Health and Precarity: Living with HIV in Japan

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Abstract

In this dissertation, I explore the ways in which Japanese responses to the HIV/AIDS epidemic can be considered ways of mitigating social precarity. I argue that, on the one hand, engagements with HIV/AIDS amongst members of the Japanese general public are often indirect because mainstream Japanese people, disturbed by associations between HIV, AIDS, death, pollution, sex and drugs, are uncomfortable engaging with the thought that these issues are part of the lives of “normal” Japanese. Discussing HIV/AIDS, then, is precarious and threatens idealized notions of Japaneseness. The response is to mitigate this form of social precarity by avoiding it or engaging with it in a superficial manner. This is evidenced by the elision of HIV and AIDS into a single term (eizu), educational materials and posters that broach the subject in vague terms, and museum exhibits that portray HIV/AIDS as a past issue domestically and an ongoing problem outside Japan.

On the other hand, yōseisha and HIV activists are uncomfortable with the flat, monolithic conceptualization of Japaneseness that leads to the stigmatization and discrimination of people living with HIV/AIDS, as well as other minorities in Japanese society. Life for yōseisha is precarious – not only because of what HIV is doing in their bodies, but also because of how they are viewed and treated in Japanese society. Avoidance or indirectness by members of the general public can extend to medical settings and professionals: finding HIV test centers or support groups may be difficult, and Japanese people living with HIV/AIDS (yōseisha) may be faced with non-HIV specialists who are afraid to treat them. Although indirectness may be considered protective for yōseisha visiting HIV-specific support services, it can be a barrier to locating those services in the first place. The general response is to mitigate this form of social precarity by pushing for direct discussions of HIV/AIDS and related topics in Japanese society. The formation of HIV/AIDS support organizations, the use of public HIV narratives to educate the general public about the illness, and actively living as “regular, healthy Japanese” in spite of idealized conceptions of Japaneseness are examples of this.
Dedication

To my many teachers, formal and informal.

Because of their generosity, diversity, and brilliance I am able to find my own strengths.

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Introduction: HIV/AIDS, Precarity and Japan as a Representative of the Global North

“Help me write a story,” Mr. T said during our interview. “Everyone tells me I should write a book about my experiences, but I hate desk work.” He laughed. I told him I’d be happy to help tell his story. So here it is. Or rather, here is the piece of his story that he chose to share at a somehow secluded café in downtown Osaka.

“I’m a hippie. I like music, nature, good coffee. When I wake up in a quiet place with good music and good coffee, it’s the best. Tokyo, Osaka, it’s a concrete jungle. I don’t like it. So I went to other places. And I was a big junkie.

I started using drugs when I was about 20. I’m 45 now. I started with marijuana and then went on to cocaine, amphetamines, heroin. Mostly, I did heroin. Amphetamines are a poor man’s drug and my family... well, they had too much money. Too many companies.

I went to LA to study, but I surfed and did drugs every day instead. I told my family, ‘I want to buy a car, send me money.’ They did, and I bought more drugs. I went to Hawaii, and I surfed and did drugs there, too. I didn’t study. I didn’t work. My family got angry and made me come back to Japan, told me I had to work. So I opened a club. It was really popular and got good reviews. I had a staff of fifteen people from all over the world. It lasted about eight months. I used every day and the club failed.

I went to Thailand, and used every day. You know, if you don’t keep taking it, you get really sick. You feel so bad. Well, in Thailand, I got arrested on drug charges. I was put on trial and went to jail there. I was in the international prison for eight and a half years. You know what? They had everything in there! Heroin, alcohol, gambling, lady-boys. The only thing they didn’t have was women. The guards were easy to bribe; their salaries are low. I think I got HIV there, in prison.

My good friend from Singapore died of AIDS in front of me in jail. I got worried. I wanted an HIV test, but for six months I couldn’t ask. I was scared. Finally, I told a Japanese missionary, a Lutheran minister who sometimes came to the jail to talk to us
once a month, that I wanted a test. He worked it out with the prison hospital and the embassy.

I took the test, and it was positive. At first I just kept thinking, ‘Die, die die...’ but I decided, ‘I don’t want to die in here! I gotta get out!’ I told the minister. He helped me get my medications, came to talk to me, helped me quit using. And finally I came back to Japan three years ago.

I contacted my old friends. I used a couple more times. It’s gotten so much easier to get drugs in Japan, hard drugs! All you need is money and to find the right person. Anyway, I thought, ‘If I do this, I’m going to die. Or I’m gonna get caught.’ I had to stop. For six months or so, I didn’t know anything about getting help here. Then I found out I have Hepatitis C. I think I got that here when I was injecting, the rates are so high.

Finally, a nurse told me to go to CHARM\(^1\). And I met Ms. E and Ms. A. They’d talk to me. We’d go out to dinner. Ms. E, she is so smart, and her heart is very, very big. She helped me a lot. Now I try to help people like me. People who can’t stop doing drugs. So many people helped me get clean, live a good life. I want to help others do the same thing.

Japan doesn’t really have many health problems. It’s a rich country. Even though I have this illness I can get treatment. But treatment in urban areas is more advanced. In the country, you have better air and water, though... it’s a trade-off. But even if I get other sicknesses, even though I have HIV, I don’t know what is going to happen tomorrow. So I need to live a happy life. There are a lot of people struggling with illnesses like cancer, but I have this illness that causes me no problems. The doctors and CHARM people tell me I can live another thirty years! I don’t want THAT!’ He said this last part with a laugh, and pulled his phone from his jeans pocket. He selected a picture and showed it to me across the table. He had gotten married just the day before!

“That’s my wife, me, and the Lutheran minister. I’m still a hippie. I still like music, nature and coffee. But now I have a cigarette every now and then, and I might drink a couple of beers. Some people drink a lot. I’m done after two or three. My wife

\(^1\) CHARM is an NGO and is discussed in Chapter 4.
and I have a dream. It’s not a big dream, but this is our dream. We hope to have a nice little café with good coffee and music and have a nice life. You know that Eagles song, ‘Take it easy?’ That is my philosophy.” (Fieldnotes, October 9, 2011).

So who is Mr. T? He is a 45-year-old man from the Kansai\(^2\) region of Japan. He works at a small company his family owns. He is married. He likes music, coffee, and nature and is very well-traveled. At the train station, I couldn’t pick him out of the crowd even though we’d met before – he found me. Sitting across the outdoor table at a café, set apart from the street and pedestrians by substantial foliage, Mr. T is quick with a joke and a smile.

From this description, Mr. T could be any number of upper-middle class, middle-aged Japanese men. But there are other things that stood out about his story.

Mr. T is an ex-junkie.

Mr. T is an ex-prisoner.

Mr. T has hepatitis C and is HIV+.

Chances are, these details stand out, even though one would never know these things from seeing him in a café, riding next to him on the train, or visiting his office as a client. He goes to work every day, wonders what tomorrow will bring, and shares his dreams for the future, just like any other average Japanese. However, these details, once known, set him apart and make him appear anything but average. Furthermore, Mr. T is willing and able to talk about his experiences frankly and directly. Once again, he is anything but average.

Going into the field, my central research question was, how do Japanese living with HIV/AIDS access health resources while at the same time avoiding or minimalizing stigmatization and discrimination? To get at this question, I decided to ask more basic questions about health and health maintenance. I found myself asking interviewees, HIV+ and HIV- alike, how they defined health, maintained their personal health, and

\(^2\) Kansai includes Mie, Nara, Wakayama, Hyogo, Kyoto, Osaka, and Shiga Prefectures (similar to states). Major metropolitan centers include the cities of Kyoto, Nara, Osaka, and Kobe.
whether or not they considered themselves to be healthy overall. Like Margaret Lock, who researched Japanese conceptions of death in order to talk about the issue of organ transplantation, I had to research health in order to talk about HIV and AIDS.

Individual experience has been my primary focus; however, individual health is of course linked to public and national health, and I needed a framework that would give order to the seeming contradictions I was faced with in collecting data. For example HIV/AIDS literacy in the general public is relatively low (which I illustrate in Chapter 1) despite the fact that Japan’s middle class comprises a significantly large percent of the population, literacy rates are high, and compliance with health initiatives (and health surveillance) is high. What accounts for such systemic lack of information when all the usual markers – socio-economic status, literacy, and reliance on biomedicine – would suggest otherwise? As I conducted my research, it became increasingly clear that HIV/AIDS is a tabooed topic. I argue that this is largely due to links to ideas of pollution and death; therefore, fears that individual Japanese “polluted” by HIV would pollute the body politic has to somehow be mitigated. Panic and chaos regarding HIV/AIDS, sex, and related issues has to be avoided. It seems that avoidance of precarity often means avoidance of the issues themselves amongst the mainstream public, although a healthy minority addresses precarity by speaking of the issues directly. Therefore, this project became a study of precarity in Japan and Japanese ways of managing precarity. This focus on precarity and HIV/AIDS gives insight into various aspects of contemporary Japanese culture, while at the same time allowing me to highlight multiple aspects of the HIV epidemic – aspects researchers specializing in HIV in other locations have described separately.

HIV/AIDS is complicated, no matter how it is studied. One way to describe this complexity is to say that HIV/AIDS follows multiple trajectories – although the reality is less linear and teleological than this wording implies. There are several examples of such trajectories. First the evolution of the virus itself as well as the human host has meant that different strains infect and cause illness in different individuals at different rates and with differing levels of severity. Second, the lifespan of a person infected with HIV depends on the age at infection and whether or not they receive optimal care, which is also
dependent on a number of factors. Now that medical treatment for the virus has been established, this also means that people who would have died fairly quickly as a result of infection are now living to become elderly, and HIV has become another factor in of caring for an aged/aging population – particularly in wealthy nations. This brings us to the evolution of science and medical technology with regards to responding to the virus, in which technologies for testing, protection of blood products and sterilization of surgical equipment, prevention, and treatment have advanced rapidly since the early 1980s in response to the epidemic. Tests are increasingly simpler to use and yield faster results, increasingly powerful and complex drugs are packaged into fewer and smaller pills with fewer side effects, and it is increasingly safer to undergo medical procedures that require surgery or blood transfusions as sterilization and screening methods improve. Additionally, epidemiological patterns of incidence and prevalence globally and locally shift and change depending upon a whole host of factors including the socio-economic status of individual people as well as nations, and culture-based understandings of gender, sexuality, family, health, and illness that influence behavior and risk of infection. Finally, the spread of information – or lack thereof – also shapes these patterns. For example, although information about HIV/AIDS increases day by day, just what is known by whom and how this information is conceptualized and used (or not) is also governed by the same factors that influence how the virus itself moves.

Such trajectories are explicated and acknowledged by a number of researchers, who write about issues such as the spread of HIV by mapping the prevalence of various strains around the world using molecular genetics (Takebe, Kusagawa, and Motomura 2004), the political economic factors codified in international politics, trade, and law that make it difficult for the poor to access prevention tools and treatment (Farmer 1992; Farmer 2001a; Kielmann 1997; Biehl and Eskerod 2007), the power imbalances in relationships – sexual and otherwise – that result in higher risk of infection for marginalized people lacking in power (Farmer 1992; Kielmann 1997; Ikegami and Higashi 2005), the various meanings ascribed to HIV clinical trials (Saethre and Stadler in press), and performative and embodied responses to HIV/AIDS (Barz 2006; Fassin 2007). Projects also document efforts to disrupt various trajectories, such as when efforts to curb epidemics through education, prevention campaigns, and treatments “work” and
yield decreases in specific groups (Thornton 2008; Robins 2004), or when they “do not work” and either have little measurable influence or engender conditions that make the epidemic worse (Fassin 2007; Hammar 2007). What is sometimes less visible is how aiming to address particular aspects of the HIV epidemic in a particular place can lead to new issues, even if the target goals are met.

Regarding Japanese trajectories, the epidemic took off in the mid-80s with a scandal involving tainted blood products and fear of the virus being spread by foreigners and women (Yamamoto et al. 2006; Seki et al. 2009; Sato 2005; Cullinane 2007; Miller 2002). Domestic factors that engendered the epidemic – failure of the Japanese government and pharmaceutical industry to protect patients from possible infection through medical care, failure of practitioners to inform them of possible exposure, and Japanese engagement in sex tourism and human trafficking for sex work, for example – were marginalized while HIV as a foreign problem seeping into the Japanese body politic through “deviant” women who engaged in prostitution, slept with foreigners, or simply enjoyed their sexual freedoms was emphasized by the media (Cullinane 2007; Miller 2002; Sato 2005). In the 1990s, patients infected through medical care won a class-action lawsuit against the Ministry of Health and the pharmaceutical companies responsible for failing to pull tainted blood products (Yamamoto et al. 2006; Seki et al. 2009). At the same time, increasingly effective anti-retroviral therapies were approved for use in Japan and kept many of those infected from progressing to AIDS and dying (Shirano and Goto, personal communication). The combination of the two signaled an end to the Japanese epidemic to the public, and media coverage plummeted. When AIDS was no longer visible, concern about HIV largely disappeared. Moreover, the perception of condoms as a tool for birth control rather than prevention of sexually transmitted infections (STIs), the lack of attention to sexual minorities, and the increasing resistance to sex education by political conservatives following this period fostered an increase in HIV incidence amongst men who have sex with men (Monobe et al. 2006; Runestad 2010). This risk category has comprised the majority of new cases in Japan since the late 1990s (Japan Foundation for AIDS Prevention 2013). However, recent data suggests that there has been an increase of HIV incidence amongst heterosexual men and women, particularly in rural areas (Nagano Prefecture 2012). A number of community-based organizations and
medical and research groups are working to address the increasing number of people living with HIV/AIDS in Japan, but the issue still remains distant to the general public. To summarize, laws to protect patients and PLWHA have improved, and treatment, prevention and care networks have also improved; however, awareness is low and HIV rates continue to rise despite Japan’s relative wealth and comprehensive national health care system. Moreover, improvements in medical technology have not led to public understanding that one can live healthily with HIV; rather, the absence of AIDS due to medication has been falsely equated to the absence of HIV, and the 1980s conception that once someone is found to be HIV+, they die, remains.

Given the way that HIV/AIDS functions on multiple levels and includes a multitude of “trajectories” such as those described above, discerning what happens when such trajectories are and are not disrupted in an equally complex way is useful for people who work and live HIV/AIDS. Two theoretical tools or frameworks can facilitate such discernment: a bio-cultural take on “going viral” and precarity. First, terminology such as virulence, pathogenicity, co-infection and syndemic are used to describe how a pathogen (including but not limited to viruses) spreads and causes disease, as well how multiple pathogens in a single organism (co-infection) or in an entire population at epidemic levels (syndemic) spread and cause disease. This terminology can be adapted to illustrate how information about illnesses, in this case HIV, “goes viral” along similar pathways as the actual virus, and how pathogens therefore intersect with information about those very pathogens in the bodies of individuals. Second, precarity can be used to demonstrate how the very action of attempting to alleviate a particular aspect of HIV may or may not “work,” but also may or may not engender the start of a whole new HIV-related issue – such as how a system of privacy may work against patients who want access to their own records.

Returning to Mr. T’s narrative, I highlight themes of representation of HIV/AIDS through images and narratives, religion, (in)visibility of social problems, embodiment, access to resources, citizenship, and performance of gender, sexual, and familial norms. I then relate them to current methods of studying HIV in the social sciences below.
HIV/AIDS: Themes and Theory

From the very beginning of my interview with Mr. T, he was interested in representation: “Help me write a story,” he asked. He wanted his story told; but through his story, he also provided insights about how HIV/AIDS has been represented. Recall that after he tested positive, all he could think about was death. Like many newly diagnosed people, an HIV diagnosis was a death sentence. For Mr. T, the possibility of dying in a Thai prison – particularly when that was not his jail sentence – was eventually his motivation to get clean, get treatment, and get home. It was not until he connected with an NGO in Osaka (CHARM) that he realized he could live for a long time with HIV, and that he could still entertain the possibility of getting married and running a nice café with his wife. In addition, Mr. T’s desire to tell his story – both to me and to audiences at AIDS Bunka Forums (discussed in Chapter 5) suggests a desire to be counted, to be heard as someone living with HIV. Moreover, the embodied process of creating and living one’s own HIV narrative, complete with transitioning views of what HIV/AIDS itself is and represents, is common to people living with HIV globally.

While Treichler’s work suggests how images and information about HIV/AIDS have proliferated and contributed to the spread of HIV in English-speaking countries (1999), Barz’s work on “singing for life” as a response to HIV/AIDS provides an example of how one constructs and performs an HIV narrative in Uganda. Described as a “medical ethnomusicology” of HIV/AIDS songs, Barz describes how HIV/AIDS-themed music can educate the public, alleviate suffering, control pain, and be used as a form of counseling, rather than centering his work on the factors that engender the spread of HIV and the progress to AIDS. He shows that “singing for life” or “singing one’s illness” is also a way to memorialize people and local history at a time when many people and family histories are lost due to AIDS deaths; in other words, it is a type of narrative. Moreover, the image of HIV/AIDS as death is accepted as the lives of those lost are collectively mourned through narrative songs, and the image is actively converted to something one can “live positively” with as songs are used as preventive tools to educate – although some songs do, indeed, perpetuate various negative images and associations of HIV as being an illness of promiscuity for example. Whereas scholars such as Farmer and Biehl illustrate how political-economic systems can make it difficult for people to
get care (discussed below), Barz shows that when politicians such as Uganda’s President Museveni and the local population view HIV as a local problem, such efforts develop organically as methods of dealing with the epidemic. I discuss issues of representations of HIV/AIDS in terms of linguistics in Chapter 1, the spread of images and ideas in Chapter 2, and in museum exhibits in Chapter 3 – all within Japan; I also describe the construction and performance of Japanese HIV narratives in Chapter 5.

The role of religion in Mr. T’s narrative is also common to illness narratives in general. For Mr. T, the key person who helped him access testing and treatment in Thailand was a Lutheran minister who did missionary work at the prison. Both men have now returned to Japan, and the same minister performed Mr. T’s wedding ceremony just the day before I spoke to him. Even though he clearly has a relationship with this minister and his church, it is important to point out that Mr. T does not talk about his spirituality or religiosity specifically. Likewise, he does not couch his recovery or treatment in terms most religion scholars or strong adherents would characterize as overtly religious. This sort of engagement with religion in Japan – which emphasizes practice and practical benefits over belief – is one Reader and Tanabe label “practically religious” (1998). Although they use this term primarily in terms of Buddhism and Shinto, it applies here as well. In Mr. T’s case, the Lutheran minister showed him an avenue to improve his life and he followed it – he still follows it; but he does not necessarily follow Lutheranism the same way American or European Lutherans would, or talk about his relationship with God as American or European Lutherans might. In fact, being a member of a Christian church makes Mr. T a minority in yet another way – Christians only account for approximately two percent of the population\(^3\). In addition, he gave no indication that anyone else at the church besides the minister was aware of his HIV status.

Somlai and colleagues describe the multitude of ways religious people and institutions may respond to the HIV/AIDS epidemic. Drawing from a survey of five places of worship in the U.S., they state that faith communities have a history of offering support and compassionate care for people in times of crisis, and that they have often

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\(^3\) The population of Japan is about 128 million people, and the ministry of education reported that there are about 2.8 million Christians in Japan (Survey of Religion Statistics 2011).
worked in prevention, support and care efforts (1997). However, the stigma attached to how a person becomes HIV+ has led to differences in how church congregations respond to such people. For example, of the people surveyed, Fundamentalists, Catholics, Protestants, Buddhists, and Unitarians, in order from highest to lowest level of agreement, believed that HIV/AIDS was a result of sinful behavior and thus could be considered divine retribution (Somlai et al. 1997). These beliefs in turn influence the degree to which churches participate in prevention and care, and the degree to which members are willing to use religious-based resources for explicitly HIV-related problems. I discuss the relationship between religion, health, and HIV/AIDS in Japan in Chapter 1.

Embodiment and selfhood are also important issues in Mr. T’s narrative. He describes himself as a hippie who loves music and coffee, his life philosophy is based on the Eagles song “Take it Easy,” he has HIV but it causes him “no problems,” and he talks about his past as a junkie and his current role in helping people like him. He draws connections to his travels, his hobbies, his drug history, and his infection: these bodily experiences are linked within him and make him who he is. This in turn influences, to some degree, what he chooses to do in the future.

Fassin approaches such issues of embodiment and HIV similarly. Utilizing a phenomenological framework to discuss HIV/AIDS in South Africa, he contextualizes the fast-paced epidemic and President Mbeki’s rejection of global North-based nosology and treatment interventions within the history of colonization and apartheid – a history that is inscribed in individual bodies and on a large scale, in the body politic (Fassin 2007). Like Farmer, Mbeki viewed AIDS as a problem of malnutrition, parasitism, bacterial infection, and poor sanitation due to poverty – and he rejected global north explanations and solutions because of the role colonization played in causing this predicament in the first place. Thus, Fassin is able to illustrate that Mbeki’s refusal to accept the biomedical explanation that HIV causes AIDS and anti-retrovirals (ARVs) can treat it, which is based on his lived experiences with apartheid and colonization, has played a significant role in the explosion of the HIV epidemic in South Africa. I discuss embodied experiences with HIV in Japan in Chapters 4-6, where I focus on experiences with care, relating narratives, and defining health vis-à-vis HIV/AIDS.
Although lack of access to resources in many parts of the world correlates with poor health and increased incidence, prevalence, and death from infectious diseases like HIV, the situation is the opposite for Mr. T. Rather, he states that his family had “too much money” and indicates his affluence played a role in his addiction and subsequent infection with HIV; this is in sharp contrast to the fact that many people in the global south engage in transactional sex in order to earn money and food needed to survive, which then increases their risk of being infected with HIV. However, Mr. T’s personal affluence and Japanese citizenship ultimately allowed him to access the social and medical resources he needed to get clean, get treatment, and live a positive life. Put another way, being poor and marginalized increases one’s risk of contracting an infectious disease and the inability to participate as a citizen (nationally or globally) in anything but a subordinate role decreases one’s chances at accessing resources to combat the infections: Mr. T’s ability to be a global consumer of travel and narcotics contributed both to his risk of infection and his ability to do something about it.

These are the very issues Farmer discusses in his analysis of HIV/AIDS in Haiti and infectious disease in general. Using a political-economic frame, Farmer contextualizes the HIV/AIDS epidemic (SIDA in Haiti) within the larger history of Haiti-U.S. diplomacy and trade (mainly the support of hydroelectric projects, tourism, the Duvalier regime) in which Haiti was financially and politically subordinated to the U.S., which supported Haitian politicians who in turn took advantage of their own people (1992). The lens of political economy also allows Farmer to illustrate how Americans looking for cheap vacations and cheap sex visited Haiti and stimulated the sex industry there amongst impoverished urbanites in cities such as Port-au-Prince, then blamed all Haitians for the spread of HIV – to the point that the CDC listed being Haitian as a risk factor for HIV (1992). He also illustrates how SIDA was framed by Haitians as both a “sent sickness” that could be based on anger or jealousy, and/or as a method used by the aristocracy to keep the poor manageable (Farmer 1992). This is all overlaid with a discussion of race and ethnicity, so that the “geography of blame” for the HIV pandemic Farmer theorizes is a racialized one. Farmer continues to utilize the same framework in his later works, where he focuses on elucidating the links between ill health to poverty, racism, and unequal access to resources at the global and local levels (2001b), as well as
the importance of alleviating “structural violence” so that marginalized people can access care rather than be blamed for their ill health (2003). I discuss access to HIV-related resources in Japan in Chapter 4, and the implications of HIV on citizenship in Chapter 6.

Mr. T’s narrative also hints at what is visible and invisible about HIV, something that differs from place to place. In Mr. T’s case, his whole story is centered on his addiction – but this is a rare story in Japan, HIV-related or not. Unlike in the U.S., Southeast Asia or the former Soviet Union where injection drug use is relatively common and HIV transmission through shared syringe use comprises a significant number of infections, intravenous drug use and syringe transmission is very low in Japan by comparison – although the figures for drug use and syringe transmission are both growing. As Mr. T himself said, it has gotten easier to get drugs in Japan; this was corroborated by medical practitioners and NGO workers in Osaka. But this is a problem that remains hidden for the most part: dwarfed by figures of sexual transmission, ignored in local museum exhibits and health education, and drowned out by narratives about HIV contracted through medical treatments and sex, illicit drug use and HIV transmission through needle use remain off the radar of most Japanese people. Thus, Mr. T’s narrative sheds some light on what is often an invisible part of the HIV story in Japan.

Thornton describes how sex networks, “unimagined” by participants and researchers before him (at least in this way), factor into the spread of HIV in different ways, depending on general configurations of relationships in different communities (2008). Comparing Uganda and South Africa, Thornton describes the social networks in each place and states that disturbing the sexual networks that facilitated the spread of HIV was easier in Uganda than in South Africa because Ugandans are more likely to own land and live a more rural lifestyle (moving around less for work and being exposed to fewer people), and more likely to see family gravesites of those lost to AIDS on a daily basis. Further, they were influenced by President Museveni advocating a “no grazing” policy regarding sexual liaisons and encouraging sex education; moreover, Ugandans had had a name for AIDS (siliimu) before it was announced by researchers from abroad, so it was easier to recognize it as a local, domestic problem (Thornton 2008). On the other hand, Thornton notes that South Africans tend to be highly mobile urban-dwellers who
interact daily with a wide range of people who have been influenced by President Mbeki’s rejection of the biomedical conceptions of and solutions for HIV/AIDS (2008). Thus, Thornton explicates the ways in which invisible, or “unimagined” social and sexual networks intersect to play a role in either fostering or inhibiting HIV epidemics. I describe how images and concepts about HIV/AIDS move through social and cognitive networks in Chapter 2.

Taking a different tack with the concept of invisibility, Biehl and Eskerod point out a similar invisibility in their work on HIV/AIDS in Brazil. First, following a political-economic framework similar to Farmer’s, the team shows how skewed access to anti-retrovirals can be both globally and within a particular nation due to the intellectual property rights held by pharmaceutical companies (2007). Although Brazil successfully fought the pharmaceutical industry so that affordable ARVs could be made available to those who needed them, Biehl and Eskerod point out that just providing medications does not ensure compliance: “access” actually requires financial stability, infrastructure, and social support to procure and consume them regularly (2007). Because HIV rates are high amongst the poor and those who use narcotics (categories that are often inclusive there), not only is access difficult, but a significant number of AIDS deaths go unrecorded. By photographing residents of a facility called Caasah over time and comparing them against public health records, the team was able to conclude that as few as a quarter of those known to have died from AIDS were recorded, making upwards of seventy five percent of AIDS deaths invisible (Biehl and Eskerod 2007). I address the issue of visibility of HIV/AIDS in Japan in Chapter 4, along with issues of access as noted above.

Another theme that comes to the fore in Mr. T’s narrative is family. In addition to referring to his family’s social standing, as discussed above, he also describes how his family reacted when he did not fulfill the social roles he was expected to fill: when he did not work or study while abroad, they got angry and ordered him to come home and work. He did this, but his club failed because he continued to use narcotics, and he left again. His family’s disapproval can be understood in terms of Japanese standards of adulthood where one studies to get a job, finds stable employment, gets married and has children to be a “good citizen” and family member. Considering that performing adulthood is based
on national conceptions of family, which are also tied to gender and sexuality. Mr. T thus failed to perform the usual roles while he was using drugs. Interestingly, what brought him closer to the “norm” of Japanese adulthood was being diagnosed with HIV. This diagnosis pushed him to quit using, return to Japan, get a job, and get married. Further, although it is difficult to gauge from his narrative how being HIV positive influences how he plays these roles, he indicates that having HIV causes him “no problems” with regard to health and daily life.

Both Cullinane and Miller articulate these points regarding HIV/AIDS in Japan, but their focus is grounded in a feminist perspective. For example, Miller illustrates how discourses of nationalism, gender, stigma and contagion link HIV/AIDS to women (particularly foreign women) by highlighting how the sex trade is described in terms of male sexual needs, work obligations and market economics; how Japanese women who participate in the sex trade are portrayed as selfish because their motivation is to earn money to buy brand goods while foreign women are perceived to participate out of economic need (and can thus be “saved” by Japanese men who buy sex); and how portraying a foreign woman in a condom is an effort to visually illustrate how foreign women specifically need to be contained because they have the potential to infect Japanese men and through them, the Japanese body politic (2002). In other words, the sexuality of Japanese men is unproblematic whether for play or procreation, while Japanese women are criticized for expressing sexuality beyond what is required to become a mother and foreign women are simultaneously considered threats, play objects, and objects to rescue vis-à-vis Japanese society.

In a similar vein, Cullinane describes how the stories of HIV/AIDS are manipulated by the media to fit Japanese ideas of sexually deviant others rather than portraying real people living with HIV/AIDS. Further, she argues that enjo kōsai, often translated to mean “compensated dating” in English, is considered a “symptom of the ailing Japanese family” in that young woman who participate in such activities lack morals and are harming Japanese society by failing to conform to sexual norms. She

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4 This can refer to a paid escort, but can also refer to a transactional relationship that includes trading sex for spending money or brand goods.
notes that people tend to blame girls but not men for *enjo kōsai*, thereby demonizing women and girls for asserting their sexuality rather than punishing men for pursuing sexual relationships with (often under age) girls. In this way, women are simultaneously blamed for spreading venereal diseases such as HIV and failing to make efforts to stimulate the falling birth rate by marrying and becoming mothers. Cullinane contextualizes this historically by illustrating how women such as the Bluestocking society, *moga*, *kogyaru*, *ganguro* and *yamamba*⁵ have also been vilified for transgressing “good wife, wise mother” norms. I discuss all these issues – family roles, sexuality, and gender in Chapter 6 alongside issues of citizenship and health.

