iceland has been working toward control over its unique isolated genetic heritage, fighting off multinational companies that are intent on turning that heritage into a tradable commodity.

In 1998, Newfoundland had its own run-in with the issue of biopiracy (as some have dubbed genetic trading). A group of scientists from Texas's Baylor College of Medicine flew into St. John's to study an extended family who suffer from ARVC, a congenital disease that renders individuals prone to cardiac arrest at an early age. The scientists spent their time in Newfoundland collecting DNA samples from family and community members and then left the province without offer of the customary follow-up treatment or genetic counseling. Access to the resulting data was not shared with local physicians or researchers, and participants in the study were never informed if they were or were not at risk for ARVC (Staples 2000). The Texas group (locally referred to as the "Texas Vampires" for "taking the blood and running") made local medical researchers aware of the need for stricter genetic-research guidelines. The response, however, from the lay population was, once again, a sense of vulnerability to, violation by, and distrust of the very authorities that are supposed to protect the population.

Trust and Community

The ARVC study, of course, did not pop up into a vacuum but rather into a culture that already had good reason to distrust authority figures, cultural elites, and foreigners. The historical events cited above—confederation, resettlement, weak resource management, and poverty—contributed to that sense of distrust, but centuries of isolation had also built a culture that looked inward for support and was wary of outsiders and those in positions of political power. Despite the fact that well over half the Newfoundland population today lives in the cities, the vast majority of families came from

the outports, generally in search of employment or education.[27] As people acculturated to urban lifestyles, they nevertheless retained networks of trust they brought with them from the outports. Due to isolation and the small, rarely changing population in rural Newfoundland, social life was intimate—you knew everyone and everything about everyone. St. John's, Corner Brook, and the other cities were bigger and more impersonal, but the population continued to value the predictability of local social networks. Searching to place those you meet by last name, family or friendship connections, and home community is commonplace across Newfoundland, as is the labeling of outsiders as "CFAs" (come from away)[28] or "mainlanders."

Numerous older ethnographies of Newfoundland continually identified social intimacy and the threat posed by strangers as significant features of outport life (Dinham 1977; Firestone 1969, 1980; Faris 1972; Szwed 1966). Paul Dinham wrote,

> In outport life, the epitome of unpredictability and thus threat is the stranger. Although treated with overt hospitality and warmth, the stranger is covertly feared, or at least is the focus of suspicion and apprehension. A stranger is someone about whom the community knows little or nothing (his origin, what type of person he is, or his reason for being in the community). Community residents depend upon each other to hold the same norms attitudes and values, thus insuring the predictability, the continuity and the coherence of social interaction. In the case of the stranger, the outport community has no knowledge of the degree to which he shares or fails to share their values. (1977:67)

Contemporary ethnographies of Newfoundland stress the incredible changes of the last three or four decades in terms of the effects of increased mobility, out-migration, urbanization, and tourism on social networks; but even while noting the expansion

27. In fact, it is said that if "you take all the 'baymen' out of St. John's, there will be no one left." As Maura Hanrahan points out, this notion puts a new twist on the much-written-about dichotomy between "townies" (those from St. John's) and "baymen" (those from rural communities) (Hanrahan 1993).

28. Novelist Jane Urquhart noted in her address to convocation at Memorial University in June 1999, after serving a period as artist in residence, "During the course of that first day [here] at least a dozen people either asked me if I was from away or informed me that I was from away"(quoted in Bella 2002:i).

of those networks, they emphasize the insider/outsider dichotomy[29] (McGrath 2001; Durdle 2001; Davis 1995; Bella 2002). In her 2001 study of women's roles in one community after the downsizing of the fishery, for example, Jodi Durdle wrote, "The dynamics of small town Newfoundland, with greater exposure (via travel and television) to outside influences, are such that most people today are much more tolerant of the behavior of *strangers or outsiders*" (139; emphasis in the original). Although the norms have changed for how many people one might see in a given day and where they might be from, Durdle's choice of the word "tolerant" betrays the continuing relevance of distinctions of "us" and "them," of who can be trusted and who can't. In the chapters that follow, those culturally significant distinctions can be seen to combine with natural boundary-making responses to disease, stranger-danger themes common to legend, and the dichotomy-making mistakes of public health. The natural human tendency to externalize disease risk combines in the Newfoundland legends with centuries of evidence that strangers and outsiders are, indeed, unpredictable and threatening. While many of these legends appear cross-culturally, they take on a different resonance when understood in the context of local Newfoundland history and experience.