Each of these tropes – representation, religion, (in)visibility, access to resources, embodiment, citizenship, and performance of roles – is overlaid with stigma, discrimination, and blame that engenders a sense of precariousness. For example, people tend to associate illness with other categories such as hemophiliacs, people viewed as promiscuous such as gay men and female sex workers, people who are poor, foreign, uneducated, prisoners, and/or drug addicts. In other words, it is associated with people “not like me,” and these form the basis of stereotypes about the illness as well as a need to put distance between those “others” and the self. People fear the people (rather than the illness) or their ways of living because they feel they threaten the status quo. When first diagnosed, people who once saw HIV and people who live with it this way may redirect their feelings of fear to feelings of shame. Ultimately, the stereotypes, fear and shame lead to stigmatization based on the illness or its associations, and this then leads to discrimination and blame. Experiences of stigmatization, discrimination, and blame leave people feeling that they have little choice or control over the many aspects of their daily lives – a sense of precarity, to put it differently.

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⁵ The Bluestocking Society consisted of a number of feminist Japanese women such as Hiratsuka Raicho and Yosano Akiko, who protested paternalistic ways of defining family and fertility. *Moga* is a shortened transliteration of “modern girl,” and referred to women in the 1920s and 30s who worked in cafes, wore make up, and dressed in European clothing. They were also considered by some to express their sexuality more freely than was considered prudent at the time. *Kogyaru* refers to cutesy girls who emphasize their (often sexual) innocence and have been common since the 1970s. *Ganguro* refers to young women who subvert the beauty ideal of pale skin by tanning and using dark make-up and white lipstick, thus constructing their own version of beauty. *Yamamba* refers to both an evil mountain witch with wild white hair and cannibalistic tendencies (from folklore) and the fashion of dressing in a manner that suggests such a person (wild, white hair, extreme make up, and disheveled clothing).
Comaroff nicely illustrates this complex picture by combining phenomenological and political-economic frameworks to conclude that HIV/AIDS is an embodiment of contradictions of governance (2006). Not only has HIV/AIDS destabilized people’s faith in biomedicine’s ability to cure, it has destabilized modern, “civilized” sensibilities about how to live disease-free by illustrating how the boundaries people set regarding such sensibilities exist in minds but are transgressed within bodies: “Would-be statesmen represent the predicament of contemporary governance as a Herculean battle to balance minimal government with maximum personal safety and self-realization, their rhetoric focusing centrally on the quality of life, understood in simultaneously moral and material terms. AIDS embodies, all too literally, core contradictions at issue in such discourse,” (Comaroff 2006:199). Living with HIV/AIDS, whether in one’s body or in one’s society, is a precarious matter. Therefore, I myself use the framework of precarity to illustrate the realities of living with HIV/AIDS in Japan in the following chapters.

**Framing HIV/AIDS: Precarity**

“Precarious” is an adjective that refers to a situation as unsafe or uncertain (Oxford Advanced Learner’s Dictionary 2010). Precarity was coined as a noun form of this word, and was originally used to describe the instability inherent in being unable to meet basic needs for food, water and shelter.

When I utilize the words precarious and precarity, I am drawing on more complex definitions. In this dissertation, precarity is both a state and a feeling. Precarity as a state includes: 1) constant change; 2) a lack of choice regarding daily life conditions – both actual and perceived; 3) the power to make choices about daily life conditions – both actual and perceived; and 4) dependence on anonymous others. Living in such a state results in feeling unsettled, unbalanced, and/or in danger. Precarity is a fact of life, a constant state for us all. However, it is felt more acutely and on more fronts by marginalized peoples who are less likely to be understood and supported by “anonymous others” in society. In other words, some people “live more precariously” than others, and some people experience more “felt precarity” than others.
Given this definition, precarity is a much more powerful tool than terms often used in social science such as indeterminancy and risk. Indeterminacy refers to the infinite number of possibilities that could happen to a given individual and takes change as a given, but is fuzzy when it comes to choice and danger. Risk addresses both choice and danger, but often links danger to the choices that individuals make. The language of risk assumes that choices are made by actors who have complete and absolute control, which allows for the stigmatization and blame of people whose supposed “lifestyle choices” increase the probability that something they have “chosen” will result in a negative outcome. In effect, the comprehensive definition of precarity I employ here combines and adds to these terms, making it possible to consider the complexity of daily life from several nuanced vantage points.

Precarity is also a social theoretical framework. As noted above, the roots of precarity are socio-economic. Ettlinger notes that it first referred to social instability due to a workforce that was comprised mostly of temporary workers (2007). In general, most recent discussions of precarity revolve around social programs created by North American and European governments in the 20th century to minimize unpredictable or unstable conditions that lead to social unrest such as food and housing shortages – issues often perceived to be out of individuals’ immediate control (Butler 2009). In other words, these programs were built to minimize both the state of precarity and felt precarity through socio-economic means. Judith Butler, however, argues that the same governments that put programs into place to prevent precarity in fact face perpetual precarity because political and economic trends give rise to marginalized peoples, who then live precarious lives based on what social networks and economic resources they do and do not have access to (2009). Essentially, she illustrates the critical flaws in assuming that the roots of precarity are only socio-economic and, as such, can be permanently solved by nation-states.

Drawing from Levinas’ theories of ethics, Butler goes on to push precarity beyond the realm of socio-economics and uses it to illustrate how the desire to alleviate fear and grief have lead to military violence and retribution in the United States, with the context of 9/11 as an example. She asserts that: 1) despite the tendency to vacillate from
violence to retribution (motivated by fear, grief and anger), there are other, less violent, possibilities; 2) to determine and implement these possibilities, “dominant forms of representation must be disrupted” for people to see more clearly what, exactly is precarious (or, causing fear and grief); and 3) forms of representation in the media that must be disrupted refer not only to content, but the way that people are encouraged to see, hear, and feel reality through consumption of media representations (2004).

In her more recent work, Butler links precarity and performativity through the example of performing gender, and by extension, sexuality: “Precarity is, of course, directly linked with gender norms, since we know that those who do not live their genders in intelligible ways are at heightened risk for harassment and violence” (2009:2). Further, “norms are not only instances of power; and they do not only reflect broader relations of power; they are one way that power operates” (Butler 2009:2). And finally, “So it is [through]… who counts as a subject and who does not… that performativity becomes linked to precarity” (Butler 2009:4). To summarize, people who perform gender and sexuality – and other roles that influence how citizenship is socially constructed (in the case of this dissertation, “Japanese-ness”) – in ways that differ from the perceived norms, experience precarity more acutely than those who do not.

An example of this “experienced precarity” is the struggle to assert rights: who has the right to do what in a given society? Butler refers to Mexicans living in California who took to the streets and sang the U.S. national anthem in English and in Spanish as an example. Drawing from Arendt, Butler states they were exercising rights they technically do not have (the right to assemble and protest) to assert that they should have them – and that this is necessary for social change (2009). Drawing from Spivak, she also notes that some degree of assimilation is required to affect social change. In this example, performance is driven by felt precarity, and is itself precarious (participants in the demonstration could have been arrested and deported, and thus the demonstration could have led to acts in direct opposition to what they had hoped); but performance can also help alleviate felt precarity by pushing for social change.

The relationship between precarity and performance is, thus, a complex one in which outcomes depend on multiple factors. However, as noted above, marginalized
people who perform roles differently than the majority feel precarity more acutely. “Precarious life characterizes such lives who do not qualify as recognizable, readable, or grievable. And in this way, precarity is rubric that brings together women, queers, transgender people, the poor, and the stateless” (Butler 2009:13). Although Butler singles out these five groups, precarity is a more comprehensive tool when we recognize that it can be applied to everyone, but with particular attention to marginalization.

Precarity can also be considered a method. What do facing change, having or not having choices, and relying on anonymous others have in common? Connections – whether that means forging or renewing connections, or functioning with a lack of connections – are an essential component of everyday life. Latour has emphasized the importance of actors – human or not – and the connections between them as important in understanding social conditions (2005). Particularly in Chapters 2 and 4, I build on this concept by considering precarity to be a sort of post-modern network theory in which the basic assumption is that who/what IS NOT connected is just as important as who/what IS connected. Such connections/non-connections can be seen as at the heart of what makes life precarious: they shape who/what is feared and grieved and what actions people take or don’t take when they feel threatened. Thus, searching out connections and non-connections in daily, lived experience can illuminate the ways in which attempts to alleviate instability, fear, grief, and suffering (which have all been used in previous work addressing precarity) can lead to a lack of support by anonymous others at the very least, and to stigmatization, blame, discrimination, and/or violence against marginalized peoples in the worst cases.

But back to precarity as theory and its applications. Butler’s choice to use precarity to illustrate the problems inherent in military violence in her 2004 work on 9/11, it seems, is an extremely calculated one. There, Butler’s concept of precarity is based on Levinasian ethics in which the alleviation of suffering is the goal in conflict resolution. Suffering and war were inextricable for Levinas, a Jewish philosopher and ethicist who survived the Second World War; this is the connection that Butler elaborates upon as she draws attention to the fear-grief-anger mediated cycle of violence and retribution into which 9/11 fits, and to the alternatives to that cycle. With the Levinasian base in place –
the focus being on the alleviation of suffering rather than the alleviation of uncertainty from not enough food or water – precarity as a lens to understand 9/11 is a natural fit.

HIV/AIDS is a natural fit, too, if we consider the ultimate goal of HIV/AIDS programs, treatment, and education to be the alleviation of suffering caused by this condition. But such efforts are about more than that. They are not just about alleviating suffering, but also about alleviating fear and uncertainty related to change, choices, and relying on unknown others. The reason that HIV/AIDS and precarity work well to illustrate these intricacies can be attributed to Butler’s “transposition” of Levinas rather than strictly to the theories of Levinas himself:

The Levinasian face is not precisely or exclusively a human face, although it communicates what is human, what is precarious, what is injurable. The media representations of the faces of the ‘enemy’ efface what is most human about the ‘face’ for Levinas. Through a cultural transposition of his philosophy, it is possible to see how dominant forms of representation can and must be disrupted for something about precariousness to be apprehended (2004:xviii).

In other words, the faces of self and other – which are not “faces” in the strictest sense, but include representations of ways of being – that are presented in the media show people what is precarious by what it includes and what it does not. For example, loss of “enemy” lives, even civilian lives, are rarely if ever grieved in the mass media, while the lives of Americans lost or injured are often mourned publically as shared losses (Butler 2004:xix). By supplementing Levinas’ concept of the “face” to include media representation (and lack of representation), Butler argues that this inability to mourn others and the ritualized way of mourning our own losses perpetuates a sense of inequality between “our” lives and “theirs,” which in turn leads to an elevated sense of being wronged (in comparison to being a wrong-doer), which then results in retribution and continued violence. Sometimes our lives seem more precarious because of them.

Compare this pattern of perceived inequality and violence to the ways in which people with stigmatizing illnesses are often blamed for their conditions, and seen as somehow less than deserving of medical attention or compassion – even in cases of people who share the same citizenship. The loss of the first HIV/AIDS victims in the United States – waves of hemophiliacs, surgical patients, babies born to drug-addicted
mothers, and gay men – barely made the news. The lives of those Americans – and Europeans and Africans who came before them or were perishing at the same time – were, then, considered less newsworthy than the trial of the gunman who tried to assassinate President Reagan. The loss of their lives was less grievous, it seems, than the loss of seven people who died in the so-called Tylenol Poisonings in Chicago in 1982 – an incident which led to immediate national media attention and a nation-wide product recall (Kasahara 2010). Moreover, while deaths due to AIDS were being ignored by the media, those living with the illness were blamed for their illness and publically admonished for spreading it – particularly men in same-sex relationships. At the same time, President Reagan refused to utter the name of the illness, researchers had to fight desperately for funds to research and treat it, and the possibility of the national blood supply being tainted was muffled – issues the mass media did not dwell on until Rock Hudson died of AIDS in 1985 (Shilts 1987). It seems that the people who were lost were somehow perceived as lesser citizens.

Returning to the context of rights described above, it is also clear that precarity and performance as a lens to understand HIV/AIDS is an equally natural fit. People living with HIV/AIDS are often considered to have transgressed the social norms of what it means to be a “normal” man, woman, and citizen. Living with an infectious disease that is most commonly spread through sex or blood can connote pollution from and “wrong behavior,” which can lead to a denial of rights, citizenship, and even personhood. Thus, the lives and deaths of such people then become less valuable than the lives and deaths of people who perform norms “correctly.” As Butler herself puts it: “It is worth remembering that one of the main questions that queer theory posed in light of the AIDS crisis was this: how does one live with the notion that one’s love is not considered love, and one’s loss is not considered loss? How does one live an unrecognizable life? If what and how you love is already a kind of nothing or non-existence, how can you possibly explain the loss of this non-thing, and how would it ever become publically grievable?” (2009:13).

Examples of this include parents blaming a same-sex partner for their child’s illness, disallowing the partner to be with the patient at home or at the hospital, and
hiding the illness from extended family and friends due to the stigmatization that may result (Shirano 2012; Shilts 1987). When next of kin are needed to make medical decisions on behalf of a patient, the partner, who is not recognized legally or perhaps even socially, has no rights to even visit a partner in the hospital – even if they were caring for the patient before the family arrived, or the patient had been estranged from his/her family. Such stories are common in both the United States and Japan.

In brief, I draw from Butler’s early work on precarity, which emphasizes alleviation of fear, grief, and suffering in general and the roles that representation play specifically, in the first three chapters of this dissertation. In the final three chapters, I utilize her more recent work on precarity, in which she links it to performativity, citizenship, and rights.

**HIV/AIDS and Bio-cultural Theory**

Understanding the HIV/AIDS milieu in Japan requires a basic knowledge of the biology and epidemiology of HIV/AIDS; moreover, as stated above, many of the concepts used by natural scientists to explain the epidemic can be used to construct a biocultural framework in such a way that the parallels and intersections between the biological and socio-cultural phenomena related to HIV/AIDS can be clearly studied. I begin with the former.

Since the illness was first recognized in 1981, 25 million people have died from AIDS (World Health Organization 2012). According the World Health Organization (WHO), 34 million people are living with HIV worldwide, and half of those infected are women; seven thousand people were infected daily in 2010, for a total of 2.7 million new cases (2012). In 2010 alone, 1.8 million people died from AIDS. The area with the highest prevalence is sub-Saharan Africa, in which five percent of the population, nearly 23 million people, is infected (World Health Organization 2012).

HIV is an enveloped lentivirus from the family * Retroviridae* (retroviruses). Retroviruses have two copies of plus, single-stranded RNA (most viral genetic material is comprised of DNA) and several enzymes enclosed inside a cylindrical core, which is encased in an icosahedral capsid (Prescott, Harley, and Klein 2005). Reverse
transcriptase, an enzyme that enables the translation of RNA into DNA, is one of the enzymes carried in the retrovirus capsid. To reproduce, a retrovirus binds to the outside of the target cell and inserts its RNA and reverse transcriptase into the host cell. In the case of HIV, the target cells are human CD4+ T cells, macrophages, langerhan cells, dendritic cells and monocytes. The viral RNA is translated into DNA, which is then incorporated into the host cell’s genome. Essentially, the virus “hijacks” the cell and causes it to produce large volumes of the virus; these viral particles bud off the cell or are released when the virus load causes the cell to lyse. The newly released virus particles then infect new cells and the process begins again. Because HIV infects cells that help the body fight infection, the body becomes increasingly more susceptible to other infections as the T cell count drops. When the T cell count drops below 400 per microliter of blood (normal levels are about 1,000 per microliter), opportunistic infections are able to overpower the immune system, making it difficult for the patient to recover from even minor illnesses such as colds or influenza (Prescott, Harley, and Klein 2005). At this point, the diagnosis shifts from HIV to AIDS (discussed below).

HIV is spread through direct, penetrative contact in which infected blood, vaginal fluids, seminal fluids, and/or breast milk enters the body of an uninfected person. It can thus be contracted through sex acts involving contact with these fluids, the sharing of IV syringes used by an infected person (either for illicit drug use or medical treatment), needle sticks in medical facilities, blood transfusions or organ transplants in which the transfused products have not been properly heat treated or screened, and during pregnancy, childbirth and breast feeding. Once in the human body, HIV attacks immune system cells, stimulates them to reproduce increasing amounts of the virus, lowers immune function, and the infected person progresses to AIDS and dies from infections they cannot fight.

Sexual transmission of HIV can be prevented by using barriers such as male condoms, female condoms and dental dams during sexual intercourse and other sex acts. Intravenous (IV) transmission can be prevented by using sterilized needles for injections. This includes providing IV drug users with clean syringes and ensuring clean syringes are used in medical facilities. Prophylactic courses of anti-retrovirals can be administered to
HIV+ expectant mothers and newborns of HIV+ mothers to stop mother-to-child transmission during pregnancy and birth; HIV+ mothers must also refrain from breastfeeding. Medical professionals who experience needle sticks can also take these prophylactics. Screening blood and organs for donation can prevent transmission through medical care.

Several HIV prophylactics are currently being developed. In July 2012, the FDA approved the first pre-exposure prophylactic (PrEP) medication for use in the United States (Center for Disease Control 2012). Tenofovir disoproxil fumarate plus emtricitabine (TDF/FTC) in pill form, commonly known as Tenofovir, was approved for use “amongst sexually active adults at risk for HIV infection” (Center for Disease Control 2012). This is just the first of many such prophylactics being developed. Gels for anal and vaginal use, and rings and films for vaginal use are all being considered as delivery mechanisms for a host of drugs that may prevent transmission of HIV (McGowan 2012). Vaccines are also still being researched. But given the complexity of the human body, the virus, the drugs being developed, and human behavior regarding sexual behaviors and STI prevention, there are several questions to address when developing these medical interventions, many of which have not yet been answered.

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6 For example:

1. Regarding the drug: What drug at what dose? What side effects are there, and how are “tolerable side effects” determined? How long does the drug stay in the body? Does it have to be applied/inserted locally, or can it travel (i.e., be taken orally)? How often must it be used to be effective? What are the long-term effects? What cannot be used with the drug (i.e. other medications, alcohol, drugs, lotions, lubricants, douches)?

2. Regarding the delivery mechanism: What drug can be administered with what technology (gel, ring, film)? Who is most likely to use what delivery mechanism? How often will the product have to be inserted/applied? Are there any risks or special instructions necessary for insertion, application, or removal – particularly in the case of a ring?

3. Regarding accessibility: Many people who would benefit most from these products live in developing nations. Can we guarantee they will be cost effective? Are they shelf stable? Can they be procured from easy-to-access facilities? Who decides who is eligible to get these technologies?

4. Regarding the socio-cultural responses: What meanings will people ascribe to these technologies? Will people’s behaviors change with the availability and use of these technologies? How will those who don’t take them view them? How will these developments change what people think about HIV and AIDS?
It is important to note that the biological variation of both the virus and the host are factors in determining who becomes infected with HIV and how quickly they progress to AIDS. Further, suites of social, cultural and environmental factors further complicate the picture. These factors are discussed more fully in Chapters 1 and 2. In any case, once someone has contracted HIV, it is not curable but it is treatable. The first round of medications, such as AZT, were developed in the late 1980s and were highly toxic and many patients said they were worse than HIV/AIDS itself. The second generation of medications, ARVs that targeted specific stages of viral production, caused fewer side-effects and noticeably slowed the progression to AIDS. Major progress has been made by combining several anti-retroviral components into increasingly smaller doses of medicine. This third generation of medications is called Highly Active Anti-Retroviral Therapy, or HAART. The components of this treatment include 1) entry inhibitors, 2) reverse transcriptase inhibitors, 3) integrase inhibitors, 4) protease inhibitors, and 5) maturation inhibitors (Prescott, Harley, and Klein 2005). By combining these, some patients can now take as little as a single pill a day. However, Japanese pharmacists note that because people are different, it takes time to find the drug regimen that best suits each patient’s body and lifestyle. Further, access rather than side effects may be more likely to determine whether or not people living with HIV take HAART – even in resource-rich countries like Japan, these pharmaceuticals can be up to $700 per month with insurance.

It is not uncommon for people to use HIV (the virus) and AIDS (the syndrome the virus causes) synonymously in common parlance, but the two are not the same. AIDS is the condition in which the immune system is unable to fight infections, and is measured medically as a CD4 count less than 400. This is also the condition in which symptoms become visible: symptoms include extreme weight loss, skin discoloration, and skin lesions. People contract bacterial, viral and fungal infections simultaneously, and may

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7 A cure is becoming more likely in specific people under specific conditions. For example, a toddler who was born with HIV now tests negative; a German patient who received a bone marrow transplant has tested negative, and there are some people who have some level of biological resistance who are either not easily infected or who do not progress to AIDS very quickly.

8 1) Prevents viral entry into a cell; 2) prevents reading and building of viral RNA; 3) prevents the splicing of viral RNA into cell RNA; 4) blocks cleavage of proteins necessary for viral production; 5) blocks capsid formation.
also suffer from cancerous tumors or lesions. Common illnesses that often lead to death include pneumonia, tuberculosis, and cancer. When the body can no longer tolerate the level of co-infection or sustained treatment, the body begins to waste, fevers rage, the person lapses into a coma as organs begin to cease functioning, and finally, the person dies. However, even people who have progressed to AIDS can continue treatment; provided they have access and support they can continue to live positive lives, although progression to AIDS does mean that they may have increased difficulty doing so.

To summarize, HIV is an infectious disease spread amongst humans when bodily fluids (excluding sweat, urine and saliva) are exchanged. It is at epidemic levels in some parts of the world. HIV can be prevented, and although there is no cure, there is treatment – but it is expensive and can be difficult to access or consume. Infection and progression to AIDS depends on the biological, physiological, and genetic status of the person, as well as the genetics of a particular viral strain. Environmental factors such as whether the person is at risk for malnutrition or other infectious or chronic conditions due to their living conditions; economic factors such as having access to medical care; and socio-cultural factors such as cultural practices, education, and having a social support network also play roles in infection, treatment, and progression to AIDS.

Likewise, as Treichler has pointed out, some information about HIV/AIDS can travel rapidly amongst people through various modes of communication (1999). She has labeled this phenomenon an “epidemic of signification.” Information about prevention and care may be difficult to find or access, leading to a lessened chance that efforts are made to prevent or treat HIV. Infection and progression to AIDS depend on what type of information a person has about the illness, how the information was packaged, and how the person processed it. This is dependent not simply on individuals, but on the social and cultural milieu of a given area such as whether sex education exists and what it includes, what the sexual norms are, and what sort of attitude it held regarding condoms, syringes, and visiting healthcare facilities or taking medications. In other words, there are similarities in how the virus moves and how information about the virus moves in society, and even more importantly, in how the biological meets the socio-cultural in human bodies as people move through the world with HIV – becoming infected, or avoiding
infection while simultaneously coming in contact with HIV/AIDS memes. I develop a bio-cultural framework based on these concepts in detail in Chapter 2, where I describe how memes about HIV/AIDS “go viral” using the terms virulence, pathogenicity, co-infection, and syndemic.

**Living Precariously in the Global North: Japan Focus**

There is a tendency to focus on precarity in the global south rather than the global north – oftentimes, for good reasons. People living in the global south tend to have less access to resources, which affects the choices they make in daily life, how they feel about those choices, and how much they must depend on others. But the tendency to focus on people in the global south as marginalized often allows those in the global north to forget about the fact that there are marginalized populations there, too. Sometimes life seems more precarious abroad than at home. Thus, it is important to address this issue by focusing on what precarity looks like in a place considered to be “healthy and wealthy.” Japan is a good choice for several reasons.

First, Japan has comparatively low annual incidence (around 1,500 new cases a year) and low prevalence (less that 0.1 percent of the population is infected) of HIV when considered alongside statistics from the United States, which reports around 40,000 new cases a year and 1 percent prevalence (Center for Disease Control 2013), and compared to South Africa, which had just under 500,000 new cases a year and the prevalence was 18 percent in 2010 (UNAIDS 2013). But such comparison masks national trends which indicate a long-term upward trend as opposed to peaks and plateaus in general, an ever-increasing number of cases resulting from unprotected male-male sexual contact in Japan, and decreased rates in MSM but increased rates in IV drug users in the US (Whelehan and Budd 2009). Moreover, national trends mask local trends in rural areas such as my field site, where an increasing number of new HIV cases are the result of unprotected heterosexual sex, not unprotected sex amongst MSM, and are thus different from the national trend (Nagano Prefecture 2012).

Second, Japan has an impressive socialized medical system in which cost of coverage and care are calibrated based on ability to pay (annual salary). For example, as a university graduate student, I paid approximately USD $300 for one year of national
coverage. A typical health examination cost approximately $60, of which I paid approximately $25. But as a high school instructor, I paid approximately $3000 for one year of national coverage and had a similar co-pay rate for health examinations. It is therefore easy to assume that if everyone is covered and costs are relatively inexpensive, people living with HIV/AIDS should be able to afford and access care and treatment easily. Unfortunately, this ignores the fact that many people living with HIV are reluctant to declare their status to their company representative, who organizes national health insurance. It also does not consider the fact that people living in rural areas may not be able (or willing) to travel to see HIV specialists, who work at designated hospitals – particularly if they feel they will be recognized. In a related vein, medical technology and medications in Japan are state-of-the-art – but this does not mean that people living with HIV do not progress to AIDS. In fact, Japan has one of the highest rates of people who are first diagnosed not with HIV, but with AIDS.

This combination of factors – supposed access to affordable and advanced medical care, and relatively low rates of HIV/AIDS – should indicate a weak relationship between everyday life, health, HIV/AIDS and precarity. But in fact, the opposite is true: the stark reality of HIV/AIDS in Japan, which includes rising rates, discrimination against people living with HIV, transmission routes that vary from rural to urban areas and include IV drug use, is made visible by using precarity as a method. And if this is the picture for Japan, perhaps it is useful to frame HIV/AIDS in terms of precarity in other nations in the global north.

In addition to advocating for attention to HIV/AIDS in wealthy nations via precarity, in this dissertation I argue that Japanese responses to HIV/AIDS seek to mitigate the precarity inherent in living with the illness, both individually and as a society. In effect, all societies’ responses can be considered in these terms. But what characterizes the Japanese responses to precarity is indirectness. Japanese language itself is indirect. Perhaps the most common example is that subject-less sentences are not only grammatically correct, but commonly used. Although it would be essentialist to state that Japanese people themselves are indirect, it is helpful to acknowledge that the Japanese often consider indirectness to be part of their culture, that there are significant examples
of indirect engagement with social issues, and that some Japanese people recognize indirectness as being problematic when it comes to public health issues like HIV/AIDS. Therefore, I highlight how HIV/AIDS is kept at a distance (and fear of pollution managed) through the use of vague terms, cursory engagement with it in the mainstream media, and museum exhibits that couch it in terms of “others” in Chapters 1-3. In Chapters 4-6, I illustrate how PLWHA and activists combat fear, discrimination, and the threat of a silent HIV/AIDS epidemic by speaking frankly about it. Thus, precarity stemming from fears about HIV/AIDS in all its forms is managed in a multitude of ways based on what about the epidemic is considered precarious, but these ways are all considered “Japanese.”

**HIV/AIDS in Japan**

The first HIV case in Japan was reported in 1985 (Sato 2005). Approximately 21,000 people in Japan are now living with HIV or AIDS (Japan Foundation for AIDS Prevention 2013). The majority of those infected are between 15 and 49 years old, and sexual intercourse is the primary mode of transmission (Japan Foundation for AIDS Prevention 2013). Men are more likely to be infected than women; Japanese men are more likely to be infected than foreign men; foreign women are more likely to be infected than Japanese women (Japan Foundation for AIDS Prevention 2013). It is estimated that the actual number of people infected is at least four times the reported number (Hashimoto et al. 2004; Yoshikura 2003) but may be up to ten times higher (Cullinane 2007). Accordingly, anywhere between 84,000 and 210,000 people may be infected. For purposes of comparison, the average number of new cases reported annually in the United States is approximately 50,000 and the cumulative estimate is nearing one million (Center for Disease Control 2013).

Takebe and colleagues have mapped the prevalence of various strains of HIV worldwide (2004). They show that HIV-1B, the predominant subtype in the United States, accounts for 74 percent of the total HIV cases in Japan and is prevalent among hemophiliacs and their partners as well as MSM (Takebe, Kusagawa, and Motomura)

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9 This equates to less than one tenth of a percent of the population in Japan and one percent of the population in the United States.
In addition, the CRF01_AE strain of HIV predominant in Thailand is also a significant presence in Japan, where it occurs mainly in heterosexuals and accounts for 20 percent of HIV cases; subtypes C (3.6 percent), A (2 percent), F (1 percent) and D (0.5 percent) are also present (Takebe, Kusagawa, and Motomura 2004). The resulting hypothesis is that a significant number of HIV-1B infections represent the cases of hemophiliacs and their subsequent (female and male) partners, while infections with other strains represent those contracted through liaisons with non-Japanese from countries such as Thailand – including sex workers encountered during sex tours, and those trafficked into Japan to work in the sex trade (Takebe, Kusagawa, and Motomura 2004)\textsuperscript{10}.

The national epidemiologic trend shows a continued increase in number of Japanese men becoming infected with HIV through same-sex relationships every year; the number of women becoming infected has been relatively stable since 1994\textsuperscript{11}. It is public perceptions, however, rather than epidemiological data such as these that seem to have come to the fore. In fact, media attention and perceptions of the HIV epidemic have generally been contrary to the national epidemiological data. At the time the first case was recognized in 1985, HIV in Japan was largely considered a disease affecting only foreigners and gay men (Sato 2005), even though the majority of cases at the time were through blood transfusions and heterosexual sex. This shifted with the epidemiological trend – but, again, in the opposite direction. Three highly sensationalized, female-centered cases reported between 1986 and 1987 prompted a shift in public perception of HIV as a disease of “sexually deviant” women (Runestad 2010), even though men were quickly becoming the larger risk group.

The three cases seemed to overshadow even the 1,432 hemophiliacs infected via treatment with Factor VIII\textsuperscript{12} from 1983 to 1988\textsuperscript{13}, who also garnered significant media

\textsuperscript{10} For explanations of the Japanese sex industry and sex tourism, please see (Allison 1994), (Kelsky 2001), and (Miller 2002).

\textsuperscript{11} There have been between 90 and 120 new female HIV cases per year, for Japanese and foreign women combined, since 1994. In comparison, cases in Japanese men increased from 150 in 1994 to 1,000 in 2008 (API-Net 2013).

\textsuperscript{12} Factor VIII occurs naturally in the body and promotes blood clotting after an injury to prevent blood loss. Due to a mutation on the X chromosome, hemophiliacs lack Factor VIII and can bleed to death if left untreated. Factor VIII is collected from donated blood and processed specifically to treat hemophilia.
attention after the cause of their infections became clear and they successfully sued the Ministry of Health and Welfare\textsuperscript{14} (Seki et al. 2002). Although this lawsuit made it clear that HIV was no longer simply a “foreign” or “gay” problem, it has been argued that, for the general public, the end of the trial in the early 1990s signified the end of the HIV epidemic amongst Japanese nationals (Sato 2005). I would extend this argument to state that it may have signified the perceived end of the HIV epidemic amongst Japanese men, ironically at a time when infections in men began to increase rapidly.

In summary, the epidemiological data indicates that the majority of the first infections in Japan were through transfusions and heterosexual sex, despite the perception that HIV was a foreign and/or gay disease. The prevalence of infection through heterosexual sex continued until 1999, when the number of Japanese MSM infected with HIV overtook the number of Japanese men who have sex with women (MSW) who are infected with HIV (Cullinane 2007). However, perceived risk groups for the first ten to fifteen years of the epidemic in Japan were foreigners (particularly foreign gay men), Japanese and foreign women (both sex workers and Japanese women who slept with foreigners) and hemophiliacs. Noticeably absent from those perceived to be at risk are Japanese men, who only appeared to get HIV if they were hemophiliac – although this is beginning to change now. Other perceptions include considering HIV as synonymous with AIDS, and the subsequent association of both HIV and AIDS with wasting and death. This is discussed in detail in Chapter 1.

Several socio-cultural factors have contributed to these trends. Sex education and condom usage are always raised when the issue of STIs is broached. Japan faces similar problems as the US in terms of establishing uniform sex education that includes HIV/AIDS: people always argue about what is suitable for children to learn in regard to sex. Because of such differences in opinion, the reality is that curriculum and lesson content differ from region to region, school to school, and teacher to teacher. Moreover, even if sex education is taught, when the focus is on family building rather than sexual

\textsuperscript{13} A number of these infections occurred because the Ministry of Health and Welfare (now the Ministry of Health, Labor and Welfare) approved the continued use of unheated Factor VIII produced by a pharmaceutical company in the United States even though it had been linked to HIV infections there.

\textsuperscript{14} Now the Ministry of Health, Labor and Welfare
health, students who are not interested in having children at that stage of their lives or who belong to sexual minority groups may feel that the content is not pertinent to them. Therefore, information about sexual health and disease prevention may not reach the students; information about condoms to prevent pregnancy may not translate to disease prevention. Particularly in the case of MSM, who do not worry about pregnancy, the use of condoms for disease prevention may seem unnecessary (Runestad 2010).

Although living with HIV/AIDS is not a common experience in Japan (prevalence is about 0.1 percent) compared to nations with endemic levels in Africa where over half the population in some communities is infected, or to wealthy nations such as the United States where prevalence is about one percent, studying HIV experiences can provide new insights into everyday life in Japan because gender, class, ethnicity, mode of transmission, age, and area of residence can all influence how an individual experiences life with HIV/AIDS. For example, with regard to gender, women tend to be blamed for contracting HIV and blamed for spreading it while men are more likely to simply be ignored. And while it may be tempting to assume that economically disadvantaged Japanese are more likely to contract HIV because of strong correlations between poverty and incidence in other locations, the relationship between socioeconomic status and epidemiological trends remain unclear in Japan: Mr. T’s story above is just one example of how wealthy citizens may also be at risk. It is clear, however, that having a socialized medical system that theoretically provides equal care to everyone across the socioeconomic spectrum does not ensure discrimination-free care or ease of access. Additionally, many Japanese people assume that HIV is a problem for non-Japanese, but the vast majority of new cases in Japan are in Japanese men. Similarly, many assume that HIV is spread through prostitution, but there is little evidence to link HIV with transaction sex in Japan: most – but not all – cases appear to be contracted through consensual, non-paid sex between men. Moreover, while the rates of HIV amongst Japanese teens and young adults in their twenties are increasing, a significant number of cases are in people in their 40s, 50s and even 60s and constitute a population that is living and growing old with HIV. This marks a shift from cases contracted through blood treatment in the 1980s and 90s to cases contracted through sex and drug use; this shift engenders different ways of talking about HIV/AIDS because people who contracted the virus through medical treatment are
considered blameless while those who contracted it through sex or drug use (or who passed the virus on to their children) are not. Finally, all people living with HIV/AIDS may experience discrimination or isolation, but isolation may be more of a problem in rural areas because they tend to have fewer medical and social resources. These are just a few of the ways in which these variables contribute to the variation in HIV/AIDS experiences; it is also important to notice the considerable difference between what is assumed to be true about “the HIV/AIDS experience” and what the realities are for various individuals.

It may be assumed that because Japan has a socialized medical system, political-economic factors are not an issue. However, this is not the case. The cost of HAART therapy in Japan, without insurance, is approximately $2500 per month. With insurance, the cost drops to $700 a month. But to get the lower rate, a person living with HIV/AIDS (PLWHA) must submit an application to be formally recognized as “disabled” due to their HIV status. Just the registration may then be a shock, setting aside the issues of disclosure necessary in order to complete this process. In rural areas, PLWHA may be hesitant to register at the city health office or go to local hospitals for care due to fears that their status will become public knowledge. Young Japanese still on their parents’ plans may face fear in telling their family members about their status or lifestyle. In fact, sometimes telling family members about their sexuality or sexual practices is scarier than telling them about their HIV status. As one of my interviewees told me, “It it not just about being HIV+. If I told my mom that, she’d want to know how I got it. I’d have to tell her I’m gay. So I haven’t told her.”

There is also the possibility that people simply are not insured. Although enrolment is compulsory, interviewees from the city health office in my rural field site told me that sometimes foreign residents refuse to pay – or perhaps, cannot pay. In the case that a PLWHA is in the country illegally, they may not be able to access care at all because to do so would alert authorities to their presence. The likelihood that people could pay for such expensive treatments without insurance is slim.

These issues are discussed in more detail in the chapters to come. For now, let us return to Mr. T, whose story appears at the beginning of the introduction. Where does he
fit in here? In many ways, he does not fit the epidemiological pattern or the common perceptions: although he is male like the majority of people living with HIV in Japan, he is not a hemophiliac, he does not have male partners, nor did he contract HIV through illicit sex. Rather, it is most likely he contracted HIV (and hepatitis) through shared syringe use, which accounts for only a small percentage of HIV transmissions amongst Japanese. His sex fits the pattern, but his transmission route does not.

Mr. T also fails to fit the popular conception that someone with HIV is a dying AIDS patient. To the contrary, he appears healthy, states HIV “causes me no problems,” and jokes that he does not want to live to be THAT old when medical staff inform him he has another 30 years or so in him. He also manages to avoid key roadblocks to income and insurance: Mr. T works at his family’s firm. This means he is probably less likely than other PLWHA to fear dismissal and discrimination due to his HIV status. This makes him financially stable enough to afford his medications. Working for his family company may also make it less stressful to claim health benefits, which would be monitored by the person at the company who is in charge of health insurance.

Where does this leave us? If we focus on Mr. T’s identities as an ex-junkie, ex-prisoner, and PLWHA, he is not the typical Japanese guy. If we focus on his experiences as a PLWHA, he is not a typical Japanese PLWHA, either. However, if we concentrate on his friendly disposition, his likes and dislikes, his dreams for the future and his comments about health, he does seem rather typical. If we go a bit further and focus on the themes drawn out in the beginning of this introduction, we can even see that he is the person he is partially because of his experiences with drugs, prison and HIV. In the following chapters, I highlight such contrasts in other individuals, organizations, and memes. This allows us to see a general pattern of precarity in everyday life, particularly with regard to health. It allows for precarity to be a framework to understand HIV/AIDS in Japan, and for HIV/AIDS to demonstrate the importance of using precarity as a research tool for complex situations.
Methods

I chose to frame my research on HIV/AIDS and precarity in terms of health when speaking with the general public for four reasons. First, telling people you want to talk to them about HIV/AIDS is much more shocking to members of the general public than telling them you would like to ask them their opinions about general health and infectious disease. They are also more likely to say that they do not know anything about HIV/AIDS (or any particular health condition) and excuse themselves from interviews than they are if the topic is health in general. I told all my interviewees I was interested in HIV/AIDS specifically after they had voiced interest in participating in the study in general, and none chose to withdraw. Therefore, it can be said that I mirrored the indirectness with which mainstream Japanese respond to HIV/AIDS in my fieldwork. I found this to be helpful: doing so allowed me to move from oblique to direct questions, both over the course of single interviews and for the duration of my fieldwork.

Second, I was interested in finding out if practical definitions of health differed based on one’s positive or negative HIV status, and how these definitions shaped pursuit of health. I wanted to know if having a chronic infectious disease precluded people from being healthy or from living a “good life.”

In addition, when talking to people living with HIV/AIDS, I chose to frame my questions in terms of both health and human rights. This helped interviewees feel that they were voicing opinions that needed to be heard and published, rather than feel as though they were research subjects.

Finally, although precarity is the common thread throughout this dissertation, it was a foreign concept to all my interviewees and I never used it in my interviews.

Connecting with people who were willing and able to talk about living with HIV/AIDS in Japan was a challenge. It was apparent in the planning stages that aligning myself with hospitals and research institutions, while crucial to accessing information about the medical system and securing research funds, was far from the simplest way of making contact with people living with HIV/AIDS. Confidentiality concerns, rules and regulations at medical establishments, and the complex relationships between patients,
hospitals and hospital staff made it unlikely that I would gain access to yōseisha and the hospital atmosphere would probably shape their narratives considerably should I meet them there. Although I conducted interviews with medical staff, I chose to contact NGO leaders and attend their functions to gain access to the target population. Consulting with medical staff while interacting with people at NGOs (and these groups were not always mutually exclusive) allowed me to understand and become part of the landscape of HIV/AIDS in Japan so that opportunities to speak with yōseisha happened. Instead of seeking yōseisha through snowball sampling, then, the yōseisha I include here often had volunteered to speak in public or volunteered themselves to speak to me privately after hearing about my interests in health, human rights and HIV/AIDS. In the following chapters, I discuss how directness or indirectness about the issues was used by Japanese interviewees to mitigate precarity. I describe this particular balance of directness as Japanese; it is important to note here that my research techniques also reflect this balance. Because of the level of indirectness common to discussions of HIV/AIDS in Japan, I myself engaged with HIV/AIDS indirectly by couching my questions about the illness in terms of health and human rights, and by placing myself in contexts where I would meet people instead of tracking them down individually.

I conducted seventy-three semi-structured interviews with community members, NGO leaders, medical and religious practitioners, and people living with HIV/AIDS from October 2010 to November 2011. Community members were selected based on their willingness to talk about health issues. PLWHA – I use the Japanese term yōseisha when speaking specifically about people living in HIV/AIDS in Japan – were approached at events where they self-identified as peer counselors for other PLWHA. Although the yōseisha sample size is small (ten total), it is a varied sample in terms of age, occupation, transmission route, and family demographics. Yōseisha were between 30 and 61 years of age. Most held full-time jobs and appeared to be moderately middle-class. Nine of the ten were male, which fits current HIV epidemiological patterns. Three of ten identified

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15 This term literally means, “positive person.” The characters used to write it are 陽性者. It was first used to describe people who tested positive for HIV antibodies, but now carries a similar meaning to PLWHA. It is not well-recognized by the general public, but it is used regularly by people who live and work with HIV and is preferred because it does not refer to the virus’s transmission mode which can be a cause for stigmatization or blame (see Chapter 5).
themselves as hemophiliacs infected through blood treatment. Two of ten described infection via needle or syringe, one from a tattoo and one from injecting drugs. The remaining yōseisha were infected through sexual intercourse, with four of the five identifying as gay\(^\text{16}\). The family size of yōseisha varied, and some lived alone while others lived with spouses, long-time partners, or immediate family members such as a parent. For non-yōseisha, efforts were made to ensure that an equal number of men and women were selected, and that a roughly equal distribution of interviewees from ages 23 to 69 (target ages were 20-70) were selected. Roughly half of the participants live in a rural setting (nearest city less than 300,000 people) in Kanto and half live in metropolitan areas in Kanto and Kansai.

I was also able to observe three basic types of events where yōseisha spoke about their experiences with HIV/AIDS. The first type was fully public forums, where people who are not HIV+ are not only allowed to join, but are actively encouraged to do so. Examples include the AIDS Bunka Forums. The second type was events that are open to the public, but cater largely to people who are living with HIV, have lost someone to AIDS, or have professional interests in HIV/AIDS. An example is the annual Candle Parade held in Kyoto every year. The third type was events that are organized for special interest groups such as medical professionals or volunteer staff. Examples include a training session for an NGO. I joined in six of these events\(^\text{17}\) over the course of a year, and listened to the public narratives of five different yōseisha. One man spoke at three of these events, another spoke at two. This afforded me the chance to gauge to what degree narratives change from person to person, and situation to situation. I was able to interview three of these five yōseisha privately, and their narratives are detailed in the introduction and Chapter 6. Additionally, I translated the written accounts of several yōseisha and their family members that were published in Place Tokyo’s booklet, Living Together, for a written comparison.

\(^{16}\) Yōseisha often dislike being associated due to the mode of transmission. I have purposefully avoided describing their transmission modes unless utilizing a quote where they themselves highlight it.

\(^{17}\) AIDS Bunka forum in Yokohama, AIDS Bunka forum in Kyoto, PLANET Candle Parade in Kyoto, a student workshop in Shiga, volunteer training in Tokyo, and a medical conference in Köbe.
I participated in an HIV/AIDS walk in Kyoto in May 2011, a week-long volunteer training course for an NGO that supports PLWHA in Tokyo in September 2011, and a conference on Japan’s socialized medical system sponsored by the Lancet in October 2011. I attended numerous lectures and community events focusing on HIV/AIDS, gender and sexuality, sexual health, and health in general – in both rural and urban areas. I also co-organized a workshop on HIV/AIDS for medical students in Shiga Prefecture.

It is also important to mention that many of the yōseisha with whom I spoke had had negative experiences with relating their narratives to journalists or researchers in the natural sciences. Many felt that journalists simply spliced together bits of what they said to fit an existing stereotype or agenda, or felt that researchers were interested in the biological “facts” of their illness but not their lived experiences. They hoped I would not repeat this tendency. But of course, I, too, have a research agenda in that I am required to fit my findings to what has already been learned in social science and anthropology. In order to reconcile the goals of research and the goals of my interviewees, I employ both short quotes and longer narrative anecdotes throughout the dissertation to illustrate and contextualize my main findings within a scholarly frame, while at the same time providing readers a chance to engage with the narratives of yōseisha, their stories as they contextualized them, and not just the “facts” or the sound bytes that comprise them. In Chapter 3, I discuss how my own work, due to disclosure and interpretation, is precarious.

A note about names. Japanese names are given Japanese style, with the family names first. Many interviewees wanted to use their real names, but others of course opted to remain anonymous. Pseudonyms are thus marked with an asterisk (*). In addition, some yōseisha use their professional names, so these are not marked with an asterisk, but are written the same way as actual names. However, those without professional names were assigned an initial, and I refer to them as Mr. T, etc, in order to afford them maximum protection.

**Chapter Outline**

In chapter 1, I discuss the definitions of health, cultural contexts of health and healthcare, and discuss how these are related to definitions of HIV/AIDS, termed eizu in
Japanese. I argue that health and *eizu* do not collocate in the minds of most Japanese, and instead *eizu* collocates with death and pollution; this makes it difficult for many Japanese to consider people who live with HIV as healthy, and it also allows them to push HIV/AIDS away from themselves and consider it not their problem. This is precarious because it is just such an attitude that contributes to increases in HIV. Furthermore, the vagaries of the term *eizu* itself engender indirect, passive engagement with HIV/AIDS.

In chapter 2, I show how HIV/AIDS-related memes become part of individual cognitive networks and the social consciousness, while traveling through social networks. Using the concepts of virulence, pathogenicity, co-infection, and syndemic, I illustrate how memes about a virus “go viral” to various degrees depending on their content, context, construction, and subsequent ability to travel through social networks. I illustrate that lack of engagement with HIV/AIDS information is just as critical as engagement with such information. The fear-avoidance dialectic described in chapter 2 can be broken through the sustained efforts of grass-roots organizations to change how people engage with HIV/AIDS in the community – namely, by encouraging forms of direct engagement with HIV/AIDS.

In chapter 3, I illustrate how memes such as those discussed in chapter 2 become “writ large” in museum exhibits. Focusing on three specific exhibits that were made public in 2010, I argue that these exhibits are mediated by aesthetics, fund-raising goals, geography and disciplinarity. These exhibits are precarious in that the frame of each exhibit excludes particular points about HIV/AIDS epidemics by necessity, but also assists in the dissemination of information about the illness and encourages collaboration with support groups. Notably, although they directly engage with HIV/AIDS as a subject, the emphasis of these exhibits is still on it as something conceptually and geographically “far away” from Japanese.

Starting with Chapter 4, I shift gears from talking about the general public’s engagement with HIV/AIDS to discussing what it is like to live with HIV/AIDS in Japan. There is a shift from representation in Chapters 1-3 to narration in Chapters 4-6. For example, in Chapter 1 I describe the importance of the words used for HIV/AIDS in Japan in a manner that reflects the lexical focus of cognitive medical anthropology in the
1960s; but in Chapter 5, I focus on public illness narratives, which parallels shifts toward discourse analysis and narrative in the field. In utilizing both approaches, I assert the importance of attention to terminology at the micro level (what words are used by whom, when, and to what effect) in conjunction with narrative analysis (who speaks in what context, and to what effect). While these approaches signify variation in terms of what researchers view as the cultural context, with the context growing increasingly broad over time, the use of more than one at a time gives the project a multi-layered effect that allows for a more nuanced discussion of cultural context than either one used alone would provide.

In addition, I focus on groups and individuals who foster direct engagement with HIV/AIDS as a problem in Japan, for the Japanese in the later chapters. These people respond to the precarity of HIV/AIDS differently because they feel it differently – what is precarious is different. While the general public is generally afraid of eizu because of its links to pollution, illness and death and therefore seek to avoid the upset that is caused by discussing these things causes, the people highlighted in Chapters 4-6 fear that HIV incidence will explode in Japan, or are members of society who feel not only the effects of the illness but the effects of discrimination by the public. Instead of avoiding HIV/AIDS and difficult topics such as sex and sexuality, these people force the issues with the hope that Japan will become a more open society and the upset they feel will be mitigated.

In Chapter 4, I demonstrate how people living with HIV/AIDS in Japan navigate support organization and medical resources, and how the existence of resources does not necessarily translate to usage of them – often because finding such places is difficult and anything but direct. I also discuss the precarity inherent in government dependence on non-governmental agencies to provide services for yōseisha without providing steady support for these NGOs. If governments are wary of admitting too loudly that HIV/AIDS is a problem in Japan, they are even less vocal about the necessity of providing financial support to help HIV+ people. However, there are a number of people in governmental and NGO offices who do push openly for such support.
In chapter 5, I describe how many yōseisha work to make HIV/AIDS more visible by speaking publicly about their experiences in various settings. I argue that these narratives are shaped by strategic disclosure of personal identifiers, control of the narrative setting and audience, and a general narrative structure from pre-diagnosis to “living positively.” Such narratives constitute a new form of education about HIV/AIDS, a new form of Japanese narrative, and also a way for yōseisha to assert their “normalness” and close proximity to audience members who may feel that HIV/AIDS is not their problem and is far away. Telling their stories is a product of felt precarity on the part of yōseisha, but it also constitutes a direct way of alleviating this precarity for them.

In chapter 6, I return to the concepts of health and HIV that I opened with in chapter 1, but focus on how issues such as sexuality, gender roles and family, and citizenship come to the fore when yōseisha are faced with disclosing and living with their HIV status. I argue that their “Japanese-ness” comes into question when they discuss their HIV status and sexuality because gender roles – particularly being able to get married and have children – are questioned. This in turn opens them up to discrimination about not being “good citizens,” and results in a sense of felt precarity on their part. When yōseisha attempt to counter this by demonstrating their normalcy and their abilities to live healthily with HIV, this can result in a sense of felt precarity on the part of Japanese people who feel that they themselves are “normal” while people living with HIV/AIDS are not.

In addition, it may be helpful to note that throughout the dissertation, I move from the minute details to the big picture in every chapter, as well as in proceeding from chapter to chapter. For example, I focusing on the micro in terms of words and images in Chapters 1 and 2, proceed to exhibitions and NGO efforts in Chapters 3 and 4, and then return to the minutia by examining public and private narratives in Chapters 5 and 6.

By the end of the dissertation, you will have a clear understanding of what precarity looks like, and what living with HIV/AIDS in Japan looks like. I also hope that I will have given readers the tools to recognize the factors and faces of precarity, so that looking for the complexity of everyday life, rather media “meme bytes,” becomes habit.
Chapter 1: Defining Health, Representing HIV/AIDS

Shirakaba Taka*18 is a 25-year-old man who was born and raised in Nagano, where he now works as a salaryman. He had sent me a text to let me know he was running a little late because he had gotten stuck at the office. He apologized for this when he arrived, and I had barely gotten started with the interview when he told me that people work too much and that it is not good for them. This made for a good segue to my question about what it means to be healthy. Taka said he really didn’t think much about it before, he had no reason to – except –

“Did you hear from Ms. T? That I got sick recently... In Japanese it’s taijōhōshin (shingles). When you get chicken pox when you’re little you don’t really recover. It hides in your nerves. When your immunity goes down, when you’re an adult and your immunity goes down, that virus comes out. And you get shingles.”

He showed me the marks that were still on his skin, and told me that they had been itchy and painful. He recounted being so fatigued that he could not get out of bed while sick, but assured me that he was basically fine. When I asked about the kanji for shingles, Taka patiently explained that hōshin is the kanji for obi19, because the way obi are used to tie clothing together is reminiscent of the connections between the lesions. He went back to explaining how he had to take time off work, and that his doctors had given him medication to take for a month. I sympathized with him, explaining that I had had Epstein-Barr20 as a university student; this virus also causes intense fatigue and can also hide in the body and come out when someone is stressed. He listened carefully, thought a moment, and concluded:

“Being healthy means not being sick.”

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18 All names marked with an asterisk are pseudonyms. Names without asterisks indicate people who chose to use their real names.
19 An obi is a sash that goes around the waist over a kimono or yukata (a cotton summer kimono).
20 It’s commonly known as mononucleosis.
I asked Taka what he knew about HIV and what image(s) came to mind when thinking about HIV.

“There is no treatment, right? Maybe. I don’t really know the symptoms... There is no one around me who has it, so I really don’t know. If a friend or someone had it, I think I could explain... anyway, it’s a bad illness.”

I asked what the letters in HIV mean, and he replied using the kanji for AIDS.

I asked if he knew how HIV is different from AIDS and his eyes widened in surprise.

“I don’t know... there is a difference?”

I explained the acronyms, and that HIV causes AIDS.

“Oh, like how the herpes virus causes illness...” (He was referring to how a herpes virus causes shingles and chicken pox.)

I went on to explain that HIV hides in people’s cells and is difficult to treat, but that there IS treatment.

“They didn’t tell us that in school! If they don’t tell us, of course we can’t understand these things... wait... So HIV is kind of like what I had. And what you had!”

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I asked what people living with HIV should do to stay healthy.

“Like everyone, they should eat right and get enough sleep. And protect their immune system.”

Close to the end of the interview, I asked, “What do you think they should teach about HIV/AIDS in schools?”

“It’s important to teach the difference between HIV/AIDS, how it’s contracted, and what symptoms occur. And that there’s treatment!”

21 「HIVは後天性免疫不全症候群。当てる？」
We talked a little bit about how treatment has changed since the beginning of the epidemic in the 1980s. As we began to close the interview, he thoughtfully commented:

“Japanese people’s images of HIV are of AIDS from the 1980s, huh...”

What can we learn from these snippets of my interview with Taka? First, we know that his definition of being healthy is a simple one: he equates it to not being sick. We also know that prior to the interview, he equated HIV with AIDS, he was unaware there was treatment, and he considered it a “bad” illness – but that his ideas had changed somewhat by the end of interview. There is also one thing that is not in Taka’s interview that may surprise someone looking for “Japanese” ways of talking about health and illness: he does not refer to any of the basic frameworks (described below) that many scholars often turn to discuss health in the Japanese context. However, as we will see, this does not mean cultural frameworks are not important for discussing health and HIV/AIDS.

In this chapter, I argue that the cultural frameworks for health and illness often described in the literature (such as Confucianism, Buddhism and Shintō frameworks) do not map neatly onto Japanese systems of health care, nor do English definitions of HIV/AIDS map neatly onto eizu (エイズ), the term most commonly used to describe the two conditions. First, I draw from scholars such as Lock (1984), Janetta (2007), Reader (1991) and others to provide an overview of Japanese concepts of health and systems of healthcare, highlighting the differences between them. Second, I draw on interviews like the one above to show that interviewees’ explanations of health are based on personal experience, which is shaped by cultural context; this reflects a similar measure of plurality and dynamism that Crandon-Malamud found when investigating how Bolivians explained and sought care for illness episodes (1993). Third, I employ classic Saussurian linguistics and Frake’s contrastive feature analysis (1962) to interview data and an HIV/AIDS educational pamphlet. This allows me to demonstrate that 1) medico-English conceptions of HIV/AIDS differ from the most common way to talk/write about the eizu and, despite being used as a stand-in for both these terms by the lay public as well as by Japanese HIV/AIDS specialists, it gives no linguistic hints about the conditions; and 2) although eizu is used to talk about both HIV and AIDS, eizu is clearly tied to death,
pollution and sickness while health is tied to concepts of everyday life, physical and mental ability, and so on. I conclude that vagaries of the term eizu, which lacks any clear indication of what the virus does or what the syndrome is and thus allows for easy association with deathly AIDS images, paired with definitions of health that hinge on the ability to go about everyday life unfettered make it nearly impossible for the Japanese public to conceptualize living healthily with HIV. Thus, the difficulties in discussing HIV/AIDS directly begins with the term eizu itself.

This situation is further complicated by fear, which also deters direct engagement with HIV/AIDS by Japanese. Because of its associations with death, pollution, and sickness – an association that began in the 1980s – eizu is feared even though there is now treatment for HIV and, as we will see, living with HIV does not necessarily mean that one is unhealthy. This fear of eizu (AIDS) discourages critical engagement that would allow for health and HIV to collocate and encourages avoidance instead; this avoidance then, endangers Japanese people because ignoring HIV/AIDS merely gives the virus more of an opportunity to move through the population. To put it simply, fear of eizu leads to avoidance that engenders outbreaks, which then leads to more fear. This is exactly the same pattern Butler uses to describe the precarious dialectic between violence and retribution and the fear that drives it (2004).

Teasing apart systems of medical philosophy, knowledge, and religion

It is beyond the scope of this dissertation to review all of Japanese medical history, or to attempt to trace lineages of concepts of health in detail; however, outlining the basic conceptual frameworks for health and illustrating the ways that health and healthcare have been taken up within these frameworks is of import to this discussion because specialists and the lay public talk about health and healthcare systems differently. Whereas members of the public (like Taka) tend to put health and healthcare in everyday pragmatic terms (being able to go to work, or socializing with friends, for example), specialists often focus on theoretical concepts underpinning health and healthcare.

Scholars tend to approach medical issues (not just in Japan) in one of two ways: they develop and research classificatory systems for ways of knowing that are often
based on religious and philosophical roots and trends, or they take a problem-based approach to explain contemporary (and in this case, Japanese) behavior. I myself follow both approaches to illustrate how these approaches have developed regarding health and healthcare in Japan; afterwards, I show how exclusive focus on these two methods is problematic for HIV/AIDS public health campaigns in Japan.

Below, I briefly outline how Confucian, Daoist, and Buddhist influences from mainland Asia (via China and Korea) have become part of contemporary Japanese culture; how Ainu and Shinto ways of knowing were transformed into “belief systems” with the formation of the Japanese nation-state; and how Western medical technologies first appeared in Japan in the 1500s (Jannetta 2007), and continued to make small advances until Japan was “opened” in the 1850s.