Medical Care and Public Health in Newfoundland

The history of medical care and public health in Newfoundland has also been traditionally a story of coping with isolation and poverty. Much of the history of health care in Newfoundland did not involve physicians or hospitals. While the first civilian hospital on the island opened in 1814 in St. John's (Pitt 1984), most health care—both before and after— was community based, handled through home remedies or local folk practitioners, particularly midwives. The establishment of a hospital in St. John's had little impact on the lives of most Newfoundlanders at the time, located, as they were, great distances from the city. During the 1890s and early 1900s a number of small cottage hospitals, inspired by Dr. Wilfred Grenfell, were created in a variety of places in Labrador and on the

29. Despite this emphasis on insiders and outsiders, Newfoundlanders are often referred to in travel literature as the kindest, most generous, most hospitable, friendliest people you will ever meet; and most visitors would agree that this is not a false stereotype.

island (Pitt 1984). Cottage hospitals were small facilities set up in strategic places around the island and Labrador, staffed initially by nurses imported from Britain. In 1949 air ambulance service was introduced in Newfoundland to transfer patients from isolated communities to larger medical centers. One year later the government purchased four boats to enable doctors and nurses to visit isolated communities. In 1958 the Hospital Insurance Act came into effect, providing free health-care coverage for all residents of the province (Pitt 1984). The challenge of cost and accessibility of health care had been at least partially addressed.

Over the years numerous modern hospitals have been created in the province, both inside and outside St. John's. Some of these facilities were meant to be temporary, established in reaction to needs resulting from specific epidemics, especially cholera and tuberculosis. Tuberculosis hit Newfoundland hard, particularly in the first decade of the twentieth century and again in the period between 1945 and 1955 (O'Brien 1994). It is not unusual to meet couples in Newfoundland who met and married in the sanatorium or families who raised other people's children while the biological parents were "in the san."[30] In 1972 the last of the sanatorium beds were closed (O'Brien 1994), leaving behind memories, for those who were old enough, of the stigma, poverty, death, and devastation caused by the epidemic.

While modern health care and hospitals are accessible today for most Newfoundlanders, there is still a shortage of physicians in rural Newfoundland, dependence on air ambulances, and some procedures that require sending patients to the mainland. As is the case in most parts of North America, government cuts have meant the closure of beds in some facilities, reduction in staff, and an insufficient supply of medical equipment. Nevertheless, Newfoundland continues to try to find innovative ways to serve its urban and rural population. The province has become a North American leader in the development and provision of telemedicine, using telecommunications links in both the delivery of health care and the education of health professionals in remote areas.

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30. TB had a lasting impact on the lives and relationships of Newfoundlanders. One couple I knew (now deceased) "reared" twenty-one children from their community while the children's parents were confined to the sanatorium. These children, now adults, were still a regular fixture in the household until the time of the couple's deaths and continued to call them "Mom" and "Dad," despite the fact that their guardianship lasted only a few years.

AIDS in Newfoundland

AIDS got a slow start in Newfoundland relative to the rest of North America, perhaps in part because of the geographical isolation. It wasn't until 1984 that the first two people in the province tested positive for HIV (MacKinnon 1993). Two years later the first case of AIDS was reported.[31] The slowness of the epidemic in hitting Newfoundland, however, was not indicative of the pace the disease would eventually take in affecting the population. While numbers of positive HIV tests still register as low in the province (210 reported from 1985 to 2002[32]), public health officials are in agreement that the figures do not present anything even close to an accurate picture of the current extent of HIV infection on the island. It is estimated that fifteen thousand people in Canada are HIV positive without knowing about their HIV status (*The Compass* 2001).