Confucianism is known for its emphasis on filial piety, social hierarchy, and male dominance (particularly in regards to a woman’s obligations to her father, husband and son). It has been part of everyday philosophical and religious life in Japan to varying degrees since its introduction in the 6th century. Men were to uphold harmony in society by fostering it first within themselves through proper diet, exercise, and sleep (Lock 1984). During the 17th century, Japanese writer Kaibara Ekken (sometimes written Ekiken) penned Yōjōkun which stipulates guidelines for daily life that include rules for eating and sexual relationships (Kaibara 2008). Janine Sawada has argued that the Meiji government re-fashioned Confucianism into a purely philosophical way to live everyday life with the formation of the modern Japanese state (2004). Thus, it is possible to link elements of bodily comportment and management that have been considered part of moral and health education in modern Japan – women encouraged to give birth for the nation (Miyake 1991) and fit bodies as patriotic bodies during war years (Igarashi 2000), for example – to Confucian influences. Contemporary emphasis on individual and social health in Japan may be, to some degree, due to Edo period Confucian influence.

Daoism does not exist as “a system” per se in contemporary Japan, having no real priesthood (Bowring 2005). In fact, Bowring puts Daoism in quotation marks for this

22 All three of these first came to Japan around 538 CE (Bowring 2005), although the ways in which they have been influential individually and socially in Japan has varied according to time period and region.
reason when he discusses it. Nevertheless, it is from Daoism that concepts of yin/yang, geomancy, and divination\(^{23}\) spring (Lock 1984; Bowring 2005). Regarding health, the primary goal is to make the body strong by nourishing \(ch'i\), which would then allow a person to have a clear understanding of the world (Lock 1984). Much like Confucianism, the elements that remain have been secularized and may be evident in contemporary practices. Fortune telling and palmistry are some such examples.

Unlike Daoism and Confucianism, Buddhism remains a strong religious institution in Japan. There are three main divisions within Buddhism: Theravada, Tantric, and Mahayana. The majority of Buddhism in contemporary Japan is Mahayana or Tantric. There are six major schools: Jōdo (Pure Land), Nichiren, Shingon, Jōdo Shinshū (True Pure Land), Tendai, and Zen. These are further broken down into sub-sects, which, for brevity, I will not list here; suffice it to say that Buddhism in Japan is diverse.

Although it is quite difficult to generalize about Japanese Buddhism given this diversity, some basic points regarding medicine can be made. Many medical theories and practices in Japan have their roots in Buddhism and were brought over by monks. Lock notes that in both Japan and China, “it was the Buddhists who built the first hospitals and administered herbs together with amulets and talismans to people of all classes” (1984:48). This is perhaps because Shakyamuni Buddha is known as the “Great Healer.” In Buddhism it is accepted that humans suffer throughout life – at birth, during sickness and old age, and at death – and this is a normal part of human existence (Birnbaum 1989). Hardacre summarizes Buddhist attitudes towards illness and healing this way: “An enduring theme in Buddhist thought is the idea of the human condition as an illness for which Buddhism is the cure, in which the Buddha is the supreme physician, and his doctrine is the greatest medicine” (1994:597). The idea that temples should be houses of healing, therefore, was perhaps naturalized in this way.

Birnbaum more specifically states that there are six classes of disease, which are caused by: 1) seasonal disturbances, 2) improper diet, 3) improper meditation, 4) negative

\(^{23}\) Smyers notes that \(Kō\) leaders may “engage in healing, geomancy and personal counseling – functions that priests at large shrines no longer perform” indicating that some of these have been done in Shinto venues (1999, 54).
spirits in the body, 5) negative spirits in the mind, or 6) karma (the results of past actions or actions in past lives) (1989). Unlike western theology, illness is not a deity’s will (Kitagawa 1989)\textsuperscript{24}. Therefore, if the illness is natural it can be treated by medical professionals. If it is karmic, the person prays to specific buddhas or bodhisattvas for the karma to be cut (Birnbaum 1989).

Reader lists several ways contemporary Japanese may seek relief from an illness and suffering or prevention of an illness at Buddhist institutions: prayer, pilgrimage, writing prayer cards (\textit{ema}), purchasing amulets or talismans (\textit{omamori}), touching figures of \textit{Yakushi Nyorai} or \textit{Binzuru},\textsuperscript{25} circumambulation of temples, or use of sacred water are all possibilities (1991). Healing or purification rituals such as \textit{kaji}\textsuperscript{26} or \textit{goma}\textsuperscript{27} may also be performed. Ritual placation of an aborted or miscarried fetus, stillborn infant, or child lost in infancy (\textit{mizuko kuyo}) may be performed if it is believed that the spirit is malevolent and causing harm. However, not all of these behaviors may be advocated or approved by all sects.\textsuperscript{28} Further, although these are considered religious practices by specialists, they are often simply considered to be cultural practices by those who undertake them (Reader and Tanabe 1998).

When people think of religion in Japan, they often think of Buddhism and Shinto. Shinto has been labeled the “indigenous religion of Japan” to differentiate it from the “foreign” traditions above – Buddhism in particular. However, this distinction makes it seem as though Shinto has always been a fully integrated belief system, separate from

\textsuperscript{24} Kitagawa also notes that the Buddhist term \textit{dukkha} elides pain, suffering, misery, sorrow (1989). Later in the chapter, I argue that \textit{eizu} elides HIV and AIDS.

\textsuperscript{25} \textit{Yakushi Nyorai} is the medicine Buddha, while \textit{Binzuru} is an arhat who ministers to those who have not achieved nirvana.

\textsuperscript{26} \textit{Kaji} can be a healing or purification ritual. Winfield describes \textit{kaji} as a type of mutual empowerment in which a priest receives the energy of \textit{Dainichi Nyorai} (the primordial Buddha who is central to Shingo esoteric Buddhism), the energy is refocused onto an object or patient, and \textit{Nyorai} is able to understand an illness (2005).

\textsuperscript{27} \textit{Goma} is an esoteric fire ceremony with a prayer or purificatory component. For example protection of the household, safe birth, healthy pregnancy, good health, traffic safety, good grades, or entry into a specific school.

\textsuperscript{28} For example, some sects, including Shinshū, do not advocate “this worldly benefits” (\textit{genze riyaku}) and therefore rituals like \textit{kaji} and \textit{goma} are not supposed to be performed. Likewise, amulets and other such commodities are not supposed to be sold. On the other hand Soto Zen has been very active in health and healing from the start (Williams 2005).
Buddhism, which is incorrect. Polytheistic at its base, Shinto developed in various forms in local contexts prior to the Meiji Restoration. The Meiji government forcibly separated Buddhist temples and Shinto shrines (an act known as shinbutsu bunri) that had grown together since Buddhism’s introduction into Japan. At that time Shinto was re-cast as the “indigenous” state religion. Importantly, the Restoration refers to restoring the emperor as the head of the nation-state (as opposed to the Shogunate). Thus, the creation myth of the islands of Japan by the gods Izanami (female) and Izanagi (male), and the myth of the Emperor as the direct descendant of the Sun Goddess Amaterasu (herself offspring of Izanami and Izanagi) were officially adopted and spread throughout the nation. Despite this organized attempt to systematically adopt a very specific type of Shinto (State Shinto), it often retained its local characteristics. Consequently, making generalizations about Shinto is just as difficult as it is in the case of Buddhism. With regard to health, however, it seems accurate to say that pollution (kegare) – which is considered both contagious and dangerous – is a fairly consistent feature. Houston notes polluting factors could include “unsanitary items, blood, human and animal death, natural disasters, societal disturbances, incest, and sodomy” (1997). Two forms of pollution have their own names: blood pollution is akafujō (赤不浄, literally, “red pollution”) and pollution from death is kurofujō (黒不浄, literally “black pollution”). At the very least, these two concepts are still in circulation today and guide contemporary sensibilities about cleanliness.

There are several other frameworks or components that do not fit into the categories outlined above, but have been influential minorities. For example Ainu, the indigenous people of Japan also have their own perspectives regarding health and healing. Notably, illness can be caused by gods (contrasting with Buddhism, but similar to Shintō) and menstrual blood is considered protective (rather than polluting as in Shinto) (Ohnuki-Tierney 1999). In addition, there are several offshoots of Buddhist, Shinto, and other religions that are collectively called New Religious Movements (NRMs) and New, New

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29 Rule by shogun.
30 At the request of the Supreme Command of Allied Powers (SCAP), Emperor Hirohito issued the Human Declaration rescript in January 1946, in which he renounced the emperor’s status as a living god (Dower 1999).
31 The Ainu are also diverse. See (Walker 2001) and (Weiner 1997).
Religious Movements (NNRMs), many of which focus on healing. Mountain ascetics (yamabushi) and blind shamanesses (itako) are religious specialists who combine elements from Buddhism, Shinto and other systems and who have also played roles in healing (Reader 1991), particularly in cases in which fox possession is suspected (Smyers 1999). There is also a small but significant and diverse Christian population. While these frameworks are not as widespread as those listed above, they are equally important to individuals and groups who practice within them.

*The scientific method and biomedicine*

The frameworks discussed above do not directly map onto systems of health care delivery in contemporary Japan, although they do influence it. The Japanese medical landscape has been heavily influenced by modernization and westernization since the Meiji Restoration, and by globalization more recently. Adoption of the Popperian scientific method and the development of biomedicine, fit to the Japanese context, has occurred with relative ease. That is to say, it was generally not difficult for Japanese to accept western disease models as they were introduced and expanded upon by Japanese practitioners and researchers. As part of everyday life in Japan, these are now de facto elements of Japanese culture. However, the Japanese are less likely to consider biomedicine “Japanese,” unlike elements of the frameworks above. Biological/anatomical explanations of pathogens and the body are considered “scientific” but biomedical interventions are sometimes considered “western,” particularly when compared to *kanpō* (glossed “Chinese medicine,” but literally “Chinese way”) practices. This is perhaps not surprising considering that the Meiji government actively sought to improve its status vis-à-vis western nations, and one way of doing so was to adopt western medical science practices to improve the health of the nation-state. Moreover, trends that emphasize “foreign” influences as inappropriate for Japanese wax and wane.

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32Biomedical theory reflects Cartesian body-mind dualism and focus on a diseased part rather than the whole body. It views illness as caused by a biological agent that can be isolated. Health is restored by eliminating or disarming the agent, encouraging or discouraging a particular immune response, or treating a symptom. Mental, physical, social and financial health are not considered in tandem. Diagnosis and treatment focus on the cell/tissue/organ in question. Development occurred in the west but has now spread to many regions around the world, so it cannot be considered a monolithic system.

33This does not mean that it was simple to change disease prevention behaviors, however.

34Medical practitioners who participate in international conference are very aware that biomedicine is practiced differently in different countries, however.
This makes it possible for contemporary Japanese to accept biomedical interventions as “scientific” (and “Japanese”) or reject them as “foreign” depending on the individual, the setting, and the treatment. I discuss biomedicine below, where I describe it as part of the Japanese medical system.

**Japanese Medical Systems for Diagnosing and Treating Illness**

In the sections above, I discussed the religious and philosophical bases for health in Japan. Due to the diversity, it is difficult to make generalizations such as “health according to Buddhists is…” or “the Shinto reaction to epidemics is…” Rather, it is important to understand the multiple factors and frameworks at work in the background when people discuss health. Further, it is important to note that although the frameworks above have shaped the contemporary medical system, the lines from theory to practice may not be so clear. For example, kanpō preparations can often be prescribed by biomedical doctors in place of pharmaceuticals, and prescriptions can be filled at biomedical pharmacies in Japan. Further complicating this issue is that what is being consumed is not necessarily made in China, derived from Chinese plants, or prepared according to Chinese instructions – let alone viewed as Buddhist, Confucian or Daoist by producers, sellers, prescribers, or consumers. In other words, frameworks for conceptualizing health and providing healthcare are not the same: the frameworks that Japanese have for discussing health and illness – individual composites of Confucian, Daoist, Buddhist, Shinto components – do not map neatly onto the elements of the contemporary medical system – biomedicine, kanpō, and alternative therapies.

Kanpō is the Japanese term for Chinese medicine and is 1) a method of diagnosing illness that focuses on balances and imbalances that can be observed by sight, touch, and palpation, and 2) a theory of practice such that the purpose of medications is to bring organ systems, and therefore the body, into balance through the use of herbal medicine based on Asian *materia medica* (natural materials used for medical purposes) and practices such as acupuncture, acupressure, moxibustion, and massage. In this system, illness is being out of balance; health is being “in balance.” In her seminal 1984 work, Margaret Lock explores the varieties of healthcare available in Japan, focusing on kanpō, acupuncture, and *amma* (massage) which all originated in China, in addition to the
Japanese massage technique shiatsu (which developed out of amma). She is careful to state that it cannot be assumed that just because the whole physical body is the focus of treatment, a person’s mental and social state are being addressed (Lock 1984:xi).

Kanpō originated in China and was brought to Japan largely by Buddhist monks. However, it was neither a uniform system nor was it static with regard to theory and practice. Goble notes that there was a shift from prayer treatment, acupuncture and moxibustion for everyday health issues (pregnancy, childbirth, daily sicknesses) to medication and treatment for wounds after war broke out in the 14th century (2005). It may also be naïve to assert that such medicine was “purely Buddhist,” having been brought to Japan by people who were also familiar with Confucianism and Daoism, which were also adopted in Japan at the same time. Moreover, kanpō developed to suit individual contexts over time, and has only recently become somewhat standardized in the clinical/pharmacy sphere. Furthermore, it is important to remember that people were not without folk materia medica, healing techniques or medical theories prior to and during the development of kanpō in Japan (recall the Shinto influences listed above). Unlike Buddhist materia medica that could not include animal products (Kitagawa 1989), there is evidence that folk materia medica included animal products (i.e. badger and turtle heads), human feces and expelled worms, and even the remains of stillborns or aborted fetuses in addition to plant materials (Goble 2005:309). It is possible that there was (and still is) some overlap in plant-based medicines. Lock noted as early as 1984 that, due to contemporary pharmaceuticalization of kanpō medicines, “Herbal medication has simply become a new class of drug…” (1984:x). Currently, kanpō is often prescribed for patients who want a “gentler” treatment than pharmaceuticals, and many are covered by national health insurance (Kojima 2010 personal communication).

Major changes in medicine occurred with the influx of Dutch texts in the 1700s, shifts towards western medicine following the Meiji restoration, and rapid advances in medical technology following the Second World War. The first major introduction of western medical knowledge was the 16th century introduction of surgical techniques in
Nagasaki\textsuperscript{35}, a region where trade with other nations was allowed despite Japan’s policy of exclusion (Jannetta 2007). The second was the translation of Kulmus’s Dutch\textsuperscript{36} medical textbooks into Japanese by Sugita Gempaku in the late 1700s (Kuriyama 1992). Because many of these textbooks focused on anatomy, with diagrams of the body and organ systems informed by autopsy studies (unlike the symbolic anatomy diagrams in Chinese texts at the time), Kuriyama has asserted that these studies changed the way Japanese physicians viewed the body (1992). For the first time, they were able to combine symbolic ways of thinking about illness with physiological data about the body. But it was nearly a hundred more years before Japan would officially open its doors to trade and modernization.

Janetta has argued that before the ports were opened in 1859, Japan had been protected from numerous infectious diseases that had devastated other parts of the world (2007). Using smallpox vaccination as a case in point, she also argues that this same seclusion prevented the flow of medical knowledge that was moving fairly rapidly in European and American contexts (Jannetta 2007). Furthermore, visiting Dutch representatives and Japanese physicians took it upon themselves to engage locals rather than the Shogunate in vaccine development and campaigns; their success encouraged the eventual support of the Bakufu (Jannetta 2007). The successes with the smallpox vaccine may have played a role in prompting Tokugawa leaders to focus on public health, which then translated into the development of university systems and professional societies, as well as publishing houses during the Meiji Restoration (Jannetta 2007).

From the time of the Meiji Restoration, Japanese medicine was made “scientific” and highly regulated. Oberlander states the adoption of western medical practices was “expected to contribute to making Japan a ‘rich country with a strong army,’” and the

\textsuperscript{35} Goble\ suggests Western \textit{materia medica} was introduced earlier through Islamic influences in Chinese medicine (Ibn Sina had experience with Greek medicine) but that this was not actively known by Japanese practitioners such as Shōzen, who wrote extensively on Japanese-Chinese \textit{materia medica} (Goble et al. 2009).

\textsuperscript{36} Although Japan was considered “closed” at this time, trade with the Dutch and other nations was carried out on the island of Dejima in Nagasaki under the surveillance of the Shogunate. A number of physicians were permitted by the Shogunate to study Dutch texts; this type of study was termed \textit{rangaku}. Physicians who practiced western medicine were called \textit{ranpō} (Jannetta 2007).
first task was to find the cause and cure for beriberi\(^{37}\) (2005). Soldiers, who received rations of rice, former shoguns and priests (who were often paid in rice) perished from beriberi, giving the government reason to fund research (Oberlander 2005). Fueled by Koch’s discoveries\(^ {38} \), many physicians believed beriberi was caused by bacteria; Takagi, however, postulated that it was a nutritional problem and sought to change the diets from rice to a barley-rice mixture (Oberlander 2005). Although Takagi’s diet was successful in curbing disease rates, he could not prove causation directly and researchers continued to look for a cause (Oberlander 2005). The pursuit of the cause/cure motivated the government to allocate funds for hospitals and laboratories – the facilities needed for modern medicine. Moreover, physicians brought together for beriberi research served as the “first generation” of scientifically trained medical researchers (Oberlander 2005).

Since the “opening” of Japan, Japanese physicians and scientists have been collaborating internationally for over a hundred years. Gaps in biomedical knowledge and technology between Japan and other developed nations are now small, as Japanese researchers are both producers and consumers of biomedical knowledge. Imported techniques, therapies or perspectives are never simply adopted at face value, however, particularly when the product is a pharmaceutical. For example, the polio vaccination in Japan was made from live virus until 2013 (Shirano 2012, personal communication). It is also worth noting that Viagra was approved for use before the birth control pill, and although the FDA recently approved Pre-exposure Prophylactics (PrEP) for HIV in the U.S., this will not be likely to happen in Japan for a number of years because pharmaceuticals in Japan, with few exceptions, are required to undergo clinical trials in Japan prior to approval (Shirano 2012, personal communication).

Of particular import to this discussion is the spread and influence of the World Health Organization’s (WHO) definition of health in Japan. All Japanese medical doctors

\[^{37}\text{Vitamin B1 (thiamine) deficiency causes beriberi. Symptoms include neural damage leading to problems with speech, movement, and coordination. It can lead to death. Beriberi in Japan was linked to eating polished rice as the main staple (barley and brown rice contain thiamine).}\]

\[^{38}\text{Koch’s postulates: 1) A particular microorganism (bacteria or virus) is found in organisms suffering from a specific illness, 2) the microorganism can be isolated and grown in culture, 3) the cultured microorganism can cause disease if introduced to a non-diseased organism, and 4) the microorganism can be re-isolated from the inoculated organism and re-identified as the same disease-causing microorganism. First tested on Bacillus anthracis (anthrax) and mycobacterium tuberculosis (Tuberculosis). Allows for carriers who test positive for an infectious agent but do not show symptoms of disease.}\]
and nurses learn the following: “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (World Health Organization 1946). However, these professionals have their own definitions of health. As we will see later in this chapter, this definition seems to set the parameters for considering health, but practitioners have not accepted it at face value.

To summarize Japanese biomedicine, it is similar to biomedicine in other countries in that it is evidence-based medicine supported by clinical trial data conducted using the scientific method. But there are differences in what treatments are favored by whom and for what reasons. And while some of these differences are due to “cultural factors,” they are often influenced by socio-economics, fear of stigma, and lack of (or perceived lack of) access. I discuss this in regard to HIV/AIDS in Japan in more depth in Chapter 4.

Of course there are several types of alternative treatments that do not fall into kanpō or biomedical categories. For our purposes, it is enough to know that there are trends in massage, diet, exercise and prayer that people often try; while they may have considerable impact on individuals, they may not become long-term additions to the Japanese healthcare landscape for the majority of Japanese. While I had expected those living with HIV in Japan to be interested in these, those I interviewed only rarely expressed interest in such trends.

**Explaining Japanese Medical Trends using Religion and Philosophy**

Classificatory approaches to discuss medical history and illness cosmology are useful when apprehending the range of cultural factors that can be at work in a particular setting. However, problem-based methods are particularly useful when health trends differ from nation to nation and people search for explanations. Problem-based studies that contextualize the issue and explore multiple factors for the trend are of critical importance because “cultural” explanations that focus on a particular aspect of illness cosmology, such as the importance of a “perfect, whole” body in Confucianism, can reduce people to a belief system and result in inaccuracies. The literature on low organ donation rates in Japan illustrate this point.
In his 2007 work, Hansen asserts that the Japanese reject transplantation because of “Confucian concepts of the body” without explaining to which concepts he is referring or elaborating on evidence for this. Similarly, Visscher states that “Oneness, nonduality and the illusion of the individuated self, are Buddhist themes… [while] Shinto ideas of vital energy, and the inseparability of human beings from nature, the spirit world and the cosmos” situate the essence of an individual in both the physical body and in social spaces (Visscher 2006:1449). Accordingly transplantation, autopsies, and withdrawing life support based on brain death are not acceptable because they are incompatible with the individual existing in social space (ie, not simply in the body). It is true that organ donation could be seen as desecrating the body according to Confucian ideals. It is also true that the idea of brain death as the death of an individual, the key factor when harvesting organs, can be challenged using Buddhist philosophy (death is determined by loss of vitality, heat and consciousness) as well as Shinto philosophy (the spirit is still present even after the body is physically dead). The problem lies in the fact these are theories based on the categories described above – not answers given by actual Japanese people. These analyses, while not exactly incorrect, are misleading because they assume that the Japanese make decisions based on these concepts alone.

Helen Hardacre goes beyond these simplified explanations in her discussion of organ transplantation by explaining the socio-religious context surrounding brain death (1994). First, she reminds readers that the doctor who completed the first heart transplantation in Japan was later accused of murder because irregularities about the surgery surfaced after the patient died (1994)\(^{39}\). This led surgeons and the general public to be wary of transplants. Second, she notes that it is difficult for religious practitioners to take a stance on brain death solely based on doctrine which was written several hundred years ago; that Japanese religious leaders have not been as “highly influential in shaping public opinion and medical practice” in Japan as they have in the United States (589); and that ethics – and therefore medical ethics – developed differently in Japan than in the

\(^{39}\) The recipient may not have needed the transplant; the donor’s status at the time of donation was questionable (Lock 2002).
US\textsuperscript{40} (590-1). Thus, legal and religious methods of officially deciding whether brain death could be equated to death (which would in turn allow transplantation), not just the topic itself, were problematic.

Lock takes the debates even further by adding an ethnographic component. She states that several Japanese commentators invoke “tradition” in their arguments about the reluctance of the Japanese to embrace brain death and organ transplantation (much like Hansen and Visscher), and argue that the lack of “culture” and historical perspective make these acceptable to Americans (2002). Lock rejects this and instead describes the varied answers informants gave about their support/rejection of these procedures. She finds that people who have the most experience with death (physicians and family members of those who were on life support and subsequently chose to turn off ventilators) often support the idea of brain death – but these same people may not agree with or accept organ transplant/donation (Lock 2002). Lock concludes that Americans and Japanese live and work with different ontologies of death; while these are certainly cultural, concepts of death (like health) cannot be reduced to “Buddhist,” “Shinto,” or “Confucian” aspects of culture (2002).

The organ transplantation and brain death research by Hansen, Visscher, Hardacre, and Lock represents a problem-based approach to medical theory and practice in Japan. In some cases (Hansen and Visscher) researchers rely too heavily on classificatory scholarship, leading them to make cultural generalizations about why Japanese rates of organ donation are low. Such research makes it sound as though all Japanese draw on these frameworks in the same way, and that reliance on these beliefs is the single most important factor for their actions (in this case, aversion to donating organs). Hardacre and Lock avoid these problems by contextualizing the issue, which allows for a myriad of factors that contribute to the trend.

So what do classificatory and problem-based approaches to medicine and health have to do with Taka, health, and HIV?

\textsuperscript{40} Rinri (ethics) is of Confucian in origin and has more of a “social responsibility” meaning than ethics in English, which is more individual.
It is what is absent that matters. Recall that Taka did not use any of the frameworks above to discuss health. In fact, as will be shown below, only one of my interviewees did – a Shinto priestess who referred to the WHO definition of health. While it is helpful for specialists to know the intellectual history of these frameworks and how they have been used over time in various places because they become part of culture (often the part that people take for granted and do not articulate directly), they are not necessarily what people cite as important.

If we consider the cultural frameworks described at the beginning of the chapter as what Stuart Hall terms “primary culture” rather than as possible explanations for behavior, then we can focus on what questions have to be answered in order to address the central research question. For example, both Hardacre and Lock realized the need to talk about *what it means to die* in order to talk about organ donation. With regard to HIV, I argue that one of the central issues is *health*, or *what it means to live a healthy life*. Quite simply, in order to talk about HIV, to find out why people fear it, avoid talking about it, and engage with it only indirectly (as is the case with most members of the general public in Japan) finding out what people think about health is essential. Finding out why they are using the terms they are using is also important. Below, I illustrate that although the cultural frameworks listed above may serve as a basis that the Japanese draw upon to explain health, they often discuss their definitions in terms of personal experience.

*Putting medical philosophy, knowledge and religion back together: Health according to the general Japanese public*

> “Many people don’t think about health until something happens. I’m like that.” (Matsukawa Shigeru*, 44, Yokohama-based salaryman)

Many of my interviewees paused to think for several moments when I asked them about what health meant to them, or if they had a particular definition of health. As evidenced by Shigeru’s comment, health is often not a primary concern unless one

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41 Hall divides elements of culture into primary culture, secondary culture, and tertiary culture. Primary culture is behavior or beliefs that are so ingrained that people cannot explain why they do what they do – rather, they often respond that “it is the way it is,” when asked. Secondary culture can be explained, but is often transmitted without explanation (like taking off one’s shoes in an entryway). Tertiary culture is something obvious even to outsiders and can be explained readily (such as clothing) (Helman 2007).
suddenly finds themselves injured or unhealthy. For many people, even if they had actively considered what it meant to be healthy in the past, the interview was the first time they had really had the chance to think about health recently:

“I haven’t really thought about what health means... Actually, I was part of a health group 20 years ago, and I looked at their documents every day for 4 years. I’m remembering things about health as I tell you!” (Maeda Natsuko*, 45, Nagano shop owner)

Mrs. Maeda’s and Mr. Matsukawa’s responses were unique in that they openly acknowledged they hadn’t thought about health for some time because they had, thankfully, been well. Most people simply took their time in answering this question, and some said it was the hardest question I asked. But everyone answered it, and when they did, they tended to draw from their own illness and recovery experiences or those of people close to them. Answers seemed to cohere around two types of definitions, the ‘negative definition’ where illness is an absence of illness, and a ‘positive definition in which people focus on a feeling of well-being or happiness.

**Negative Definitions of Health**

Several interviewees asserted that health was the absence of one factor or another. For example, Ise Nobu*, a 34-year-old salaryman, stated that health is the absence of illness, disease and fatigue, citing his own experiences with temporary facial paralysis resulting from a bout of shingles. Similarly, 23-year-old NGO representative Maekawa Ryūta noted that health meant not having too much physical, mental or spiritual stress while Nakata Azumasa* (43) commented that one should not eat, drink or smoke too much. And like Taka stated in the opening anecdote, two other 20-something salarymen stated that health was simply being “not sick.”

While men tended to name the factors that should be absent (sickness, stress, fatigue), women tended to discuss deviation from health in more vague terms of dis-ease but also tended to be more reflexive about what effects changes in health status had on individual and social levels:
“Being unhealthy is when I don’t feel like myself. Maybe physically, or maybe from pressure, so mentally.” (Akutagawa Juna*, 38, landscape architect)

Further, Juna noted that recently she had had to take medication daily for an illness episode, and that “Taking medicine every day changes how you feel about health.” While taking medication could become routine, knowing that she had to take it to be healthy shifted her understanding about what she could expect from her body. Knowing that you have to rely on medications to heal you or prevent illness is a reminder that the human body has weaknesses. It can also be a daily reminder of illness or difference.

Twenty-eight-year-old Suzuki Ryow described lack of health as a sense of physical or mental suffering from inside the body. But Ryow’s insights were more social rather than individual:

“The world is made by and for healthy people. Only healthy people really participate in society. Healthy people should seek out and help those who aren’t.”

Ryow’s comments are particularly powerful when considering the fear and discrimination that surrounds HIV and other stigmatizing conditions, the classification of individuals who feel they were born the wrong gender as suffering from “Gender Identity Disorder” (and are therefore considered “sick”), and the lack of infrastructure for special needs individuals in Japan lead many people to be excluded or feel excluded from everyday life in Japan. While Juna’s comments indicate increased self-awareness with regard to health and illness, Ryow’s are a call for social awareness.

**Negative-Positive Definitions of Health**

Some interviewees described health in terms of the absence of some factors and the presence of others. For example, a 33-year-old Buddhist priest described health as being disease-free and mentally happy, adding that part of being happy is being surrounded by others. His wife added that being healthy meant being illness-free and having lots of energy. She was careful to note that being injured, say, with a broken arm, did not mean one was unhealthy.

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42 Carolyn Stevens has written extensively about how Japan, despite its advanced building technologies and design, still fails to be user-friendly for those in wheelchairs, for example (2007).
Azamino Masa*, a 37 year old salaryman described health as “gotai manzoku” – being able to move around and be free from pain. This is significant coming from Masa: he works so much overtime that he often suffers from back pain, and despite having accumulated a lot of vacation time he has difficulty using it to rest because of work and familial obligations. For example, the day I interviewed him, he opted to keep the fact he was taking the day off secret from his family because he found it more relaxing to be interviewed about health and HIV with friends over lunch than to do household projects. I got the feeling that his explanation of “gotai manzoku” was not just about physically being able to move his body, but also about being able to have some choice about or control over doing what he wanted to do.

In fact, a number of interviewees who put health in “positive” terms did so by describing health in two basic ways: they either described health as physical and mental as the priest and Juna allude to above, or in “everyday” terms like Masa.

**Positive Definitions of Health**

“Health is physical and mental. It’s living with nature,” explained Shiozawa Mihoko, a 31 year old salarywoman who moved back to her rural hometown and changed her diet as part of her efforts to overcome depression. In a similar vein, Yamada Kazuaki, a 29 year old engineering student defined health as having physical, environmental and mental/spiritual components, and caregiver Sano Chika added that social networks are important. In fact, a large sample size of my interviewees stipulated that health was comprised of two or more of the following: physical, mental, social, environmental, and spiritual factors. Interviewees were more likely to supplement these comments with practical definitions:

“Health is being able to do everyday things.” (Maeda Natsuko*, 45).

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43 Gotai manzoku (五体満足). Literally, “satisfied with your five limbs.” It means to be able to use your arms, legs and head without inhibitions.

44 Many interviewees, including Mr. Yamada, used the Japanese term kokoro (心) to describe an aspect of health. When I followed up on how people defined this term, it was explained as mind and spirit and different from the body.
Although Matsukawa Shigeru* (44) pointed out that health is individual, and what people do to be healthy is therefore different (he described his exercise regimen as an example), several interviewees listed the ability to do “everyday things” like moving around freely, eating properly, exercising, going to work, socializing, and smiling and laughing as what it meant to be healthy. The vast majority of interviewees listed eating three balanced meals a day, getting enough sleep and exercise, avoiding stress, and being social as ways to maintain health. Sonoda Mirei* (25) referred to these factors as “living right.”45 Further, one young woman noted that not being able to do these things is a sure sign that something is wrong:

“When you aren’t healthy, you can’t do anything – even eat or sleep properly.” (Yamashita Yuriko*, 28).

Therefore, according to interviewees, doing “everyday things” 1) constituted health, 2) served to maintain health, and 3) was impossible if one were unhealthy. Although these may seem contradictory or circular, they are logical when considering that all the interviewees considered health to be plural and have multiple causes and effects. So it was possible for one to be depressed and thus not be able to eat (Yamashita Yuriko*), for one to be physically sick and not able to eat (Shirakaba Taka*), for not eating properly to be partially responsible for depression (Shiozawa Mihoko), or for not eating properly to cause health problems (Nakata Azumasa).

Further, some interviewees alluded to the concept of being healthy in spite of issues that could be seen as health problems. For example, acupuncturist Kitano Azusa* (38) asserted that a little stress can be a positive thing in terms of improving yourself, but too much will have negative impacts on your mental and physical health. One interviewee in particular talked about pushing through difficulties to become healthy:

“A few years ago, I found out I can’t have children. At first, I was really shocked and depressed. But then I thought, ‘I still have a life!’ And then I thought, ‘Being mentally ill is not being able to see things from multiple vantage points.’” (Takano Tomomi, 40).

45 Tadashii seikatsu (正しい生活).
Instead, she listed positive experiences in her life, including time with friends and family, the ability to travel, and her close relationship with her nephews. These helped her out of her depression. Tomomi refused to let a biological reality, one that can be highly stigmatized in Japan, define her daily existence. In fact, it could be argued that her very standpoint, “I still have a life!” is the epitome of health. Some health practitioners I interviewed had this opinion.

“Life is not scientific. No one is ‘healthy.’ If you think you’re healthy, then you are.” (Anazawa Sadao, 69, retired surgeon).

“In general, I think most Japanese think about health as physical well-being. But it is a very difficult (problematic) definition... Some people, no, most people have some trouble in their bodies... There is no perfect social or physical well-being. There is no such thing as total health... I think health is to have some purpose in life.” (Kojima Eigo, 42, gasteroenterologist).

A junior doctor working with Dr. Kojima drew the connections between components of health, stating that if someone was mentally or socially sick, they would eventually get a physical problem – and that conversely, someone with physical problems could develop mental or social problems because of exclusion.

Of course, there is the issue that what makes health difficult, and precarious, is that people do not always have choices. People cannot simply choose not to have cancer or HIV. But they can choose to try to live positively with these conditions. One of the problems with this is illustrated by the comments of a city hall official:

“Health is living a life you won’t be embarrassed by. So, in other words, would I be embarrassed if someone saw me doing this? I didn’t think much about it before getting married and having kids. But when my kids were born, I thought, I have to be a good person because my kids will mimic what I do.” (Nagai Manabu*, 34)

Mr. Nagai’s comments were meant to be positive, to illustrate that one needs to teach the basics of life, of being a good person, by example – something he does on a daily basis. He is a friendly man who smiles a lot; you can find him in the park on the
weekends playing with his young daughters. He volunteered to go to tsunami-devastated areas to help with the clean up after the March 11, 2011 earthquake, and he continues to engage in efforts to support evacuees who live in his city. At the office, he works hard to make sure all city residents, foreigners included, are registered for health care. It is not an exaggeration to say he is a well-meaning, exemplary member of the community.

But there is one problem with his statement, one he did not realize because of his own sincerity and earnestness: embarrassment is based on being judged by others. Much like how people cannot decide whether or not they develop cancer, people cannot control how they are seen and judged by others. When people are judged for having a health condition, such as HIV, they tend to do exactly what Dr. Kojima’s junior doctor asserted: they become socially and mentally isolated on top of having a physical condition, making it even more difficult to get the care and support they need. Thus, stigma and discrimination contributes to difficulties in maintaining health. I return to this in the conclusions to this chapter.

In summary, health is…

According to my interviewees, health has physical, mental, social, environmental, and spiritual components. Connections were often drawn between these components, and interviewees often referred to their own experiences with illness and recovery in explaining their definitions of health. Health was referred to as the absence of illness, stress, fatigue, and behaviors that lead to illness such as overeating, drinking and smoking; it was also described in very practical terms such as being able to do “everyday things.”

These answers are, perhaps, not shocking and may seem to follow common sense. However, these points are important for two reasons. First, although the components described match up with points that could be considered references to Confucianism, Buddhism or Shinto (gotai manzoku, tadashii seikatsu, etc), they also fit the WHO definition of health. However, only two people, a 62 year old Shinto priestess and a 58 year old nurse, actually referred to the WHO definition of health, and no one overtly discussed health in terms of the cultural frameworks scholars tend to use when explaining
Japanese medical history and possible reasons for medical trends. This is not to say that these frameworks are not influential or are unimportant, however. As Reader and Tanabe have pointed out, the Japanese often participate in activities scholars consider religious although Japanese people often do not describe them as such (1998). In the same way, Japanese people describe health in ways that scholars see as relating to religious and medical categories, even though the people themselves do not describe them as such. Again, this indicates that the cultural frameworks are not at work in the ways that scholars such as Hansen and Visscher suggest; rather, they are functioning as examples of primary culture, as I assert above.

Data from these interviews also reinforces what we know about people’s concepts of health – namely, that they are dynamic and individual: people build their own frameworks based on their experiences, which shape and are shaped by elements of larger frameworks scholars know as grand theories and the lay public knows as “culture.” Crandon-Malamud illustrated that her interviewees commonly tried a number of treatments for a single illness episode, and provided a variety of rationale to do so based on who the listener was (1993). Considering the plurality of health and healthcare frameworks available to Japanese people, it seems logical to consider that individuals draw from them in unique ways based on their personal experiences with illness. However, as I will argue below, sometimes a lack of experience with a particular illness, such as HIV/AIDS, combines with particular aspects of a cultural framework that leads to large-scale fear and endangers public health. I turn to this issue below, where I discuss the origins of the term エイズ(eizu), how it is different from HIV/AIDS, and how collocation with specific images prevents many Japanese people from considering HIV as an illness one can live with healthily.

**HIV/AIDS: An illness by any other name…**

The act of naming is powerful, regardless of whether someone is naming a child, a new species, or an illness. Naming can reflect power, pride, ignorance and other characteristics of the person or people doing the naming. The medical community, for
example, tends to use the discoverers’ names (Creutzfeldt-Jakob’s Disease\textsuperscript{46}), the place a disease was discovered (Marburg Virus or Lyme Disease), a descriptor of the actual disease or its symptoms (smallpox or typhus), or a genetic factor, (H1N1) when naming diseases. Sometimes the name changes when more is learned about the illness (“Black Death” became “Bubonic Plague”), or if a name carries a stigma deemed inappropriate to the threat the disease poses (leprosy became Hansen’s Disease.) Sometimes the name is simply too complicated for everyday use and the “official” name goes largely unknown while other names develop in the public sphere. This seems to have been the case for ALS (amyotrophic lateral sclerosis, or Lou Gehrig’s Disease) – and for eizu (エイズ) in Japan. Regardless of which pattern is followed, the creation of medical terminology can often illustrate the ongoing processes of fear, prejudice, education, acceptance of the medical condition being named. The chance to compare different names for the same illness provides a unique opportunity to observe how the very terminology people use can shape perceptions of the illness and what health means in relation to it.

The basic history of naming HIV/AIDS in English is as follows: Prior to the discovery of the virus, the condition was often referred to as “gay cancer” (in reference to the prevalence of Karposi’s Sarcoma) or Gay-Related Immuno Deficiency (GRID)\textsuperscript{47}, among others. Acquired Immune Deficiency Syndrome became an accepted medical term when it was used in an article in \textit{Morbidity and Mortality Weekly Report} in the fall of 1982 (Preda 2005). Prior to that, the co-incidence of extreme immunodeficiency, wasting, yeast infections, and \textit{pneumocystis carinii} and/or Kaposi’s Sarcoma was labeled “community acquired,” “severe acquired immunodeficiency,” “Kaposi’s Sarcoma and Opportunistic Infections Syndrome” (KSOI Syndrome), “gay compromise syndrome,” and “Gay Related Immune Deficiency” or GRID (Preda 2005). ACIDS (Acquired Community Immune Deficiency Syndrome) and CAIDS (Community Acquired Immune Deficiency) were proposed around the same time as GRID. The CDC, sensitive to the fact that the epidemic was probably not limited to MSM or communities per se, often

\textsuperscript{46} Commonly known as “Mad Cow Disease.”
\textsuperscript{47} Debates as to what the virus and syndrome should be called raged for several years, and the former President of South Africa has refused to recognize HIV as the cause of AIDS.
used the term “Epidemic of Immune Deficiency.” The lay public often talked about the illness as “gay cancer” or “the gay plague.”

Human Immunodeficiency Virus (HIV) was first isolated by Luc Montagnier in France in 1984 and Richard Gallo demonstrated that HIV is the agent that causes Acquired Immune Deficiency Syndrome (AIDS) in the United States the same year (Prusiner 2002). But naming HIV was not a simple matter. Montagnier first called it RUB, which was a re-arrangement of the initials of the patient from whom he had drawn the cells he used to isolate the virus (Shilts 1987). He switched to LAV (lymphadenopathy-associated virus) in 1983 when he had a better idea of what the virus was doing in the body. By that time, Gallo was also conducting research on the virus and, wanting to associate it with viruses he had previously discovered, called it HTLV-III in 1984 (Shilts 1987). Even various US health offices (such as the National Institute for Allergies and Infectious Disease and the CDC) fought over whether to refer to the virus as HTLV III or LAV, because some offices were more strongly tied to Gallo, while others sided with Montagnier (Shilts 1987). Eventually, it became clear that Gallo was researching the same virus Montagnier had isolated, outside parties encouraged the adoption of the name HIV, and Gallo was able to prove that HIV causes AIDS.

However, just because a name is adopted in one place and used in another does not mean that all the possible meanings are transferred along with it. For example, recall my conversation with Taka about HIV vs. AIDS in the beginning of this chapter:

“There is no treatment, right? Maybe. I don’t really know the symptoms...There is no one around me who has it, so I really don’t know. If a friend or someone had it, I think I could explain... anyway, it’s a bad illness.”

I asked what the letters mean, and he replied using the kanji for AIDS.

I asked if he knows how HIV is different from AIDS and his eyes widened in surprise.

“I don’t know... there is a difference?”
This is a conversation I had many times during the course of my research. I asked each interviewee about HIV first, then about AIDS. Nearly every time, the interviewee exhibited shock or confusion when I asked about AIDS, stating something to the effect that they were under the impression that HIV and AIDS were the same thing as Taka does above. However, the inability of Japanese people to distinguish between these two terms becomes less mysterious when the usages for HIV/AIDS, エイズ (eizu, a Japanization of AIDS), and the Japanese kanji terms are parsed. Further, in Saussurian terms, it became apparent that the signified is not the same as it is for the medico-English terms: what was happening in my interviews was that I was talking about HIV or AIDS, and my interviewees were talking about エイズ. This realization was critical in understanding why my interviewees reacted the way they did when I shifted from focusing on HIV to AIDS, the difficulties experienced by specialists in selecting terms when preparing materials and programs about HIV/AIDS, and the tendency to equate HIV+ to dying from AIDS.

**Naming HIV and AIDS in Japan**

There are several ways to discuss HIV/AIDS in Japan, each with its own particular history and nuance. The English names came first and HIV, AIDS, or HIV/AIDS have been used in Japan since the 1980s. The English names were translated directly into Japanese in the early 1980s as well: *hito men’eki fuzen uirusu* (ヒト免疫不全ウイルス) for HIV and *kōtensei men’eki fuzen shōkōgun* (後天性免疫不全症候群) for AIDS. However, the Japanese tend to shorten words when possible, and may also put foreign words into Japanese syllables instead of using Japanese even when it exists. Thus, *Matsumotokiyoshi*, a popular drugstore chain, becomes *Matsukiyo*, and *doa* is used for door instead of *tobira* (扉). Thus it is probably not surprising that, given the length of the kanji and brevity of the English acronyms that *eizu* (エイズ), the Japanese pronunciation of AIDS, came into parlance and is written in katakana. Currently, HIV, AIDS, HIV/AIDS, HIV/エイズ, エイズ、人免疫不全ウイルス、and 後天免疫不全症候群, seven terms/combinations in all, can be used discuss HIV/AIDS in Japan.

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48 Japanese is written using *hiragana*, a syllabic alphabet, and *kanji*, characters of Chinese origin. *Katakana* is a second syllabic alphabet used specifically to write foreign words and names.
Presence, however, does not indicate levels of use or shared understanding of a term. For example, every interviewee recognized the term HIV, and some knew H was for human and V was for virus. None knew what AIDS stood for. Although it is perhaps unfair to expect native speakers of Japanese to know what English acronyms stand for, the trends were similar for the Japanese terms: most of my interviewees from the general public said they were unaware that there are Japanese words (in kanji) for HIV and AIDS. Some knew that there were kanji, but could not recall the words. And some conflated the two names. Recall that Taka gave the kanji for AIDS when I asked him about the Japanese name for HIV. Similarly, a 45-year-old housewife wrote out the kanji for AIDS on the interview sheet when I asked about the kanji for HIV. Interestingly, no one did the opposite – no one gave the kanji for HIV in place of the kanji for AIDS even though the kanji name for HIV is shorter.

Thus, most Japanese do not know the kanji names for HIV or AIDS and therefore do not use them; although they recognize and sometimes use the terms HIV and AIDS, they do not know what the letters stand for. The katakana name, エイズ, is used most frequently as will be discussed below. This is significant because HIV, AIDS and エイズ do not have any inherent meaning for Japanese people like the kanji might. What happens to the body, and the distinctions between HIV and AIDS are lost – particularly when HIV and AIDS are elided into the term エイズ. As Akutagawa Juna* succinctly stated,

“Using English blocks or softens the meaning.”

I return to the role of エイズ in shaping conceptions about HIV/AIDS at the end of the chapter.

**What is written**

As stated above the kanji terms for HIV and AIDS are rarely used by the general public. Interestingly, this tendency also holds true for organizations that work directly
with HIV/AIDS. Even in medical documents, kanji use is rare. For example, in the Ministry of Heath, Labor and Welfare White Paper on HIV/AIDS for 2009 the Ministry opted to use HIV/エイズ. When discussing policy, HIV/エイズ is used. When medical aspects of the conditions are the focus, for example when discussing patients, the Ministry distinguishes between PLWH and PLWA by calling them HIV patients and AIDS patients (only the word “patient” is in kanji). The most common place for the kanji to occur is in textbooks or education booklets where HIV and AIDS are explained; however, after the explanation, it is often HIV and エイズ that are used (see below).

エイズ is a particularly flexible term, and is used on all sorts of printed materials relating to HIV/AIDS: condom wrappers, advertisements for HIV checks, STI information booklets, and posters for HIV/AIDS awareness are just a few examples. Although it can be a highly useful way to describe the social conditions surrounding HIV/AIDS, it can also lead to confusion when it is used as a stand-in for HIV and AIDS as well as HIV/AIDS. This sometimes occurs in the same document. I use an education brochure produced by Kyoto City (2012) to illustrate the difficulties this causes below.

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49 A White Paper is a document written by governments and businesses to help understand an issue so that decisions about it can be made.
50 When I conducted interviews, I distinguished between the two by asking about HIV using the katakana pronunciations, eichi ai vi (エイチ・アイ・ヴィー) for HIV and eizu for AIDS). I also spelled out AIDS for clarification. Japanese people who live and/or work with HIV/AIDS discuss it in formal or semi-formal settings using HIV/エイズ.
Figures 1, 2, and 3 are from the cover of the booklet. First, note エイズ is written in red on the cover, overlaying AIDS written in English. In this instance, エイズ is pictorially equated with AIDS. (Figure 1) Second, note that a speech bubble above the character reads, “I want you to know more about エイズ.” Here, エイズ is contextually both HIV and AIDS. (Figure 2) Third, エイズ is discussed inside the front cover (Figure 3) as something that is increasing, that treatment is improving, and that the reader needs to take time to learn more about it. Characters below the text are reading a book with “AIDS” on the cover. Thus, pictorially, エイズ is AIDS, but content-wise it is clear that エイズ is HIV and AIDS.
To summarize, エイズ is used to mean both AIDS and HIV/AIDS on the cover; determining just what is meant by エイズ is similarly complicated in the Table of Contents (Figure 4). For example:

P2 “What kind of illness is エイズ?”
Here, エイズ is HIV and AIDS.

P4 “What is the route of infection for エイズ?”
Here, エイズ is HIV; it is not AIDS because AIDS is not transmitted.

P6 “How do you prevent エイズ?”
Here, エイズ is HIV, not AIDS, because the context is preventing infection.

P8 “How do you get tested for エイズ?”
Here, エイズ is HIV; there is no test for AIDS.

P10 “What do you do if you’re infected?”

The topic is HIV because AIDS is not an infection.

P12 “How do you treat PLWHA?”

The topic is people who have either HIV or AIDS.

To clarify, エイズ is AIDS or HIV/AIDS on the cover; in the Table of Contents エイズ can mean HIV or HIV/AIDS. That エイズ is used to mean all three terms (HIV, AIDS and HIV/AIDS) – sometimes at the exclusion of particular terms – becomes increasingly clear upon surveying the contents of the booklet.
On page 2 (Figure 5), for example, the content on the blackboard can be translated as follows: “エイズ is an illness in which, once infected with HIV, you lose immune resistance and get sick quickly.” Considering the juxtaposition with HIV and the association to loss of immunity and being sick, エイズ is AIDS (and not HIV). Following this pattern, the part numbered 1 in lavender reads, “Being infected with HIV does not = エイズ” Again, エイズ is AIDS and clearly not HIV – despite the fact that エイズ was on the cover and in the Table of Contents to mean HIV.
The difficulties culminate on page 10, the section entitled, “What should you do if you find out you have it?” (shown above, figure 6). The blackboard reads “If you notice quickly and get treatment, it’s possible to prevent the progression to エイズ and live as before.” Here, エイズ is clearly AIDS, as on page 2.

In the starred section below, it reads “You can control エイズ,” clearly referring to HIV in the same way as in the Table of Contents.

But then it reads, “The scariest thing about エイズ is not knowing about it.” Here エイズ is both HIV and AIDS as it is on the cover.

To summarize: according to this booklet エイズ is sometimes AIDS (but not always), sometimes HIV (but not always), and sometimes both HIV and AIDS (but not always). Sometimes エイズ means HIV, AIDS and HIV/AIDS all on the same page.
Although not all organizations use エイズ this loosely, it is not uncommon. Such usage indicates that even HIV/AIDS specialists may have difficulty parsing the terminology. Given that specialists have this kind of difficulty, it is understandable that interviewees like Taka were confused when I asked them what the difference was between HIV and AIDS. In their minds, both HIV and AIDS are エイズ.

At this point, we can say that, linguistically speaking, エイズ does not map neatly onto the English terms HIV, AIDS or HIV/AIDS. Clearly, there is something different about how エイズ is conceptualized. According to Saussure, a sign (word) is comprised of a signified (a concept) and a signifier (linguistic component assigned to a concept). The sign, in this case is a word. For native English speakers familiar with HIV/AIDS, the signified is the virus in the case of HIV; in the case of AIDS, the signified is the condition of having a depleted immune system that cannot fight off disease – and possibly images of suffering and death. So what is the signified, or the concept of エイズ? I asked interviewees to tell me what images or associations they could make with エイズ.

**Images of エイズ**

“It is scary, incurable and has nothing to do with me.”
(Several interviewees, male and female, from 20s to 60s)

“It’s a deadly illness… that feels far away” (Katagiri Mika*, 45).

Like Taka, most interviewees said that they did not know anyone with HIV/AIDS. General consensus was that it felt far away. A few interviewees noted that anyone could get it, but then stated that if you live a “normal life” you could prevent it. One friend even asked me why I was studying HIV/AIDS instead of something that affected everyone like cancer. This is in a place that has the same per capita rate of HIV incidence as Tokyo and Osaka; the difference is that transmission via heterosexual sex is on the rise.

In addition to feeling that エイズ is far away, interviewees like Mrs. Katagiri, Mr. Nakata, and Ms. Sonoda, felt it was incurable, deadly and scary. Having no inherent
linguistic clues about what HIV or AIDS meant, no experience with people living with HIV, and only vague memories of what they learned in health classes\textsuperscript{51}, interviewees’ images of エイズ were shaped mostly by their media experiences of the illness. These included celebrity cases such as Magic Johnson\textsuperscript{52}, Ryan White\textsuperscript{53}, or Kawada Ryuhei\textsuperscript{54} and movies or televisions shows such as *Philadelphia*\textsuperscript{55}, *Priscilla Queen of the Desert*\textsuperscript{56}, and *God, Please Give Me More Time*\textsuperscript{57}. Ms. Takano noted that she had seen a documentary on the world’s children in which children with HIV did not play with other children.

It is significant that most of these images are not domestic, they are foreign. Kawada Ryūhei is not widely known even though he is a politician; those who do know of him know he was infected through medical treatment, an issue which is considered to be “over” in Japan. God, *Please Give Me More Time* focuses on teenage prostitution and culminates in the death of the heroine, although her husband and daughter (who was conceived without taking precautions to avoid transmission) live on HIV free. Given these examples, it is not difficult to see why エイズ feels far away; and perhaps images of dying from AIDS from *Philadelphia* or *God, Please Give Me More Time* leave more lasting impressions or are more visible than Magic Johnson and Kawada Ryūhei living with HIV. Furthermore, the geographic and social distance indicated by interviewees’ descriptions of eizu as “far away” is perhaps not surprising considering the Japanese terms *uchi* (inside) and *soto* (outside), a dichotomous set of words common in daily conversation, connote the same sense of geographic and social distance.

\textsuperscript{51} Discussed in more depth in Chapter 2.
\textsuperscript{52} Former NBA player who came out as living with HIV in 1991; the interviewee who mentioned him is a sports fan.
\textsuperscript{53} Hemophiliac boy from Indiana who contracted HIV through medical treatment and worked as an activist until his death in 1990 at 18 years old. The interviewee who listed him was living in the US at the time of White’s death.
\textsuperscript{54} A Japanese politician who contracted HIV and hepatitis C as an infant. His comments appear in Chapters 5-6.
\textsuperscript{55} Starring Tom Hanks; the 1993 film portrays a gay man’s struggle to prove he was wrongfully dismissed from his law office for having AIDS.
\textsuperscript{56} A 1994 Australian film that portrays a group of queens’ (cross-dressing gay men) journey through the Outback; the movie alludes to HIV/AIDS.
\textsuperscript{57} *Kamisama mō sukoshi dake* (「神様、もう少しだけ」). A 1998 Japanese television drama that depicts a high school girl contracting HIV through prostitution, getting married, having a baby, and dying (while her partner and baby live HIV free).
エイズ Speak?

エイズ is the simplest way to converse about HIV/AIDS in Japanese. Given the alternatives, it makes sense that this is the word people often use. However, using エイズ to talk about HIV and AIDS creates problems of representation not unlike those Shilts described in regards to “AIDS Speak” in the United States: the more people talked about AIDS, the more their words reflected fear and the less they reflected physical realities. One of Shilts’ examples is “avoiding bodily fluids” (1987). This was code for blood and “bodily fluids exchanged during sex,” meaning ejaculate, pre-ejaculate and vaginal fluids. “Bodily fluids” was used because people were afraid to use these terms, and thus problems arose because urine, sweat, and saliva are also bodily fluids. A similar thing happened in Japan: Seki and colleagues assert that because Japanese people were told HIV/AIDS was not spread through “everyday contact,” some assumed that HIV was not an infectious disease (Seki et al. 2009). So what else happens with エイズ speak in Japan?

As noted above, people do not use the kanji to talk about HIV or AIDS, nor do they use the English words. They talk about エイズ. Moreover, talking about エイズ is similar to talking about AIDS in English in that the conversation is about being very sick with an incurable disease and dying. They are not talking about being HIV+, and this makes it difficult to talk about health.

Recall Taka’s closing comment to me:

“Japanese people’s images of HIV are of AIDS from the 1980s, huh?”

The images from the 1980s were AIDS images because AIDS came first. The suffering and the death related to AIDS was what could be seen. These images are persistent, and live on in the word エイズ whether written or spoken – or represented pictorially. Consider the following:
In preparation for the 2012 Asia-Oceania Congress of Sexology (AOCS), Dr. Yuko Higashi held a poster contest in which she asked Japanese college students to make posters with the theme, “Sexual health for all in a diverse world.” Over fifty posters were submitted, and the vast majority of them focused on HIV/AIDS. The participants of AOCS, including Dr. Higashi, were shocked when the posters were displayed because they tended to conflate HIV and AIDS, and/or associated it with death or the end of one’s social life. For example, poster 1 depicted a revolver covered with a condom, and the ejaculate-drenched words, “Dead or Alive.” Poster 2 featured a bleeding eye, with the words “Momentary pleasure brings you a lifetime of regret.” Poster 3 depicted a video game sex scene between a woman and a fiery devil, with the words “Game Over No Continue” across the screen. Poster 4 depicted the shadow of a Puck-like figure (a male with horns) in black against a gray background, and featured the words, “When not knowing it, you have the shade of a virus” in red. Poster 5 depicted a woman in a red bra and jeans, her head covered by a grim reaper mask with the letters HIV printed on it. Her fingers make an OK mark, but the picture is spattered in blood. The words, “I’m safety today!” are written in white while “Already infected” is written in red. Perhaps most germane to the discussion of the signified and the images of HIV/AIDS is this poster:

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58 Dr. Higashi publishes in English, so I have written her name with her family name second here.
59 The “safety today” is a reference to women’s “safe days” when they can engage in sex without the fear of getting pregnant – and therefore, a condom is considered unnecessary.
The H and the V of HIV are dripping with blood, while the I is a reddish condom – all on a black background, and accentuated with blood spatter. Under the H, a naked man holds a skeleton, and under the V a naked woman holds a skeleton. A naked man and woman are “safe” inside the condom. “It’s easy” is written in yellow, and in smaller, white letters, “Easy to prevent, easy to get” are printed below. In even smaller print, “The eizu virus enters the body and attacks the immune system, and in the end you die from basic infections. This is easily prevented by being careful in your daily life.”

What do these posters tell us? Consider the pervasiveness of the death theme: guns, blood, grim reapers, and the color black all indicate death. In addition, pollution and possibly transgression are indicated by blood, devils, characters with horns, and the color red. Using the poster above as a concrete example, we can see that HIV is equated to eizu (written in small type), and this is pictorially equated to death as represented by the skeletons and the blood. Although the message that HIV leads to illness and death and the importance of condoms are absolutely right, the depiction is that HIV is the same as AIDS and leads to death no matter what: there is no image of living positively with HIV. This generates fear, which is supposed to encourage condom use, but fear can also lead people to avoid confronting the realities of HIV. Moreover, it is difficult to resist attributing these images to Shintō concepts of red and black pollution discussed above; but such a simplified view is problematic, as there are many social factors that contribute to fear of HIV/AIDS along with a lack of knowledge about the virus that combine to make the production of such images possible. What we can say is that the term eizu to some degree signifies illness, pollution and death

**Health and エイズ**

To summarize, in Saussurian terms, HIV and AIDS are signifiers and signs; what is signified by these acronyms are the full names of the conditions as well as the virus and the actual syndromes as they occur in people. Although most Japanese interviewees recognize HIV and AIDS, they do not associate them with these signifieds the way that English speakers familiar with HIV/AIDS do. Rather, what happens is that both terms are often converted to エイズ in the minds of interviewees, and what is signified by エイズ
is an incurable sexually transmitted disease that results in death. Therefore, HIV and AIDS in Japan cannot really be called floating signifiers, or signifiers that have no actual shared signified, because this is not really what is happening. HIV and AIDS and エイズ in Japan have different signifieds than HIV, AIDS and HIV/AIDS do in English speaking countries, and this also means that for many members of the Japanese public, there is no signifier, no word, to talk about just the virus that causes AIDS.