Numerous issues about the disease itself work against the accuracy of surveillance reports: individuals may be infected but symptom free, thus reducing the likelihood of testing; individuals may test HIV negative despite being positive, due to the recentness of infection; and anecdotal evidence suggests that some may donate blood as a way to assess HIV status, assuming that any problems detected will be flagged and they will be contacted.

In Newfoundland a series of specialized issues affecting statistical accuracy appear to take on significance. Fear of loss of anonymity is generally recognized by public health as a tremendous factor in the choice of individuals not to test. The relationship between anonymity and confidentiality of report and the rules of public-health reportage in Newfoundland have continually been cited as problematic for practitioners and the public alike (Goldstein 1991:2). Two types of tests are available, one that supplies a written report linked to your name and another non-nominal coded test in which the individual checks back for results. All positive tests, however,

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31. HIV is the virus that causes AIDS. It attacks the T cells in our immune system, making us vulnerable to a series of opportunistic infections (such as Kaposi's sarcoma and pneumocystis pneumonia). AIDS is used to refer to the syndrome itself. One can be HIV positive for some time without developing the constellation of opportunistic infections that are associated with the disease. The distinction is important for a number of reasons but most especially because, as AIDS activists have argued, AIDS is the last stage of a much longer chronic viral process.
32. From Health Canada, *HIV and AIDS in Canada: Surveillance Report to June 30, 2002*. Division of HIV/AIDS Epidemiology and Surveillance, November 2002.

are reportable for statistical surveillance purposes. The nature of this "mandatory reporting" in terms of anonymity issues is confusing and causes concern in the lay population. Statistical reporting, contact tracing, partner notification, and other similar issues made public through the media create a level of distrust and discomfort with the true anonymity of the testing mechanism. Numerous individuals interviewed as part of this project expressed serious doubt concerning the availability of completely anonymous tests in the province. Discomfort with the anonymity of the testing mechanism, of course, is not particular to Newfoundland, but the nature of small community lifestyle with little opportunity for any type of anonymity highlights the concern. I was told repeatedly by interviewees, "I would never go to those test sites. You don't know what they do with the information, and anyone could see you going in." It is common for individuals wishing to check their HIV status but fearing loss of anonymity to test while visiting other provinces (McKinnon 1993; Jackson 1992b). This practice, while ensuring a greater level of comfort in terms of identity protection, means the positive result will be reflected in the statistics of the province that provides the test, not the province of residence.

What convinces public health officials that Newfoundland rates of infection are much higher than surveillance data suggest are the results of a Department of Health study done in the early 1990s across Canada, in which blood samples were collected from pregnant women between the ages of fifteen and twenty-nine for anonymous HIV testing (Ratnam 1994). Newfoundland rates of seropositive blood samples were by far the highest in the country, with one in every 900 samples testing positive. These rates compared with one in 1,600 in Quebec, one in 3,700 in British Columbia, and one in 9,100 in Manitoba. Figures released from the study in 1992 indicated that Newfoundland had the highest number of pregnant women with HIV, per capita, in the country (Jackson 1992a).

Rates of infection in Newfoundland show much higher ratios of women to men than are reported elsewhere in North America (Bartlett 2001). While average North American ratios stand at about 8:1[33] (meaning that for every eight males who are HIV positive, one

33. Ratios of male to female infection are changing in North America in general, indicating that women are far more at risk than they were earlier in the epidemic. For a discussion of global male/female ratios, see Marge Berer and Sunanda Ray (1993).

female is infected), in Newfoundland the ratio stands at 3:1 (for every three males infected, one female is HIV positive). The high ratio of HIV-positive women in a province with relatively low IV-drug-user and blood-product infections suggests a high incidence of heterosexual transmission.

The high incidence of HIV infection among women in the province is consistent with the information revealed in surveys of sexuality and risk behaviors among Newfoundland youth. Several of these surveys indicate that Newfoundland and Labrador youth are more sexually active, earlier, with more partners than other teens in Canada and that protected sex is not the norm (King 1989; Cregheur, Casey, and Banfield 1992; MacKinnon 1993; Donovan 1995). Sixty-three percent of grade-eleven students in the province report being sexually active (Cregheur, Casey, and Banfield 1992). Follow-up studies administered in 1988 (King 1989) and 1992 (Cregheur, Casey, and Banfield 1992) indicate that this percentage is not in decline in the face of HIV but, rather, is on the rise.