Furthermore, according to Frake’s contrastive feature analysis in which something can be defined according to what it is not (1962), it is possible to consider that the perception that エイズ is an incurable (sometimes untreatable), deadly, and scary infectious disease (what English speakers would call AIDS) leaves no room to talk about HIV because it is not something that fits within the health lexicon. Because HIV=AIDS=death, it cannot possibly equal health. In practical terms, it is very difficult to talk about having a healthy life living with HIV, regardless of what cultural frameworks one draws from because, as we will see in Chapter 2, Japanese people have very few personal experiences with HIV.

However, given that most Japanese people have very practical working definitions of health based on personal experiences, if associations can be shifted from HIV=AIDS=death to HIV+treatment="being able to live normally,” this could change. Perhaps one way to do so is find a way to talk about HIV as separate from AIDS (and death) so that health and HIV can collocate. In fact, this is exactly what had happened by the end of the interview with Taka, after I had explained the current realities of HIV/AIDS. He was even able to relate HIV to similarities between shingles, mononucleosis and HIV:

“So HIV is kind of like what I had. And what you had!” (Taka)

It seems from Taka’s comment that this association has been broken. Butler describes how retribution for violence is often done out of fear with the hopes of ending feelings of uncertainty and vulnerability, but perpetuates the cycle because retribution leads to more violence, more retribution, and more of the same feelings (2004). A similar pattern is happening with HIV in Japan. Long associated with AIDS, pollution, and death,
eizu is feared. People attempt to avoid it, to mitigate this fear, by not talking about it (for example, in sex education) and/or by referring to it as someone else’s problem, or as something that is far away in other countries, or to people who are different from “me.” This avoidance merely perpetuates the problem, however, because avoiding talking about HIV/AIDS does not equate to avoiding behavior that leads to transmission of HIV. Rather, it creates the conditions for it to be able to spread through the population. As more outbreaks are recorded, fear increases. People feel a sense of danger, but try and avoid it – this puts them in even more danger than they would be in if they faced it directly. However, if more people were able to forge new connections like Taka did, the cycle would start to break. Butler notes this must be done by changing not only the information people get, but the way that people interpret it (2004). I discuss how this is being done in Chapter 2.

**Conclusions**

The cultural factors that influence ways of thinking about health in Japan, do not neatly overlap the basic conceptual framework of contemporary Japanese healthcare. Furthermore, focus on these frameworks neither provides a uniform explanation for responses to illness nor fosters dialogue about being able to live healthy lives despite having a medical condition or illness. Interviewees’ conceptualizations of health are flexible, and reflect internalization of cultural frameworks that in turn give order to their personal experiences with illness.

Furthermore, interviewees’ use of eizu to refer to both HIV and AIDS illustrates how these terms defy simple equivalencies, despite the fact that kanji terms directly translated from English exist. Usage of the term eizu represents a form of indirect or vague engagement with HIV/AIDS: the term itself does not give speakers a clear concept for what the virus or syndrome are or what they do in the body and this allows them to keep a conceptual distance from HIV/AIDS. While this response mitigates fear of the illness, it engenders further precarity because elision of HIV and AIDS encourages avoidance which in turn creates conditions for HIV to spread more easily throughout the population.
However, although *eizu* is conceptually linked to illness, pollution and death, these associations can be broken when people are encouraged to think about the virus and the syndrome separately; it also becomes possible to consider living healthily with HIV. Taka, for example, went from stating that being healthy means not being sick and considering HIV/AIDS as a difficult sickness, to considering HIV as treatable and then asserting that people living with HIV should do what every other Japanese does to stay healthy: eat right, get enough sleep, and protect their immune system. Therefore, although response to precarity posed by HIV/AIDS is currently met with avoidance and indirect engagement with HIV/AIDS, this can be changed. Indeed, in the next chapter I describe how Japanese activists work to combat HIV/AIDS directly and foster exactly the same changes my interview with Taka effected.
Chapter 2: Going Viral: Learning Networks and the Transmission of HIV/AIDS Memes

I reached my destination on Friday night, and Mari was waiting for me at the train station. “C’mon, we’re having a party tonight because we finished our exams today. We can try out the red ribbon nail kit with the girls at the party and then work on the other preparation tomorrow,” she said excitedly, as we hurried down the street and up some stairs to her classmate’s apartment. Mari and I were working on an HIV event for a group of medical students, her classmates, that was scheduled to take place on Sunday.

Our hostess opened the door, pushed my baggage into a corner, and introduced me around in what seemed to be one sweeping movement. Women – the party was comprised entirely of female students – shifted around the table to make room for us, filled plates and drink cups and handed them to us, without much of a break in the conversations. Food appeared, was consumed, and plates and garbage were removed from the table in a steady stream. When it slowed, the nail art kit, sent to us by our friend Tomoko in Tokyo, came out. We looked through the colors, and someone read the directions for applying the red ribbon stickers. As we painted each other’s nails and applied the stickers, the conversation turned to sex and condoms.

“Actually, I’ve never seen a condom,” commented one of the med students.

“WHAT?!?” several incredulous voices shouted in unison.

“It’s true…” the young woman laughed nervously, and there was a flurry of digging through purses and bags punctuated with comments like, “I can’t believe it…” and “Well, we can’t have that…” “I know I have one in here somewhere…” And finally, several appeared on the table. Talk shifted to types of condoms and preferences.

“Do you have a bottle, a banana or a cucumber?” I asked the host. She nodded, looking puzzled. “Why?”

“We can show her how to use a condom using one of those things.”
“Hear that? She’s going to show you how!!” one of the more senior students exclaimed, poking the condom virgin.

The hostess, laughing, motioned for me to follow her into the kitchen, where she opened the refrigerator. She dug out three bottles, each containing some type of sauce, and held them out to me. I selected one and went back to my seat.

I handed the bottle and a condom, still wrapped, to our friend. She looked down at them for several moments. The other women stared at us with curiosity.

“Open the condom,” I encouraged her. She tore the wrapper and pulled it out with her thumb and forefinger and stared at it. I showed her how to tell which side was which, and as she began putting it on the bottle, the advice started pouring out from the other women amidst gales of laughter:

“Make sure you don’t put it on backwards!”

“Cut your nails before you have sex! You could break the condom!”

“Don’t push too hard!”

“Tie it up when you take it off or that stuff will get everywhere!”

“Oh, it tore! Good thing that’s just a bottle!”

“Too bad we don’t have a banana or a cucumber. Those are more like real penises!” (Field notes, November 11, 2011)

In Chapter 1, I showed that many of my interviewees associated HIV with AIDS and death, and that this is a common association to make. I argued that this association is supported by the use of the term eizu, and that such associations foster indirect engagement with HIV/AIDS. However, there are pockets of people in Japan who have more positive impressions about HIV/AIDS and who do make direct efforts to learn about the condition. The women in the anecdote above, for example, were willing to learn more about the illness and sexual health, and show their support for people living with HIV by painting red ribbons on each other’s nails and participating in a workshop
on HIV/AIDS on their day off. But the anecdote above shows more than just that. What this story illustrates so well is the plurality of types of HIV/AIDS-related ideas (memes, which I describe below), the variation in how they move and become part of people’s lives and – with regard to this anecdote specifically – the importance and effectiveness of learning about sexual health in small, safe groups of friends. This anecdote also illustrates the conditions for which complex information about HIV/AIDS – information that helps break the precarity cycle discussed in Chapter 1 – moves. In this chapter, I argue that 1) although there are Japanese people who directly engage with HIV/AIDS, they are in the minority; 2) that opportunities to engage directly with HIV/AIDS are few in Japan; and 3) that this is because frank information about HIV/AIDS is often complicated and therefore does not flow through the public with the same ease that stereotyped images and misinformation do. I conclude that the HIV/AIDS memes circulating in Japan constitute indirect engagement with the illness that mitigates fear of HIV/AIDS but helps create the conditions for its spread – much in the same way that the vagaries of the use of the term eizu does.

To do this, I first define the terms “meme” and “go viral,” differentiating between how sociobiologists and the lay public conceive of them. Focusing on memes, I borrow Kristeva’s concept of intertextuality to describe how multiple forms of a meme can exist, interact (or not) with one another, and hold a variety of meaning for various individuals even when individuals are faced with the same meme (Sim and Van Loon 2009; Midttun and Kristeva 2006). In addition, I utilize cognitive and social network theories by Allert (2004), Trapajos (2003) and Neiagus (1998) to illustrate how memes move through and become integrated into cognitive and social networks – which I collectively call learning networks60 – in individuals. Shifting focus to the societal level I assert that, rather than adhere to the gene-meme metaphor, a viral metaphor is more useful for understanding how memes, which are culturally constructed and mediated, influence public and global health by engendering stigmatization and blame (Briggs and Mantini-Briggs 2003).

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60 By learning networks, I refer to both formal and informal modes of learning. This includes sex education lectures, hearing celebrities speak about or give concerts as HIV/AIDS tributes, going to exhibits that directly or tangentially address HIV/AIDS, first-hand experience with STIs to STI testing, and learning from peers – such as in the anecdote above. It also includes cognitive and social networks, which I discuss more fully below.
What is a Meme?

Sociobiologists often introduce meme theory with a discussion of learning, memory, and the concept of “dual inheritance” (Plotkin 1996). According to evolutionary biologists, the ability to learn and to remember what is learned dates to 550 million years ago; the intelligence required for these skills is considered to contribute to fitness and the reproductive success of individuals (Plotkin 1996). The development of memory led hominids to develop the ability to mimic one another, talk, and use symbols. Thus, “dual inheritance” refers to the development of physiological characteristics that improve biological fitness that also enable the development of social characteristics (Plotkin 1996). The idea that cultural change could be mediated by selection processes and dual inheritance was first postulated in the 1950s, and it is within this context that Richard Dawkins developed and coined the term “meme” in his 1976 book, The Selfish Gene. Essentially, Dawkins presents memes as the cultural analog to genes.

What began as a discussion of how humans were able to develop culture as hominids developed memory and the ability to learn, cultural evolution through mimetics has recently paralleled genetics through discussions of recessive and dominant memes, meme transmission through higher order knowledge systems, meme persistence, and linked loci of memes. However, the meme-gene metaphor has been challenged by those who caution that linking memes and genes may lead to the erroneous conclusion that cultural or personal traits have biological realities that can be linked to “race” or ethnicity. In addition, there is lack of consensus among those who use mimetics: Rose notes that, among other things, sociobiologists themselves have not been able to agree on a definition for meme, particularly with regard to whether or not a meme is a message or a replicator or both (1998). Practically speaking, some definitions of meme postulated by sociobiologists are so narrow that some types of learning are considered memes while others are not (Plotkin 1996). A more general definition would allow more flexibility. Luckily, the general public’s definition of meme may do just that.

When Dawkins coined the term meme, the term was adopted and has been used with regularity by the general public. For example, Merriam Webster defines meme as “an idea, behavior, style, or usage that spreads from person to person within a culture”
(2013). One could say that the term itself became a meme. Moreover, Dawkins inadvertently introduced another concept in his discussion of memes: “going viral.” The concept first appears in his description of how memes leap “from brain to brain… when you plant a fertile meme in my mind you literally parasitize my brain, turning it into a vehicle for the meme’s propagation in just the way that a virus may parasitize the genetic mechanism of a host cell” (Dawkins 1989:192 emphasis added61). Notice the shift from comparing memes to genes, to comparing memes to viruses and parasites. Rather than discussing meme expression as similar to gene expression, the focus is meme infection. Further, whereas Dawkins goes to great pains to state genes as replicators are quite value-free in spite of his extensive use of personification, he does not make the same effort with regard to memes, allowing the association with viruses and parasitization to be seen negatively. In other words, not only are the message and the vehicle for delivery conflated in this definition of replicators, Dawkins has switched metaphors and added a negative value regarding how memes move. Like meme, going viral has become part of the lay lexicon: Dictionary.com defines “going viral” as “to move rapidly via the internet” or become “very popular through circulating quickly from person to person” (2013). Thus, Dawkins provided the groundwork for the meme-gene metaphor that sociobiologists have been utilizing, as well as the concept of “memes going viral” which was taken up by the public.

The lay definitions of meme and going viral are quite broad, while the sociobiological use of meme is comparatively narrow (“go viral” is generally not used by sociobiologists62). Thus, I recast both terms in such a way that they are more rigorous than what are used by the public while, at the same time, meme is divested of the evolutionary context used by sociobiologists. This way, we can focus on viral movement and integration of memes throughout populations without the connection to fitness of the

61 These words are actually from Dawkins’ friend N.K. Humphrey, who wrote on his draft, but Dawkins uses them to highlight his meaning (Dawkins 1989). The negative connotation given here is probably unintentional, but remains nonetheless. I would argue it is this section that is partially responsible for inspiring Brodie to write Virus of the Mind, in which the author argues it is possible to “disinfect” one’s mind by getting rid of harmful meme-viruses (2009).

62 There is a tendency, however, to associate memes with viruses, infection and danger instead of genes: Dennett repeats Dawkins’ negative valuation of memes that is based on this comparison, referring to memes as “promiscuous” and “unquarantinable” (1990:131).
human species, and go beyond general discussions of spread and speed. Therefore, in this chapter, a meme is what Dennett calls a “distinct memorable unit” (in Brodie 2009:8) that can be transmitted to others and integrated into one’s cognitive network via one’s social network. Furthermore, memes are intertextual: they can exist in multiple forms and be understood in a multitude of ways. Later in the chapter, I provide an expansion of the term “go viral” that is useful for describing meme movement at the population level.

**The Power of Memes**

To illustrate the basic points about memes made above, I return to the red ribbon manicure party. The party involved the spread, or perhaps the reinforcement, of a well-known meme: the red ribbon63. The significance of the ribbon went unexplained at the party because everyone recognized it. Its appropriateness for the setting also went unquestioned because the participants knew about the HIV/AIDS event that weekend, which they were all planning to attend, and knew we were doing a “test run” of the nail kit. Evaluating it in this context, the red ribbon as a meme fit the definitions and characteristic described above: the red ribbon is a distinct, memorable unit that represents HIV/AIDS awareness to the participants; it is intertextual in that it could be found on HIV/AIDS awareness posters, bracelets (I wore one all weekend), and actual ribbons and pins (which were worn by some participants, including myself); and the social environment has been fairly open to red ribbons as HIV/AIDS awareness symbols since they went into circulation in 1991.

The red ribbon meme was spread through the female medical student social network at this particular school when the stickers were applied as part of the manicure – the second meme. Its place in each person’s (cognitive) learning network was likely linked to their existing understanding and previous experiences with the symbol when women actively affixed the sticker to someone else’s nails, and passively allowed it to be glued onto their own during the third meme, the party. Although no one at the party really considered these actions in terms of mimetics per se, they were conscious of the fact that its existence on their nails symbolized their commitment to the HIV/AIDS cause. Tomoko, my friend who sent the kit, however, did state that she did so precisely to spread

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63 Since 1991, the red ribbon has been signified awareness and support for those living with HIV/AIDS.
the word, or to reinforce the meme of the red ribbon. She further explained the rationale for spreading the message through nail art like this:

“When you have your nails done, someone has to touch you. And usually you talk. Even if it’s just small talk. But that contact – touching, talking – it’s important. And with the red ribbon nail art itself, it takes time to put on. And it can’t be taken off easily like a pin or a shirt. You think about the application, and the removal. It takes time and effort.”

(Yoshida Tomoko, Field notes March 10, 2011)

In other words, having someone physically paint the ribbon on your body requires sustained, conscious awareness of the meme and your acceptance of it – and it also requires contact with another person. It is a social contract, and a form of embodied activism. The parameters are decided by the nail artist and the “client,” painted and affixed to the nails, and witnessed by all the other artist-client pairs participating. Although it is common to have a set of artists at an event who paint participants’ nails, in our case, we swapped roles. Artists became “clients” and vice versa, further deepening the social contract and the strength of the red ribbon meme. For many of these women, the contract was “renewed” or “re-written” a few days later when we brought out the kit again at a party after the main events and encouraged others to participate. Thus, the act of manicuring the red ribbon itself became a meme. As a distinct memorable unit that involved the transmission of the first meme to participants (and those who later noticed the nail art) through interactions of people within social networks, the red ribbon meme and the concept of red ribbon nail art became part of the participants’ learning network.

Parts of the party (eating, nail painting, putting the condom on the bottle), or even the whole party itself, may be considered a meme. Having manicure parties, not just having the manicure done, is becoming popularized; this party was only one group of many that received the nail kit for these purposes. Moreover, the participants became vehicles for the meme, and the party allowed for the reinforcement and spread of the red ribbon meme. The meme spreads to people’s cognitive networks through interactions of individuals in social networks. But for these social networks to become meme paths, the members have to interact and, in this case, the party was the medium for that interaction. As Dennett argues, for memes to continue to exist, they need to remain in minds and spread through networks (1990). If a meme stops moving, it “dies” as people die;
moreover, having a network does not ensure that the meme moves. Dennett states that without a vehicle to spread a meme, the meme ceases to exist (1990); but a pathway for the meme to travel is also required.

Finally, HIV/AIDS is made increasingly relevant to these women as they go through medical school, participate in HIV/AIDS workshops, paint red ribbons on their nails, hear talks by people living with HIV/AIDS, and make plans to participate in local HIV/AIDS events. These discrete memories, memes, are tied together in their minds to form what they know of HIV/AIDS. A framework, a cognitive network comprised of memes, develops in individuals and spreads via social networks. These networks subsequently become a “learning network.”

The Power of Meme Absence

Whereas experiences like the manicure party reaffirm the relevance of HIV/AIDS awareness to the participants, lack of experience can reaffirm the perceived irrelevance of HIV/AIDS awareness to others. Unlike the people who participated in the events I attended, many members of the general public have not had the opportunity to actively engage with HIV/AIDS. When someone does not actively engage with a topic, the learning networks are comprised of more indirect and passive sources, such as images of emaciated AIDS patients that were common in the mass media in the 1980s. As we saw in Chapter 1, interviewees often associated HIV with AIDS, death, and being incurable. In addition, many were unable to recall what was taught regarding HIV in sex education (if they had it); some mistakenly thought that HIV could be transmitted by mosquitoes or was the same illness as hemophilia.64 HIV was often associated with promiscuous sex, or living a lifestyle that was “not normal.” Some interviewees cited the fact that they “don’t know anyone with HIV”, as rationale for the lack of importance of HIV research in Japan – even when they lived in areas with large per capital incidence and prevalence of HIV. In other words, little or no exposure to HIV-related memes that emphasized the biological and epidemiological realities of HIV/AIDS and/or the growing epidemic in Japan, paired with exposure to memes regarding “outside” risk groups (discussed in more detail below),

64 The mosquito question was asked by a male college student in a seminar on HIV in Kyoto; the hemophilia question from a male interviewee in his 40s in November 2010.
left them with vague ideas about HIV in general, and in their locale specifically, and included the following:

1. HIV=AIDS=death, or the wasting AIDS patient as symbolic of HIV
2. The “promiscuous” young female as HIV vector, as symbolized by the teenaged character from God, Please Give Me More Time who dies of AIDS
3. HIV as a “gay” or “foreign” problem (not a domestic issue)

Memes such as these led several interviewees to conclude:

“If you live a normal life, you won’t get HIV.”

These memes inspire fear and stigmatization of people living with HIV because 1) people are unsure of how the disease is spread and whether or not there is medication for it (despite the existence of both information and treatment), 2) people tend to equate HIV with lifestyles or behaviors different from their own (even though their own behaviors may be equally “risky”), and 3) people tend to associate HIV with risk groups and claim distance from such people (“I only have sex with Japanese” or “I’m not gay”) as protective against infection.

To summarize, memes, actively and passively integrated and transmitted, form the basis of what people know about HIV/AIDS. Because of the integration and transmission of particularly negative memes obscure the realities of HIV and allow people to feel separate from it, it is possible to consider that such integration and transmission are factors that put people at higher risk for contracting HIV. Medical anthropologists such as Briggs and Mantini-Briggs have shown how patterns of discrimination and blame (evident in actions, words, treatment, and imagery) contribute to epidemics of infectious disease. I build on this by describing how the patterns of information and disease transmission not only resemble one another, but they directly influence one another because of the ways that both information and infectious diseases travel through social networks.

Fuutsuuna seikatsu ni shitara, HIV ni naranai. 「封通な生活にしたら、HIVにならない。」

These answers were given by callers to HIV/AIDS help lines according to AF, field notes December 2010.
Networks and Network Theories

“Network” has been a buzzword in both academic and lay circles for the past several years. Educators have identified networks as important to pedagogy and to developing curriculum (Allert 2004; Trapajos 2003). Further, network analysis has been utilized by researchers specializing in relationships that engender the spread of HIV (Thornton 2008) as well as possible methods for the treatment and prevention of HIV (Neiagus 1998). However, most research focuses either on cognitive or social networks, and not the relationship between the two. For example, researchers such as Allert and Trapajos focus on cognitive networks important for learning, while Thornton focuses on socio-sexual networks. To remedy this, I discuss both the cognitive networks and the social networks involved when people learn about HIV/AIDS. I define and differentiate between networks in the following ways:

1. Learning involves both cognitive and social networks
2. Cognitive networks consist of memes
3. Social networks are pathways for the transmission of memes (human minds are the vehicle)
4. Culture influences transmission and integration

The HIV/AIDS “Learning networks”

I stood in the front of the room, facing the medical students and a few community members who had opted to spend their free Sunday at our workshop on HIV/AIDS. My role was to explain anthropology, medical anthropology, cultural parameters of health and illness, stigma and blame, anthropological perspectives of HIV/AIDS, and my research – all in two, 45-minute presentations in “easy English.” I started in, asking questions as I went; I found myself fueled by a level of audience participation I had hoped for but not expected. The audience members were engaged and inquisitive. At the close of my second talk, I showed a few pictures from the AIDS Candle Parade in Kyoto from the previous May and explained the event. “Actually, this is where I met Mari and Keiko, our organizers. And I also met Dr. Shirano, who is here with us today. I recommend that you participate next year if you are interested. Or, if you decide to
specialize in another area, try volunteering with a community-based organization like this one. You will learn a lot of things you cannot learn in the classroom.” (Field notes, November 13, 2011)

I built my talks with several ideas in mind. Learning is interactive and context-dependent. People learn readily when they can associate a new piece of information with other pieces that they already know, can associate it with a specific experience or person/people, and/or are exposed to a concept in multiple contexts. As they learn, their perceptions shift to accommodate new information. Factors like association and contextualization contribute to a person’s ability to recall what was learned, as well as one’s ability to relate a single concept to other, related concepts.

Thus, when giving the lectures, I related anthropology to other social sciences with which the audience members were familiar; provided Japan-specific examples of age, gender, and ethnic differences with regard to clinical visits; discussed stigma and blame with regard to cholera outside of Japan; and then finally discussed stigma, discrimination and blame for HIV in Japan. It was my goal to link what I know about the given topics to what the participants assumedly already knew through the workshop. In other words, I consciously transmitted various memes about HIV/AIDS to their individual cognitive networks through their social networks in a culturally appropriate manner (a medical lecture).

Considering the participants in the workshop, a series of educated guesses about how the information was processed can be made. The participants in the workshop were mostly medical students, so the topic of HIV/AIDS was not new to them. What was new was considering health, illness and HIV/AIDS in cultural context; theoretically, they were able to associate this new information to what they had previously learned and experienced through their studies. Moreover, the workshop was organized by fellow classmates, members they like and respect. Participants extended this respect and affection to the guest speakers, of whom I was one, and who they knew to be friends with both organizers, Mari and Keiko. In other words, they associated the new information with previously learned information about HIV; additionally, they associated the information and the event with Mari, Keiko, their classmates, and the guest speakers.
This multiple contextualization at both the cognitive and social levels should, in theory, lead to greater recall or greater impact of the information. Although I was not able to immediately gauge the effectiveness of this at the time in any way other than audience enthusiasm and expressions of gratitude that followed, I was able to determine there was at least some impact several months later. I return to this as the close of the chapter.

One interviewee in my rural field site proved to be very knowledgeable about HIV/AIDS, and equally reflexive about her learning processes. Her attention to detail and interest in learning in general prove valuable in that we can partially reconstruct how she learned about HIV/AIDS. Therefore, I use her experiences to illustrate my points about meme transmission and integration in learning networks.

Sato Misa* is a 28-year-old, vivacious, and sporty English teacher from a rural area a few hours from Tokyo. She asked if she could do the interview in English because she was applying for a new job and wanted the practice. She rides a motorcycle on her days off and likes to travel. She left home to go to a four-year university in an urban region, lived abroad, and now is back in her home state working full-time teaching English. When questioned about her basic knowledge of HIV/AIDS, her responses fit what is generally considered to be true of the illness in Japan: she listed all the infection routes, noted that prevention included education, condom use, and sex with a single partner, and stated that the rates of HIV are increasing in our area. Put simply, in terms of HIV/AIDS awareness, she was one of the most knowledgeable members of the general public with whom I spoke. She describes her learning experiences regarding HIV/AIDS as follows:

“I was in university... I think... like 20 years old. (About 2002) And I took a lecture about international something. And Wada Sensei used to work for Obuchi naikaku (was in Prime Minister Obuchi’s cabinet). And he, I don’t know why he mentioned HIV, but he tried to raise awareness among the students. And, we (referring to her friends) were really freaked out! ... We really talked a lot. We thought, we should just go and check [to see if we have it]. And then we’d know [our HIV statuses]. We made a call. And they told us when the facility was open. So we went there and did the blood test, and the results came out after two or three weeks. We had to go again and get the paper [results]. And there are not only young people but old men as well. And... it was so long
ago... but anyway, none of us had HIV. I think that was a good thing. But after that medical check, we, at least me, I changed my mind. We have to really have safe sex. You know?

... I really don’t remember whether I had that education, sex education about AIDS in junior high or high school, but I really remember [the class in] university... I also self-educated myself when I went to Canada, because where I was, there is a library and there are a few sections like AIDS section, HIV section, and I watched the videos. By myself. And that was interesting... I learned about HIV [and] also I, probably, consciously became more careful. All my actions. So, that’s why I watched... I just noticed that there were videos about HIV, and I was interested in HIV and AIDS a lot, so that’s why I watched. And there are a few, like, teenage kids in the video, actual people talking about their experiences with AIDS, and that was quite something. I guess you can’t really see that kind of video in Japan. So I just watched for my curiosity.” (Sato Misa, 28. December 5, 2010.)

Monobe and colleagues assert that people learn just as much, if not more, about particular subjects like STIs through “informal learning,” or experiences outside the classroom (Monobe et al. 2006); furthermore, the Japanese Association for Sex Education (JASE) survey from 1999 concluded that the sexual behaviors of young Japanese people are most influenced by information from the mass media (including television and manga67), while other research indicated a strong reliance on information from friends (Ikegami and Higashi 2005). Piecing together Misa’s experiences with HIV/AIDS, we can see how “informal learning” and interaction with her friends contributed to her knowledge base about HIV; we can also see how an intense emotional experience can trigger an ever-increasing interest in, and knowledge base about, a subject. HIV/AIDS education prior to university seems to have had little impact on Misa, regardless of whether it failed to be engaging or was absent completely. Her first memorable experience was one that inspired fear: she and her classmates were implored to get an HIV test by a professor they liked and respected. He reportedly told them, “If you’ve ever had sex, you should get tested!” Misa stated this came at a time when she

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67 Japanese-style comics.
had recently watched a re-run of *God, Please Give me More Time*, a television drama about a Japanese school girl who contracts HIV through prostitution that first aired in 1998. The young female protagonist dies of AIDS. Misa looked up test sites and got a test with her friends; sharing these experiences with them probably heightened her memory of it, and she could still recall the protocol and the various people she saw when they went to get their results. Afterwards, she was inspired to watch HIV/AIDS educational videos in Canada, which she viewed as special opportunities she could not have in Japan.

These experiences have connected in Misa’s mind, forming a synergistic network of memes related to HIV/AIDS in her consciousness – a “cognitive learning network” that becomes increasingly complex as she engages with HIV/AIDS individually and socially. She becomes more and more likely to notice issues surrounding HIV/AIDS with each new experience, partially explaining why she is acutely aware that HIV is a growing problem in her region. She noticed a short article about it in the newspaper and recalls seeing posters on the walls of her junior high that caution students about it. Even so, she comments that there is not enough information about it, people still seem unaware of it, and people do not talk about it. In other words, the establishment and maintenance of this HIV/AIDS cognitive network increases the likelihood that she will notice when it is discussed – *and also notice when it is not.* For example, she noted it was rarely discussed in her old school, and when it was, it was associated with blood rather than sex – probably because this was seen as more appropriate for junior high students.