The surveys also indicate that Newfoundland youth are not likely to be taking precautions for HIV. The live-birth rate among fifteen- to nineteen-year-olds in Newfoundland is 1.3 times the national rate (MacKinnon 1993). In 1988 (King 1989) the Canada Youth and AIDS national survey found that Newfoundland youth conveyed strongly negative attitudes toward condom use. In a follow-up study done of Newfoundland youth sexuality in 1991, Cregheur, Casey, and Banfield found that 35 percent of the teens surveyed reported that they would be embarrassed to buy condoms, and an additional 54 percent indicated that carrying a condom suggested a willingness to have sex. While survey information of this type is patchy in Newfoundland,[34] it paints a picture of high-risk sexual activity. This, combined with high incidence of chlamydia, genital warts, and other sexually transmitted diseases in the province[35] (Donovan 1995; MacKinnon 1993), indicates a situation that, as MacKinnon notes, is ripe for HIV transmission.

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34. Unfortunately, knowledge, belief, and behavior studies in the province privilege teen responses and do not focus with the same detail on comparative adult data. While the population seen as most at risk falls into the fifteen to thirty-five age group, less is known about the upper age brackets.

35. The presence of other sexually transmitted diseases creates a positive environment for HIV transmission through the presence of inflamation and small lesions. Women infected with chlamydia have a substantially increased risk of acquiring HIV if exposed to the virus.

In the early 1990s the province discovered it had cause for alarm. Public health officials began to detect a clustering of HIV-positive individuals within a twenty-five kilometer stretch of communities along the Conception Bay North Coast. By 1995, thirty-one women, nine men, and three infants tested positive for HIV in an area that has a population of only 27,000, including just over 8,600 in the fifteen to thirty=five age range (Donovan 1995). All of the adult women and eight of the nine men reported no identifiable risk factor other than heterosexual sex (Donovan 1995). Case studies failed to identify the reason for the clustering in the area, but it was clear that the presence of such high numbers of HIV-positive individuals in such a small geographic area indicated the likelihood of numerous others who were unaware of their HIV status but capable of transmitting the virus. The AIDS crisis in Conception Bay North meant that the province had to seriously, and quickly, alter its approach to the disease.

The Conception Bay North situation was complicated by the rural nature of the communities involved. Rural communities, by virtue of their geography, can provide the perfect conditions for wildfire transmission. Further, access to education, information, and treatment is more limited outside urban areas, and mobility for treatment is not easily afforded in communities that relied so heavily on the (now-defunct) fishery for employment (Bartlett 2001). Federal funding and support are difficult to muster when the crisis, clearly seen in the province, amounts to less than 1 percent of the total national HIV situation. Rural health care, by definition, affects small numbers of people spread over large distances—an expensive and difficult undertaking and one that finds little sympathy across a large country dealing with larger numbers of infection.

Comprehending what is going on with AIDS in Conception Bay North and in Newfoundland in general requires understanding how risk is constructed by both the lay public and those responsible for public health. Surveys, like those that have provided some of the data used here, arise out of official perceptions of risk. Oriented toward teenagers and focused on age of first sexual activity (although neither factor in and of itself constitutes risk), the surveys come from and construct a story of HIV transmission—young people, impulsive, screwing around before they are mature enough, afraid to buy condoms, and exercising the mind/body disconnect that adults attribute to youth. The story is one we have heard before

and is perhaps a narrative that has some truth to it. But it is a flattened story, one without orientation, complicating action, or narrative depth. Certainly, the story-making process is unavoidable. But what is problematic about that process is that it doesn't necessarily have the capacity to hear or to record alternative perceptions or alternative stories. It simply touches the person running and says, "Tag, you've got AIDS." The idea behind the chapters that follow is to hear some alternative stories and explore some alternative perceptions of risk. Who's "it," who's not, and why might be far more instructive than initially meets the eye.