However, as noted above, Misa’s grasp of HIV/AIDS is above average. This is also true for the medical students who participated in the workshop. So what is the average?

At the close of every interview, I asked interviewees if there was anything they wanted to ask me about HIV/AIDS, my research or myself in general. I meant this as a courtesy to them, as I usually spent 90 minutes asking them fairly personal questions. While I had expected people to ask about my motivations for doing this research, or perhaps some personal questions, most people used this time to ask me more about HIV/AIDS. They typically wanted information, to refresh their memories, or to find out
how to learn more. In fact, an interview with a well-educated, well-traveled 45-year-old businessman came to a close with this statement:

“I learned everything you told me a long time ago, but I forgot. I wonder why?”
(Matsukawa Shigeru*, 45)

Every interviewee could say something about HIV/AIDS. But almost no one had such clear memories about what they knew and how they learned it. I suggest this is due to a general lack of opportunities to engage with HIV/AIDS in direct, meaningful ways. They may hear about it, or look it up once, and then forget about it. Somehow, what they heard does not connect to other concepts or experiences they have had in a way that makes it easy to recall. In part, it is about quantity and the interval of time that has passed since they came across this information. But it is also about quality and intensity. Some kind of personal connection, or personalized meaning, is required. In other words, HIV/AIDS is part of the average Japanese person’s “learning network” to a lesser extent than is, say, general health, because they are not faced with it as often, nor have they been able to tie it to their personal lives or social interactions. In other words, they lack direct, active engagement with HIV/AIDS – and passive, indirect engagement seems to be decreasing, too. For example, the booklet about HIV/AIDS written by a large metropolitan health department (and featured in Chapter 1), states that, “The media pays less and less attention to eizu, so it’s being forgotten. How much do you really know?” (Kyoto City Social Health and Welfare Office 2012).

If people have few chances to actively engage with particular issues such as HIV/AIDS, which is the case in Japan, their understanding of that concept or the realities surrounding it remains fuzzy or blurred. This is exemplified in the misunderstanding that eizu=HIV=AIDS=death discussed in Chapter 1, and by a comment from a close friend, who lives in an area in which incidence of HIV is on par with that of Tokyo and Osaka, and who asked me,

“Why are you studying eizu instead of something that is everywhere like cancer? Eizu is so far away.” (Katagiri Mika, February 28, 2011)
Another possibility is that people, regardless of how many chances they have to learn about something, are influenced by a singular, shocking experience or image. For example, one interviewee stated that,

“My image of HIV is Magic Johnson. He got it when all those people were dying. I thought, oh, he’s going to die now, too. When people get AIDS they die.” (Nakata Azumasa, August 27, 2011)

It is a fair question to ask whether or not people from other countries are any different. In fact, I found that North Americans living in Japan and Japanese people who had studied for several years abroad had a much clearer sense of the biology and epidemiology of HIV/AIDS in general than did most of the Japanese I interviewed. For example, American college students on an exchange program to Japan were quick to say that HIV is the cause of AIDS, that you lose immune function and get sick, and that it is a sexually transmitted disease that can be prevented by using condoms.

In fact, some Japanese people commented that it was living abroad that forced them to consider difficult issues like sex and STIs in new ways. Mari confided that her mother, a medical doctor, had bought her condoms and made sure she knew how to use them before studying abroad. “She didn’t want me to go crazy!” she laughed (Field notes, November 11, 2011). And a 35-year-old Buddhist priest related a conversation he had had with friends while studying abroad: “Sex came up. I said, ‘Can’t we talk about something normal?’ And their response was, ‘Sex isn’t normal for you?’” (Field notes, July 26, 2011.) He realized that up until that point, talking about sex really hadn’t been a “normal” thing, and sex had not been a “normal” topic of conversation.

But foreign residents of Japan were just as likely as Japanese interviewees to mention shocking images or famous people associated with HIV/AIDS. A young female American undergraduate told me her image of HIV was blood on a basketball. “I love basketball and have watched games with my dad since I was little. After Magic Johnson got it, they were so careful whenever there was blood on the court. Stop the game, mop up the blood…” (Field notes, October 6, 2011). When asked about images of HIV/AIDS, foreign residents named Rock Hudson, Ryan White, and Freddie Mercury (all of whom died of AIDS), as well as Liz Taylor and Bono (who have both campaigned for HIV awareness).
Although these observations about similarities and differences between foreign expatriates or Japanese people who have lived abroad are anecdotal, they suggest that something is different between Japanese and non-Japanese learning networks on HIV/AIDS. The memes in these networks differ due to the ways people are encouraged to actively and passively engage with HIV/AIDS conceptually and socially, and in turn shape, and are shaped by, factors like politics (what information about sex is allowed to be taught to whom), education (what information is actually taught and how), and social norms (what the purposes of sex are and how to be a “good citizen” and how this influences politics and education) – in short, culture. In other words, cultural differences shape the content and the flow of information through both the social and cognitive networks that constitute learning networks.

**Memes and “Going Viral”**

With a working definition of memes in place, a sense of the limitations of the meme-gene metaphor, and a hypothesis for how memes become part of an individual’s cognitive network and move through social networks via interaction, I return to the concept of “going viral” to describe the movement of memes at the population level. As discussed above, “going viral” refers to the rapid pace – perceived as “virus-like” – at which information spreads through a network. It also has the connotation that the content provokes a strong reaction of sorts – which is part of the reason for the rapid spread. The content may contain something perceived to be damaging (as in the case when a video of wrong-doing surfaces) or the spread itself can be considered damaging (such as when politicians experience “bad PR”).

To what degree a meme is transmitted and integrated into learning networks is determined by several factors, including the degree to which the meme shocks the receiver by inducing extreme emotions such as fear, anger, or laughter-inducing glee. It helps if the meme is novel, short, and easily shareable via a network. Many of these concepts were researched and developed as marketing strategies in the 1990s (viral marketing). Mechanisms for active and passive spread and uptake are also required.

Consider a popular viral video, “David After Dentist,” in which a father records his son’s behavior and frustrations as he prepares to go home while still in a post-surgery,
anesthesia-induced haze. Uploaded in January of 2009, it has over 100,000,000 views. It was followed by a spoof (which also went viral and has over 13 million views) and several interviews with David and his family on network television. The video and the subsequent, related episodes sparked debates on whether or not people should upload videos of their children, the affects of anesthesia on young patients, and whether or not it was acceptable to laugh at a child under the influence of pain medication (in fact, over 20,000 people have “disliked” the video). It is impossible to gauge exactly how this video influenced viewers; however, there seems to be a significant number of people who, when they think of visits to the dentist, oral surgery, anesthesia, experiences with drugs, and children under the influence of drugs, will recall this video and possibly the issues surrounding it.

This video nicely illustrates the basic concept of the meme described above. “David After Dentist” is a distinct memorable unit, and is not inherently negative or damaging. It is short (two minutes) and easily shareable through YouTube and social networking sites. The everyday content ensures that a broad, general audience can relate to it, while at the same time engendering strong responses from viewers ranging from amusement, to sympathy, to anger.

But it is worth pausing to consider what this video is not, and how that also has contributed to its spread. For instance, “David After Dentist” is not staged. The filming had no underlying agenda. It was not, at first, intended to be seen by millions of people. These factors are part of its appeal; moreover, these factors are skillfully emulated in marketing. Despite the fact that commercials, for example, are staged, that there is an agenda, and that they are meant to be seen by millions, they are made to appear as innocent and everyday as “David.” What doesn’t go viral is complexity. Complexity confuses. I will return to this below.

*Extending the “going viral” metaphor: When information about a virus “goes viral”…*

Should the “going viral” metaphor, when applied to a meme, stop at the speed of transmission? Is this metaphor only applicable to the movement of information? Or, like a pathogen, are there other parameters to judge transmission? Can memes actually cause
disease? Of course not all memes “go viral,” and not all that “go viral” are considered to cause damage by all who are exposed to them. Nonetheless, some memes do “go viral” and some are harmful. Utilizing additional infectious disease-related terminology to discuss this, allows for a deeper, more academic, analysis of the “going viral” metaphor. Specifically, discussing “going viral” in terms of virulence, pathogenicity, co-infection, and syndemics can help us understand the ways that meme contribute to epidemics, so I illustrate first how they are used regarding HIV biologically, and then how they can be applied to memes about HIV.

**Virulence**

Virulence refers to a pathogen’s ability to spread. For example, cold viruses and influenza are generally considered highly virulent because they are easily spread through coughing and sneezing and remain active outside of the body, while HIV is considered to have relatively low virulence because it is spread through bodily fluids and becomes inactive quickly once outside the body.

HIV virulence depends on genetic variations of the virus and the human host, as well as physiological conditions at the site of entry into the human body. First, HIV developed from two separate strains of simian immunodeficiency virus (SIV), one from chimpanzees and ones from sooty mangabees – probably about one hundred years ago. Within these strains, there are multiple sub-strains, and these sub-strains have different characteristics. For example, some are more likely to be passed to fetuses during pregnancy than others.

Second, the genetic make-up of individual humans also plays a part in determining how infection with HIV affects people. It is premature to say that anyone is immune to HIV; however, specific genetic mutations, particularly those that code for proteins that comprise the chemokine receptors on the outside of cells, which allow the RNA particles to enter host cells, are likely to slow viral production and thus the progression to AIDS. In other words, human genetics play a role in how virulent a strain of HIV is in an individual, as well as at the population level depending on the frequency of “protective” genes.
Third, there is significant interplay between human physiology (the HIV “environment”) and HIV, particularly when introduced to the body during sexual intercourse. For example, consider that women who engage in unprotected vaginal or anal intercourse and men who engage in unprotected receptive anal intercourse (RAI) in particular are at higher risk for becoming infected with HIV. There are several reasons for this, including the fact that HIV essentially harnesses the immune response that is activated during intercourse. Penetration of the anus, vagina, or mouth can cause small abrasions, creating physical entry points for the virus; additionally, contrary to popular belief, use of lubricants may exacerbate this and make abrasions worse. Many lubricants\textsuperscript{68} are glycerin-based, and glycerin can damage or cause massive sloughing of epithelial cells that would have served as a physical barrier to the virus\textsuperscript{69}. The vaginal epithelial layer is very thin during menstruation and pregnancy (and generally thins as women age), which means that transmission may occur more readily at these times (Veazey 2012). Moreover, the presence of seminal fluid does two things: first, in women, it increases the pH of the vagina, temporarily inhibiting bacterial growth that may protect against infection\textsuperscript{70} (Herold 2012; Cone 2012); second, as a “non-self” substance, seminal fluid triggers an immune response\textsuperscript{71} (Herold 2012). This means that macrophages, T cells and langerhan cells are “called” to the region and are then basically in place to be infected. It is no exaggeration to say that once HIV is in the body, it can make rather efficient use of the body’s defenses to propagate. Therefore, behavior, physiology, and the immune response are factors in how virulent HIV is to an individual or society.

\textbf{Pathogenicity}

Pathogenicity refers to a pathogen’s ability to cause disease. Again, genetic diversity of the pathogen and the host are key factors with regard to HIV. Just as some strains are more virulent than others (more easily transmitted), some strains are more efficient at debilitating the immune system than others. This means that people with more pathogenic strains progress to AIDS faster than people with less pathogenic strains who

\textsuperscript{68} Lubricants are not evaluated by the FDA because they are not medicines. (Stahlman 2012)
\textsuperscript{69} Douches are also thought to contribute to the spread of STIs through cell damage (Stahlman 2012)
\textsuperscript{70} Lactic acid and peroxide producing bacteria are considered protective against HIV and gonorrhea.
\textsuperscript{71} The spermicide Nonoxynol 9, often used on condoms, causes inflammation that also triggers an immune response (Herold 2012).
live under similar conditions. In addition, some strains are more resistant to medication, and are thus more likely to impair the immune system (which causes disease). Further, as noted above, humans are also genetically diverse and some individuals may be less susceptible to HIV if the virus is unable to enter target cells. Thus, the same strain may be less pathogenic for one person than it is for another.

**Co-infection**

Co-infection refers to simultaneous infection by two or more pathogens (such as HIV and syphilis) or two or more strains of a pathogen (such as two strains of HIV) in an individual. Co-infection may lead to the emergence of newer, more virulent, more pathogenic strains of a single virus; it may also facilitate transmission. For example, syphilis lesions make it more likely that HIV will be spread through these open sores. Co-infection may also complicate treatment by forcing practitioners to prioritize infections, since simultaneous treatment may not be efficacious.

**Syndemic**

A syndemic refers to the co-occurrence of two or more epidemics in a population such that they act synergistically to damage public and/or global health. With regard to HIV, overall health status, the ability to access resources and medications, empowerment, and awareness are key factors that determine how being HIV+ effects daily life. People in poor health in general are less likely to able to physically tolerate medications even if they have access to them and take them regularly. In places where malnutrition, poverty, and violence are said to be at epidemic levels, outbreaks of cholera, malaria, tuberculosis, and various STIs may also be at epidemic levels. In this way, HIV/AIDS is one component of a sydemic.

**When Memes Go Viral**

Now that the components of “going viral” have been laid out, I explore how memes go viral using “woman as HIV vector,” a very tenacious meme in Japan, as an example. In 1986, it was reported – but not confirmed – that a Filipina sex worker with AIDS was working in a hostess bar in Matsumoto City, Nagano Prefecture (Miller 2002). This information was essentially a rumor, and was extremely virulent: it made local and
national news, prompted a slew of magazine articles and was labeled as the first “official” Japanese AIDS Panic (Miller 2002). Its rapid, extensive spread helped solidify HIV as a problem of foreign female sex workers – textually and visually – in the eyes of the general public and amongst HIV/AIDS education groups. Five years later in 1991, for example, a condom campaign encouraging Japanese (men) to protect themselves when they went abroad featured a foreign woman encased in a condom. The poster was created by the Japan Foundation for AIDS Prevention, which is supported by the Japanese government.

Recall that HIV virulence is relative and depends on genetics and physiological-behavioral factors. In terms of the virulence of the “woman as HIV vector” meme, the fact that this particular strain caused a panic and that it was officially recognized as such is indicative of its relative virulence when compared to other topics in the news. Furthermore, the use of dramatic terminology like “Japayukisan” who “give the gift of American AIDS” in some publications (Miller 2002) may have fostered the transmission of the meme considering the waves of men who sought HIV testing in Matsumoto following publication of such pieces. This is similar to the ways in which some strains of HIV are more transmissible than others because of their genetic make-up. And finally, the publication of rumors in both dailies and weeklies ensured that this information would be seen by a large percentage of the Japanese population, which mimics the ways in which HIV transmission is engendered by introducing the virus in such a way that it has the greatest chance of entering target cells.

So how pathogenic is the “woman as HIV vector” meme? Has it really been causing illness, or at least, encouraging the spread of HIV? Recall that viral and human genetics are factors in determining whether or not an infected person will progress from HIV to AIDS – the indicator that HIV has caused illness. The corollary here is that “woman as vector” meme has facilitated a discriminatory view of women that has also indirectly facilitated the transmission of HIV.

Consider that between 1986 and 2000, the people most likely to be diagnosed with HIV in Japan were hemophiliacs, the majority of whom are men, many of whom are heterosexual, and some of whom are married. Thus, HIV was first mainly transmitted
through blood products, then to partners of patients (who were mostly female), and then
to patients’ unborn children. (One such example is politician Kawada Ryuhei, whose
narrative appears in Chapter 6). Despite this, the media representations focused on cases
that included foreign women, Japanese women who had sex with foreign men, or women
perceived as “loose;” Japanese hemophiliacs did not make the news until they began
suing for damages in the mid-1990s.

The virulence of the “woman as vector” meme allowed the general population,
particularly men, to feel that it was women, particularly foreign women and those who
led “abnormal” sex lives, who had and spread HIV. This stigmatizing meme provided an
avenue for fear of and blame for the spread of HIV within Japan. At the same time, the
primary risk group, hemophiliac men and their families, were ignored and went without
the support they desperately needed. The spread of this inaccurate meme gave Japanese
men, particularly men who have sex with men (MSM), a false sense of security. Since
2000, the vast majority of Japanese cases of HIV have been amongst MSM, and
according to Ministry of Health, Labor and Welfare ninety-seven percent of the newly
reported cases of HIV in 2013 were in men. It can be said that the transmission of this
female-centered meme has indirectly fostered the transmission of HIV amongst Japanese
men.

In addition, it is possible to consider that members of the general public have been
co-infected with variations of the “woman as HIV vector” meme. Following the
Matsumoto Panic, which focused on foreign female prostitutes as HIV vectors, two
subsequent AIDS Panics focused on women made headlines. In 1987, the case of the first
Japanese woman to die of AIDS complications was taken up by the media and termed
The Köbe Incident, or The Second AIDS Panic. When it was hypothesized that she was
infected by her “foreign sailor lover,” the media ignored him and published her name and
picture (Cullinane 2007; Sato 2005). “Woman as HIV vector” became “Japanese women
who sleep with foreigners are HIV vectors.”

The Third AIDS Panic, also known as The Kōchi Incident, also took place in
1987. This time, the media focused on the first pregnant Japanese woman to be diagnosed
with HIV. She was reported to have contracted HIV from her hemophiliac partner, who
was again ignored. The woman was chastised for transmitting HIV to her innocent baby, and many people believed it would be better to have an abortion in the third trimester (which is illegal) than give birth to an HIV+ child. “Women as HIV vector” became “Japanese women can spread HIV to babies and innocents”.

Furthermore, a fourth strain surfaced in the 1990s in the form of the TV drama “God, Please Give Me More Time.” The heroine of the series is a young school girl who contracts HIV through “compensated dating” and dies. However, before her death she falls in love, has unprotected sex with her partner, and has a child – but neither the child nor the partner contract HIV. Although this is technically possible now due to advances in treatment, it was incredibly unrealistic at the time of broadcast. “Woman as HIV vector” became “greedy Japanese women who have sex for goods get HIV.” Again, the older salaryman who infected the school girl is ignored; further, the beloved partner with whom she has a child goes uninfected. It seems that the price of this school girl’s “greed” and “lack of morals” is HIV infection that culminates in death from AIDS. Thus, the combined message of all these strains of this particular meme is that women (foreign and Japanese) get and transmit HIV, while Japanese men are safe.

Further, co-infection with memes about sex, such as sex being strictly for family building (which is common in sex education programs, when they exist), condoms as birth control and not disease prevention tools, and condoms as “un-lady-like” by women and “mood killers” among men (Ikegami 2002), is also a factor. Family building and birth control may not be on the radar of MSM, who have the highest rates of infection; high incidence of HIV among Japanese in their twenties and thirties also corresponds to the “sex education bashing” by political conservatives that limited sex education in the early 2000s. In other words, the absence of messages about sex and HIV that are relevant to young people in school paired with erroneous memes about these issues in the mass media can contribute to HIV incidence.

72 What can be seen from the pattern of these Incidents is that the more difficult it became to describe HIV cases in Japan as occurring among foreign or sexually “deviant” Others, the more strongly women were blamed for the spread of HIV. MSW, the “norm” of Japanese society, were never the center of HIV attention; and neither were MSM, who have been marginalized to the extent that many Japanese deny their existence outside certain districts in Tokyo (McLelland 2000).
Framing co-incidence of the three AIDS Panics and memes about sex as co-infection, it is possible to say that these memes form a learning network in which the idea that women are considered vectors of HIV is instilled when HVI comes up as a topic for discussion. Such co-infection contributes to the spread of this assumption and the creation of new memes that support it. The results of a poster contest themed “In a Diverse World, Sexual Health for All” in Osaka in 2012 (discussed in Chapter 1) illustrate this point. Of approximately fifty-two posters, forty-four referred to HIV/AIDS in some way. Of those, two depicted men only, eleven depicted men and women, and twelve depicted women only. In other words, thirteen posters included male figures while twenty-three focused on women. These depictions ranged from women taking a “keep out” stance in relation to pathogens, to a naked woman with virus spewing from the genital region, to a woman smiling down at her blackened, dying infant with the words, “Mother, please notice!” Given that only ten of the cases of HIV/AIDS in the first quarter of 2013 in Japan were in women (compared to 350 in men), and that there was just one case of mother-to-child transmission, the focus on women is disproportionate in comparison with the reality of HIV/AIDS incidence; it also signals continued integration and transmission of variants of the “woman as vector” meme.

Finally, let’s consider syndemism. Recall that syndemism describes simultaneously occurring epidemics that have synergistic effects (2003). Homophobia, sexism, and ethnocentrism, amongst others, may be considered social epidemics; the spread of misinformation about HIV/AIDS or other illnesses may be bolstered by these “epidemics.” Miller alluded to this in the late 1990s, when she stated that the rapid spread of the “(foreign) women as HIV vector” meme was due to already ingrained fears about foreigners and women who did not fit the conservative/traditional stereotype. Expanding upon this, the fact that many Japanese deny the existence of homosexuality in Japan, the fact that gender equality lags behind, and the fact that notions of “Japanese uniqueness” (nihonjinron) continue to prevail, all work synergistically to allow the spread, by those (mostly men) who have political power, of the most damaging meme of all: “HIV has nothing to do with me, and if I live a ‘normal life’ I am safe.” Based on the vague phraseology that HIV “cannot be spread through everyday contact” in education materials and posters distributed by the Ministry of Education, Culture, Sports, Science
and Technology (MEXT), and interpreted as a disease of “abnormal” people who do “abnormal” things, this meme allows the heterosexual (often male) majority to blame foreign and “loose” Japanese women, forgets people infected through medical treatment and the Japanese institutions involved in that, ignores male participation in the sex industry, ignores Japanese men who have sex with men, and allows the general public to feel that HIV is not their problem or the problem of “good Japanese.” Codified in prescriptions and proscriptions of sex education and general education, these syndemics result in structural violence that fosters the spread of HIV and endangers public health: Japanese men who have sex with men continue to contract HIV, continue to transmit it, and continue to die of AIDS complications in urban areas. In the U.S. during the 1980s, activists often said that silence equals death, referring to the fact that not talking about HIV/AIDS would lead to transmission of HIV and death from AIDS. In the case I have outlined here, it is not just silence that is the problem. Rather, the transmission of particular types of information paired with silence about others, has fostered the transmission of HIV in Japan such that the biggest risk group (Japanese men) feels that HIV has nothing to do with them.

Discussion: Friends, Community, and Viral Information

Thus far, the discussion of memes, networks, and “going viral” has focused on the passive and active acquisition of memes, rather than on the people who actively spread memes. Of course, the distinction between the two in reality is quite blurred, because people both acquire and transmit memes; however, separating the two is useful in showing the mechanics of the processes. In this section, I discuss how community-based organizations work to combat memes they view as detrimental while recognizing that the messages they hope to spread can rarely be pushed to “go viral.” Rather, their message-memes must be transmitted in ways that are less visible than “viral” memes and are more akin to standard ways of learning, such as through school lessons that required sustained effort to absorb due to their complexity. Several of the groups I worked with do this by building upon or expanding social networks.
**Friends, Community-Based Organizations, and Cognitive Learning Networks**

The fact that there are venues outside of formal education settings to discuss HIV/AIDS in Japan is a result of the conscious actions of community-based organizations (some of which will be discussed in Chapter 4) as well as various government offices and NGOs. As noted above, not all memes are virulent or pathogenic; however, short memes with shock value that can be readily introduced to a network can be efficiently transmitted. So could the information put out by CBOs “go viral” to counteract viral, pathogenic memes? The truth is that information about something as complicated as HIV/AIDS, and training that might engender more critical assessments of information, are difficult if not impossible to package this way. Activists, therefore, find themselves working against “viral” information and images from television, magazines, and other forms of mass media such as those discussed above – without being able to utilize the mass media in the same ways.

Images such as the dying AIDS patient, female vector, or promiscuous individual as trenchant HIV-related memes in the social consciousness are difficult to combat, and local groups have been trying to educate at a more grass-roots level. Operating with the knowledge that information from *friends* was the second most important factor that influenced the sexual behaviors of young Japanese people, a group at my rural field site conducted its own survey, and found that most people in the area did indeed get information about sex and sexual health from their friends. They then opted to train students to educate their peers about HIV/AIDS and related issues such as sex and sexuality. The Happy Life Peers (HLP, pronounced help!) group leader Sano Chika outlined the need for this succinctly at an HIV/AIDS forum, “It’s good to talk with friends when you have a problem. But what if your peers have bad information? That is why we need to support peer education. We need to make sure people give their peers good information.” (Field notes August 2011). The group advocates a model in which high school and college students with an interest in sexual health study with older students and medical practitioners, and then pass on that information to their peers. They

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73 Support organizations such as NGOs, NPOs, and CBOs will be discussed in detail in Chapter 4. Here, it is important to note that such organizations of provide support that governments or businesses are unwilling or unable to provide.
advocate for improved sexual health by encouraging people to talk about sex, understand what behaviors can lead to transmission of sexually transmitted infections, use condoms to prevent disease and unwanted pregnancies, and support the reality of sexual diversity. The HLP model relies on the natural curiosity of young Japanese people, the presence of a receptive peer audience, and a source of “good information” – which at the present time is a select few established professionals who have agreed to work with the program. They engage the same group structure used in companies and schools in Japan, where senior members (senpai) support and educate the junior members (kōhai). However, teaching “good information” is not enough; as one interviewee pointed out:

“This generation uses the internet, and if they rely on information that happens to be wrong, it’s really dangerous... You also have to become a person who knows how to judge information – if it’s right or wrong. And if you don’t know, you have to ask. And you can’t just ask one person. You need to ask two or three people. Then you can find out for sure if it’s just a rumor or not...” (Mr. E October 23, 2011).

Teaching people how to distinguish between rumor and information – whether gleaned from conversation, the mass media or the internet – is an issue that must be considered by groups like HLP. Rather than simply teaching “correct information,” teaching skills to evaluate information is key, and this is one of the problems that has plagued Japanese education in general for decades (Rohlen 1983). Being able to critically evaluate sources and judge their content should make individuals more aware of the memes they face, and in turn the proliferation and spread of misleading memes should be less successful. But this approach is time consuming, and not at all amenable to transmission (it only allows for low virulence). Furthermore, balanced information about sexual health is often detailed and, by definition, not sensationalized. These factors also work against such information being easily transmitted. In lay terms, it is not likely to “go viral.”

Community-Based Organizations and the Social Learning Network

Concentrating on the social component of learning networks as a way of influencing individual cognitive networks like HLP does is an important start, and many other groups have followed suit. “I felt much better after going to the clinic and getting
information than just looking on the internet,” wrote a visitor to a metropolitan STI clinic. This comment, printed on a clinic brochure, illustrates the importance of both gaining information from a trusted source in person and having the space necessary for that interaction to occur. This detail has not escaped Ms. Shirasawa, a retired nurse at my rural field site who converted the first floor of her home into a community health center. She focuses on fostering social connections, although her intentions are much broader than the ones of the STI clinic. When I visited her home with Misa, whose experiences with HIV I detailed above, the importance of spaces like this and the impacts they have were clear:

Misa picked me up to take me to Ms. Shirasawa’s home and “health room.” The two of them had worked at the same school when Misa was a first year teacher. When we started talking about sex education in our interview, Misa had recommended her. “She really is a super nurse! She’s always helping people. I was lucky to work with her,” Misa comments as she drives. “Actually, after you finish talking to her, I have some things I want to ask her myself…”

We ended up lost in the labyrinthine neighborhood, and Ms. Shirasawa drove out to find us. It was easy to see why Misa calls her “super nurse”: for a tiny, gray-haired woman, she is bursting with energy. After finding us, she kept waving to us in the rearview mirror as we followed her home. We pulled into her driveway and were not even out of the car when she started enthusiastically greeting Misa, whom she hadn’t seen for some time.

Stepping into the entry of the house, Ms. Shirasawa ushered us directly into her center. Misa had told her about my interest in sex education, and she started pulling things off the shelves as soon as we entered: books for children and mothers, dolls with sex organs (she showed me that the female one “gives birth” by pulling out the placenta and baby), and finger puppets. The room has a full library, a reading corner, and a roundtable for discussions. “Anyone can come in here and ask whatever they want and not feel shy! They can learn at their own pace.”

She suddenly stopped herself. “Oh, we haven’t even done introductions yet!” She said, laughing. The two of us sat at the table while Misa curled up with a book.
I noticed a rack of beadwork on the table: cartoon characters, frogs, insects, cell phone straps. I pointed to it, and Ms. Shirasawa smiled. “Yes, a girl who comes here makes those. People can just come here. Maybe they need some place to go. This girl came in and brought her beads. She asked if she could sell them. I said sure. Well, another girl came in and saw them. She liked one and bought it, then left a message for the first girl asking if she would make her another one. They decided to meet, and now they’re friends! You know, this is a rural area and people should know each other, but they are not connected anymore. They are absorbed in things like the internet. They need more contact with actual people... And they need places where they can find information about health and their bodies. This space, those things can happen here.” (Field notes, January 29, 2011)

Ms. Shirasawa, having taught in municipal schools, knows what resources students have and do not have there. She is also in touch with the needs of parents, who are often unsure of what to tell their children about sex and sexual health. Most importantly, she is aware of the health needs of her neighborhood. In this case, what is transmitted or “goes viral” is her reputation as a caring community member and health educator, not any specific message about health. People come and find the information or companionship they need, and she has information on every health-related topic. She invites active engagement and provides the space necessary for it to happen.

Ms. Shirasawa also continues to engage in health education, particularly sex education, in the municipal sphere despite retirement. She is on the curriculum committee for sex education and is working to improve the clarity of sex education materials for elementary and junior high schools in the region. She is an example of someone who works to improve understanding of HIV/AIDS and health in general on multiple fronts, and through both cognitive and social networks – although just what “memes” she is spreading are tailored to individuals and specific settings rather than articulated in meme-bytes for large-scale consumption.

**Channeling the “viral” without the pathogenic?**

Building networks and transmitting complex information takes time. In theory, it should be possible to engineer a meme so that it can be a positive influence – to use viral characteristics to increase awareness, much like how microbiologists and geneticists have
found that retroviruses (the same family HIV is in) in the human genome may be mobilized to fight cancer (Matsui et al. 2010). Indeed, some groups have attempted to actively address HIV/AIDS through television dramas and movies. However, despite good intentions, such efforts may be problematic because information about HIV/AIDS is simplified and packaged as entertainment. Ikegami Chizuko from Place Tokyo had this to say about television dramas such as “God, please give me more time” that address HIV/AIDS:

“Those shows have merits and demerits. That one was in 1997, maybe. The merit: it was a popular show, so lots of people watched it. They realized it [HIV] was a sexually transmitted disease, and a lot of people got tested. But, the demerit is they associated the reason for sexual transmission as sex work, not love relationships. So it’s from ‘bad sex.’ With ‘bad sex’ you get an STI, but with ‘good sex’ you’re fine. There was that misunderstanding, that prejudice. If you got HIV, you were a ‘bad guy’ or a ‘bad girl’.”
(Field notes, December 9, 2010)

Here we see how programs can set up the framework for stigmatization and blame: only “bad” people who have “bad” sex get HIV/AIDS. Sometimes programs have these destructive memes built-in, unconsciously; sometimes people make associations the creators did not intend. These are the hazards of trying to increase awareness through entertainment. When asked about the quality of information about HIV/AIDS and the mass media, a trilingual HIV/AIDS counselor in Yokohama, gave the following answer:

P: “Where do you think they’re learning about HIV?”

A: “Television. And next is probably internet. Some comics or magazines, of course. But mainly internet and the television.”

P: “Do you think this information is accurate?”

A: “No. Unfortunately, I have to say it’s biased. For I guess especially those show biz people. They use that to become more famous I guess. They say, I’m doing a good thing! But those people really don’t know what they’re doing or what really HIV/AIDS means. That’s very sad. And I’m pretty disturbed about that.”
P: “If HIV prevention programs were up to you, what would you do?”

A: “I guess, I’m gonna have to use television.”

P: “So what kind of TV would you do? If the stuff they’re getting now is not correct...”

A: “No, I know. First of all, I’m gonna have to educate those people who are going on television. Like singers, actors, or speaking people, whatever, models, whatever. They’ve gotta have good HIV/AIDS education. They are gonna have to be willing to do that. Without getting paid. If they really wanted to do it, if they really think it’s very important, I’m gonna test them first! They have to know the truth, how serious it is. So they’re gonna have to get educated first. Then upon the condition of being educated, then finally, ‘Well, would you like to do that? Because somebody like me, if I do it, nobody listens. But if YOU did it, you have the power because you are famous.’ Then I’m gonna use their popularity... But those people have to really know. They have to reach the level that they can educate others. Otherwise, they should never do that. That’s my thinking. But then when I think about it, how many of those TV people would do that?” (Abbey Frew, October 2010).

Abbey acknowledges the power of the mass media and celebrities, saying he would like to harness the system and the fame of celebrities; but he also noted that few famous people in Japan are truly committed to HIV awareness and know enough about it to be part of a sustained campaign. Later in the interview, Abbey referred to HIV/AIDS advocacy by celebrities as a trend, not much different than other pop culture trends in Japan:

“They had the international conference on AIDS, the first in Asia, [in Yokohama.] It was the Tenth international, I believe. And that time, about 300 to 400 different organizations were established, posters everywhere. But in English. And those TV personnel people like singers, famous singers, and movie stars, those people were wearing STOPAIDS t-shirts. But they really didn’t know why or what it was. But because of that, you know people are talking about AIDS more frequently. Not as a truth, but a fashion. But better than nothing, OK. We hope if they know a little bit, they will study
further. To you know, find out what it is. Unfortunately, they don’t do that here. If it’s fashion, then ‘Ok, that’s finished.’”

P: “And then just finished, when the fashion is over…”

A: “And then they’re looking for another one, and they changed that. You know, like even food... like a trendy food. After 6 months, you can’t find it anywhere. That happens not only to food but people. Singers or talents. People get tired of it and they are looking for a new one.”

In describing the way that celebrities treat HIV as a trend, Abbey touched on the very same problem that public health officials have: sustaining awareness that HIV and other STIs are important. In Japan, television dramas are short and finish in less than a year, unlike American soap operas that can last for decades. Food trends change every season and every year. For example, Pepsi puts out an “original” cola every summer.

Abbey essentially noted that attention to public health issues can be the same if people do not see it as important. He contrasted this with the eco movement later in the interview, describing how people recently have stopped using so much packaging. But unlike environmental issues that are not going away and affect everyone, HIV seems “over” to many people – particularly since the close of the class-action lawsuits against the government in the late 1990s by people infected with tainted blood in the 1980s and early 90s (Ikegami 2010, Field notes December 2010). In fact, the media generally only runs stories about HIV/AIDS twice a year: in December for World AIDS Day and in spring when the yearly statistics come out.

Abbey highlighted another catch-22 in trying to use pop culture networks to do education: to be used for education, the people in the networks have to be educated and society has to be ready to hear the messages:

“[After doing a community education program, I think] Oh my gosh, how many of those people here really, really listened to us? Not with their ears but with their heart?
And what kind of other organizations, or what kind of crowds are we gonna have to

74 The word “talent” is often used in place of “celebrity” in Japan.
75 During the time the research was conducted, shiso (beefsteak leaf) and baobob (an African fruit) flavored colas were on the market.
target? But I have no answer because, OK, first you gonna [try to] protect younger
people [through education]. But then, society has to change. Society has to change so
that we can use TV commercials or we can use those big company names to do that, and
that’s the adults world, so we’re gonna have to educate them as well. Because they are
the ones who provide TV commercials and stuff. Even some of the Japanese TV programs
promote sex. I mean, not the right kind of sex. Risky sex. They provide that! So, again
that’s the reason my answer is not only young people, not only adults, but they have to do
it on many levels... Sponsors for those TV programs have to be educated. So that there
are so many people who have to be educated at the same time. And continuously.
Because times change. Generations change. So, it does not stop. There has to be a part of,
it has to be a part of the system. For society. That would be really successful, actually. So
well, but if you stop it, it’s stopped. Maybe ANY is invisible. Yet, just being here itself is
very important.”

Abbey knows television education would, in theory, be successful if it could be
carried out on a large scale with “correct” information and a receptive audience. And yet,
this is not realistic at in Japan at this point. Noting that his organization lacks visibility to
some degree – you can really only see it if you go looking for it – its presence makes a
difference by supporting those who call or visit, seeking information.

Both Ms. Ikegami and Abbey recognize the “merits and demerits” of using
existing networks such as television to help with HIV/AIDS awareness, particularly the
images that sell – both in terms of what images are “necessary” for the success
(consumption) of a show, and for the images of philanthropy that pop icons may use to
continue to sell themselves. Abbey in particular hints at the potential danger of celebrities
being connected to a specific “trend” like HIV/AIDS awareness once the initial hype is
past: without moving on, they, too, may fall out of the limelight. Without being
constantly integrated and re-integrated into the public consciousness in novel ways, they
are lost – just like knowledge of HIV/AIDS is. Thus, like retroviral therapy, attempts to
use the networks that allow for “going viral” for more complex, educational purposes are
having difficulties moving from theory to practical application.
**Memes and Precarity**

From the standpoint of HIV/AIDS activists and epidemiologists, there are two threats to Japanese society to be dealt with: the spread of the virus itself and the spread of misinformation about it. Public health is precarious when HIV/AIDS incidence increases; because misinformation can contribute to incidence, it also contributes to the precarity of public health. To mitigate this precarity, to mitigate the threat HIV poses to public health, the ways in which Japanese people think and behave must change. Indirect engagement through vague terminology and inaccurate memes could be replaced by more active engagement such as that advocated by HLP and Place Tokyo.

As Butler has argued, breaking precarious patterns requires changing not just the information people are exposed to, but how they evaluate it (2004). However, as we have seen in the examples above, this takes time and cannot be done en masse by engineering “educational information” to “go viral” and counteract “pathogenic memes.” As Ikegami demonstrates, messages about HIV/AIDS in entertainment are primarily that – entertainment. As such, messages have to be simplified and, as a result, can give people stereotyped impressions of the illness that are more damaging than helpful. Abbey describes another problem: that to educate about HIV/AIDS in a meaningful way on television, the audience must be ready to hear the message – and many of them are not. For example, conservative governments often put extremely tight restrictions on sex education (Monobe et al. 2006), but are less likely to restrict sex in television and manga (Ikegami, personal communication 2010). Therefore, it seems that the complexity of HIV/AIDS educational messages, the contradictory goals of education and entertainment in the mass media, and the lack of preparedness in the public audience make engineering “educational memes” in the mass media incredibly difficult.

Because of this, there are a number of groups and individuals, such as Ms. Shirasawa and HLP, that are attempting to draw attention to HIV/AIDS and sexual health in innovative ways. Given their grass-roots popularity, lack of connection to governing bodies (which can impose conservative restrictions), and adaptability to local people, it seems that these efforts are likely to foster increased attention to HIV/AIDS in non-stereotyped ways. In turn, these efforts may garner enough support to make it possible to
harness the mass media in more productive ways than has been possible in the past. In other words, mitigating precarity through direct engagement may have to happen at the local level (small scale) and move to the national level (large scale), rather than the other way around. For example, NHK has recently started a series called “Connecting Hearts,” which highlights different types of lifestyles in Japan, documentary-style. In 2010, this included a segment on living with HIV and highlighted some of the people who work at Place Tokyo, the first HIV/AIDS-related organization in Japan (which is profiled in Chapter 4). This was likely made possible by the twenty years of grassroots work NGOs like Place Tokyo have put into the community. Little by little, “pathogenic memes” can be, and are being, broken when Place Tokyo and HLP opt to mitigate the fear of HIV/AIDS by talking about it directly and encouraging members of the general public to talk about it, too.

The researcher in the network

“Um, excuse me… Pamela? Do you remember me?”

I turned to face a young woman who had approached me at the PLANET Candle Parade in Kyoto. I greeted her, and my mind started going through the mental files of where I could have met her. Her face was familiar, but I just couldn’t place her. I’m terrible at hiding these things, and she noticed.

“It’s okay, there were a lot of people there. Mari is my classmate… I was at the workshop you organized with her at our school,” she said graciously. THEN I remembered. “Many classmates wanted to come today, but a lot have exams.” We talked for a few more minutes before starting the walk.

While walking with my candle in hand, I recalled telling the students how I met Mari and Keiko at the walk last year, how they could get hands-on experience with medical issues working with local groups, and how I closed my talk with a picture from the 2011 walk and a comment that I would love to see them at the walk this year. And here was this young woman and several of her friends. The organizer had given them the job of passing out information to the people we passed on the sidewalks. With bright eyes

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76 The program is called hāto wo tsunagō (「ハートをつなごう」) in Japanese.
and smiles, they handed out bags with information about HIV and other STIs, STOP AIDS bracelets, red ribbon pins, and condoms. (Field notes, May 19, 2012.)

When you work as an educator, you often do not know exactly how you have influenced your students. You hope for the best and try to avoid making mistakes with the subject matter or with the students. The same is true for researchers and members of the community in which they live. Although the dissertation is evidence to the effect that my interviewees are part of my social and cognitive networks, it was also obvious to all of us in the project that I am part of the social networks of my interviewees; interacting with at least some of them caused shifts in their cognitive networks. This is not always discussed, and it is not always necessary to discuss it. But in this case, people saw me as a teacher and asked me questions during interviews, so I answered them as best I could and gave them brochures on sexual health when they expressed interest. I taught formally when asked, and found myself face to face with participants I had met in November at the Candle Parade in May – although Mari and Keiko had also been instrumental in encouraging these students to come. And sometimes my own information came back around to me. For example, I interviewed a friend of a friend who told me that HIV was increasing in our area. I asked her how she knew. Our mutual friend, who had asked me about my research a week ago and had been unaware of this fact until I mentioned it, had told her. As Ambros notes, it can be important to emplace the researcher (Ambros 2009), to acknowledge that the very presence of the researcher may mean something to other people involved. Every teacher has students who may forget the lessons taught but remember the teacher; conversely, some may remember the lessons but forget the teacher. Some may forget both, but still be influenced in some way. When there is evidence that a teacher/researcher has been influential, it should be acknowledged; in research, it should be explained, particularly when the actions of the researcher have a visible impact on the interviewees.

Conclusions
Whereas I illustrated the significance of the vagaries of the term eizu in the ongoing HIV/AIDS epidemic in Japan in Chapter 1, in this chapter I focused on how the spread of specific memes also fosters the spread of HIV. In order to make meme a
functional term for this discussion, I returned to Dawkins’ original uses of the term, divested it of the evolutionary basis that is used by sociobiologists such as Plotkin and Dennett, and expanded its lay meaning. Then, based on data from interviews, participant observation and previous research, we can draw a number of conclusions about HIV/AIDS related memes. For example, HIV/AIDS-related memes may or may not go viral and some are more influential than others, such as “woman as HIV vector” versus condoms for disease prevention. Transmission and integration of memes may have “positive” or “negative” outcomes such as increased HIV testing versus the spread of inaccurate information. Not all memes travel rapidly through a population (if at all); they may simply influence members of a small group, such as the memories of those who attended the manicure party. Memes are both actively and passively acquired and transmitted. For example, memes may enter cognitive networks through activities such as painting a red ribbon on someone’s fingernails (active) or seeing someone’s red-ribbon manicure as she pays for her lunch (passive). However, viral memes about HIV/AIDS rarely convey complex, accurate information.

Drawing from the work of several network specialists, I also showed how memes work synergistically in the minds of interviewees to form their cognitive networks about HIV/AIDS, and spread though people’s interactions in social networks, the combination of which I term “learning networks.” Understanding learning networks and how they are formed helps us understand how individual people know what they know and how that information moves. Moreover, it helps us understand what they do not know or remember based on what is not present as well as what is not transmitted. This expands upon the “epidemic of signification” theories by Treichler by acknowledging how gaps in people’s knowledge allow for the spread of misinformation. The spread of problematic memes, such as HIV being spread through sex work as highlighted by a television drama, can also set up the frameworks of stigmatization and blame: associating HIV with sex workers provides an outlet for blame in the same way that Briggs and Mantini-Briggs showed that indigenous people in South America were blamed for cholera epidemics (2003).
From there, I expanded the meme-virus metaphor to illustrate how particular phrases and images have become part of the popular consciousness. But in addition to illustrating the patterns of blame and the cultural factors involved in building them as Briggs and Mantini Briggs do (2003), discussion of how memes about viruses goes viral makes it possible to illustrate the ways in which information about HIV and the virus itself meet in human bodies. To do this, I used the terms virulence, pathogencity, co-infection, and syndemic to expand the lay concept of “going viral,” noting that some information “goes viral” while other information does not. I also showed that even if information is less amenable to “going viral,” it can contribute to changes in the cognitive networks of those who choose to engage directly with HIV/AIDS, such as HLP members and participants in the manicure party, and can be transmitted in novel ways so that even people who have previously engaged with HIV/AIDS only indirectly may learn more about the conditions. Efforts to increase direct, active learning about HIV/AIDS can mitigate the threat – the precarity – HIV presents to Japanese society. Such efforts by an increasing number of activists may suggest that Japanese people may be more and more willing to discuss HIV/AIDS openly and directly if given the chance to do so in “safe” settings. Finally, I discussed how my becoming part of the social network in the field influenced how interviewees and other members of the community conceptualized HIV/AIDS.

Although grass-roots organizations are making sustained efforts to improve awareness of HIV/AIDS and sexual health by pushing for more direct engagement with these topics, this is not a simple endeavor because most Japanese people are uncomfortable with these topics. In fact, abandoning indirectness often proves difficult. In the next chapter, I describe how memes like the ones described here may be writ large in museum exhibits, noting that even when efforts are made to encourage the public to learn about HIV/AIDS, the “packaging” of the topic still allows people to perceive it as something that is “someone else’s problem.”
Chapter 3: Representing and Exhibiting HIV/AIDS: Memes Writ Large

“What a change to go from the busy streets, crowded with well-heeled young couples consuming products from Chanel, Hermes, and the like, to the gallery where Magnum Photos and the Global Fund to Fight AIDS, Malaria, and TB are showing an exhibit on the recovery of people in developing nations who suffer from these illnesses. In contrast to the noisy, glamour-filled streets, the 11th floor is gray and tomb-like. The two rooms utilized for the exhibit are filled with an absence of the energy below. Few dare to even murmur comments about what they see in the photos. And what do they see?

I know what I see.

From my vantage point, I am overcome by the level of poverty and the seeming lack of choice in these patients’ lives. Their homes and lives couldn’t be more different from the shops in Ginza below and the people in them: many precariously built one-room homes, some larger and more stable-looking homes, one of them what I would call moderately middle class house by American standards. The people are Africans, Indians, South East Asians, and Russians: Others by geographic location, ethnicity, and/or social class. I’m left with questions, criticisms, and a desire to find out more about this exhibit, to dig deeper.

I’m wondering how what I saw differs from what the other visitors saw? Do they want to dig deeper? Do exhibits really do that to people?” (Field notes, September 12, 2010)

By happenstance, the “Access to Life” exhibit described above was held in the Ginza area of Tokyo during the first month of my fieldwork. I was doubly lucky in that a colleague alerted me to it just before I headed to Tokyo for a trip. Although there was no PR about the exhibit where I lived, he somehow had heard about it in Boston and emailed me about it. That email at the beginning of my time in Japan set the stage for my whole project because going to “Access to Life” got me thinking about how specific perspectives of HIV/AIDS are constructed and consumed. Upon entering the exhibit, for
example, I could not help but notice how effectively the photographs worked to represent a particular interpretation of HIV/AIDS, the stark difference between the people in the photographs and the audience members who viewed them, and the worlds-away feeling between Ginza and the communities portrayed. These distinctions jumped out at me, and left lasting impressions as I continued my field work.

My luck continued over the next few months. I was able to view two more exhibits that highlighted HIV/AIDS to varying degrees. “Love’s Body” opened at the Tokyo Metropolitan Museum of Photography, and the permanent exhibit at Liberty Osaka, which includes a display dedicated to HIV/AIDS, was updated. The same issues – representation and interpretation, us/them distinctions, and the importance of the location and space in which these interpretations took place – continued to recur, despite differences in audience, organizers, goals, and financial and political support.

Because I had not set out to analyze museum exhibits, my engagement with them was relatively haphazard at first. I took notes about what I saw and how I reacted, gathered brochures and catalogs, and observed the audience as best I could. I got my courage up and contacted the curators, and they were all gracious enough to grant me interviews. I did not interview audience members because the temporary exhibits appeared on my radar so quickly; when I visited the permanent exhibit, I was often one of the only people there. I attempted to make up for this later by reading reviews. In hindsight, I wish I had focused more on being the interviewing anthropologist than the engaged audience member; however, print materials and curator interviews provided plenty of data for analysis of the most common ways to represent HIV/AIDS in Japan.

What ultimately becomes clear when sifting through the particulars of each of these exhibits is the variety of perspectives of HIV/AIDS that are possible – and that it is not possible to cover each perspective in every exhibit. Focus or specialization is required. Organizers already know this (Alpers 1991). They know that representations are precarious because trained focus on a particular aspect of an issue excludes or minimizes other aspects by design, possibly to the point that viewers become unable to see them; on

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HIV-related exhibits are rare events in Japan; since viewing these exhibits, I have not seen notification of any similar efforts in the past three years.
the other hand, attempting to show everything dilutes the importance of a particular aspect and may make little impact. Thus, how much information, how much context to provide to a busy, impatient audience becomes a struggle for the most conscientious of organizers. There is always a danger of exhibiting too much or too little\(^78\), and either can cause the message organizers hope to portray to be lost.

Representation is, therefore, precarious; but representations can also engender or mitigate precarity. Recall from the Introduction that precarity is about constant change, the power or lack of power to make choices (perceived or actual) and dependence on anonymous others. By representing HIV/AIDS in a particular way to a particular audience in a particular space and place, a very specific message or set of messages is made public and becomes part of what I described in Chapter 2 as a “learning network.” Exhibits are constructed of memes and become spaces in which memes are writ large as the public is invited to experience them. What people experience influences how they interact with others. What people experience at HIV/AIDS exhibits shapes what they know about HIV/AIDS, the people who have it, and the places where it is a visible problem. It encourages them to associate the illness with countries, ways of living, and actions people chose to make or were forced to make. These experiences result in judgments about the people portrayed, with either positive or negative results. For example, people may become more or less accepting of people living with HIV/AIDS depending on whether or not they view those portrayed as choosing a life that led to infection or as simply being victims of circumstance. These judgments can translate into supportive or discriminatory behaviors, such as financial support of HIV/AIDS initiatives or the firing of an HIV+ employee. These behaviors then directly influence a sense of felt precarity in both the audience as they view the exhibit, and people living with HIV if their livelihoods are made better or worse through the audience’s assessments and actions. Speaking in general terms, Morris-Suzuki describes this interplay between photography and social memory this way: “Photographs influence the way people remember and understand the past; but the way we take, see and respond to photographs is in turn shaped by social forces”(Morris-Suzuki 2005:82–3). Therefore, there is a sense of

\(^{78}\) “Too much or too little” is a simplification here. Quantity per se is not necessarily the issue – the “how” and “how much of what details” and “in what context” are important considerations.
precary at every level of production and consumption of an exhibit, from photographing and being photographed, selecting photographs, putting them in an order, giving them context and captions, and advertising and presenting them to the public.

In this chapter, I illustrate how photography, concepts of “us” and “them” inherent in photographs, and the places photographs are exhibited shape representation in general, and representations of HIV/AIDS specifically. I also illustrate the extent to which particular HIV/AIDS-related memes exist in Japan, and how exhibits such as the three detailed here function as spaces where such memes are “writ large” and thus act as vehicles for them to “go viral.” To do this, I discuss a fine art exhibit, a photojournalism exhibit, and a local history exhibit in terms of disciplinarity, representation of Others, and location, respectively. In doing this, it becomes clear that despite what we can label “active engagement” with HIV/AIDS in comparison to the avoidance or passive engagement at detailed in Chapters 1 and 2, these exhibits are still characterized by indirectness. In much the same way that the term eizu engenders vague discussion of HIV and AIDS and the spread of particular memes obfuscates epidemiological realities of HIV/AIDS, museum exhibits in Japan rely on audience members to draw associations between the conditions and risk groups indirectly. For example, particular pieces become HIV/AIDS pieces through titles or proximity to other works, such as a thematically vague video being included in “Love’s Body”; risk groups are indicated through the placement of pieces and the absence or downplay of specific groups of people, such as the absence of global north examples in “Access to Life” or the shifting placements of PLWHA displays in “The Brilliance of Life”.

I begin with an analysis of disciplinarity in “Love’s Body.” I provide the context of the curator’s previous exhibits, her goals in disrupting the genre of the nude and social constraints on the body, and photography in general. Drawing on Ogura’s assertion that the message in photographs, not just the image itself, “changes with possession and repossession” (1998:180) and Berger’s argument that the order and placement of art in an exhibit are meant to express a distinct message (even if the curator claims interpretation is open to the viewer) (1977), I am able to highlight how the discipline of fine art photography both allows the curator to put forth a powerful critique of what is considered
to be a “normal body,” and yet limits what she considers to be fine art photographic representations of HIV/AIDS to those trained in western techniques. Describing the inclusion of Cho Yukio’s video and figurines, I also show how works may only be recognized as “Art in the Age of AIDS” when viewed with the other works in the exhibit and/or under the English language title of the exhibit because of the vagaries in the work and in the Japanese language exhibit title.

Second, I examine “Access to Life” in terms of us/them representations. Here, I highlight the ways in which the practical, political, and financial goals of the sponsors and organizers combined to produce an exhibit that rather forcefully juxtaposes those living with HIV/AIDS in the global south with affluent Japanese people. Following Baxandall’s assertion that “there is no exhibition without construction and… appropriation” (1991:34), I argue that while this method of focusing on what “we” need to do for “them” is effective in achieving the goal of garnering funds for ARVs, it ultimately promotes the stereotype of HIV as an illness from “somewhere else” and disallows the audience to consider the rising number of HIV/AIDS cases amongst Japanese people – which are, ironically, particularly high in Tokyo, where the exhibit took place. Further, I argue that failure to include information about HIV epidemics in the global north in this exhibit encourages audience members to simultaneously engage with HIV/AIDS indirectly through exoticized Others and avoid discussion of epidemics amongst minority groups within their own societies.

Third, I analyze the re-making of “The Brilliance of Life,” the only permanent exhibit of the three HIV/AIDS exhibits reviewed here, in terms of political location. Following Crimp and Lawler’s assertion that site specificity is “political specificity” (1993:182) and that particular museums have specific identities as memory repositories (Crane 2006) (Conn 2006), in this section I focus on the geographic significance of the Liberty Human Rights Museum (LHRM) in Naniwa, Osaka. Located in an area widely known to be a former outcaste site, LHRM was first constructed as a tribute to those who participated in the leather trade in Osaka and, due to their work with blood and animal products, were considered unclean. Over the years, LHRM has become a center that promotes diversity and the human rights of minorities in Japan, which includes people
living with HIV/AIDS. However, municipal sponsorship of the museum shapes the ways the museum is allowed to package these messages. Thus, the HIV/AIDS display (and all others in the museum) is the site of dynamic conflict between ultra-nationalist politicians, curators, and local communities and as such illustrates just who wields the most power at a given time. I also argue that indirect linkages due to spatial placement of the HIV/AIDS display and other displays within the larger exhibit, which change over time, is indicative of how sponsors viewed HIV/AIDS in relation to patient rights and/or the rights of sexual minorities at different times.

Because all exhibits are manifestations of particular ways of seeing on the part of artists, curators, and organizers, they indicate disciplined “gazes” akin to the medical gaze described by Foucault. Whereas Foucault essentially asserted that medical training changes the way the body is viewed such that the disease rather than the patient becomes the focus, training in fine art, global health, and politics leads people to view HIV/AIDS in very specific ways – ways that are passed on to audiences through their viewership at exhibits. By definition, the gaze is trained on an element or set of elements to the exclusion of others; therefore, a holistic view of HIV/AIDS only seems possible when a multitude of exhibits are experienced. However, it may be possible to adjust these lenses such that the representations are contextualized; thus, following Marzio’s assertion that criticism can engender improvement and awareness and fight “apathy and disregard” for minorities, I give some suggestions about how this may be done (1991:123). In the conclusion, I discuss the connection between the disciplinarity and consequent gazes behind each of these exhibits, how they encourage direct or indirect engagement with HIV/AIDS through the uptake and spread of some of the memes described in previous chapters, and their roles in mitigating the precarity posed by rising HIV/AIDS rates or the precarity posed by the fear related to it.
“Love’s Body: Art in the Age of AIDS”

「ラヴズ・ボディー 生と性を巡る表現」

“Love’s Body” was a temporary exhibit unique to the Tokyo Metropolitan Museum of Photography in the Ebisu neighborhood of Tokyo. It was curated by Kasahara Michiko, the chief curator, who is fairly well-known in the art world for her expertise on fine art exhibits that focus on the body. This particular exhibit featured seventy-eight works by artists William Yang (Australian), AA Bronson (Canadian), Sunil Gupta (Canadian), Cho Yukio (Japanese), Felix Gonzales-Torres (Cuban), Herve Guilbert (French), Peter Hujar (American), and David Wojnarovicz (American). All of these artists work with HIV/AIDS as a subject matter in some way, and the latter four artists died from AIDS-related causes; however not all the pieces engage HIV/AIDS directly. The works span from 1976 to 2010, and include both black-and-white and color photographs of people, scenery and scenes from everyday life. A short film, figurines, and a light installation were also included. The basic goals of the exhibit were to encourage public engagement of social issues such as sexuality and HIV, while at the same time “present[ing] works that are powerful enough to… influence aspects of art and photography while reappraising and redefining their meaning” (Kasahara 2010).

The exhibit was open from October 2 to December 5, 2010, and about 23,000 people attended (360 people a day). The target audience was people who lack awareness about HIV/AIDS. Special events included Couples’ Day, where both same-sex and opposite-sex partners could gain entry with two-for-the-price-of-one (800 yen) tickets, floor lectures for college students who came with their classes, and a poetry reading in which local celebrities read works by HIV+ individuals. During the interview, the curator commented that she hoped the exhibit would give Japanese people, particularly young Japanese, the chance to talk about sex, sexual health and HIV since they don’t get many chances to do that in school. She felt the exhibit was moderately successful but would have liked to see another 7,000 people or so visit (Field notes December 2010).

79 “ラヴズ・ボディー 生と性を巡る表現” Translation: “Love’s body expressed through life and sex.”
Organizers included the Tokyo Metropolitan Museum of Photography, the Tokyo Metropolitan Foundation for History and Culture (the parent organization of the Museum), and the Asahi Shimbun. Supporting organizations included the Japan Arts Fund, the Ishibashi Foundation, the Asahi Beer Arts Foundation, the Asian Cultural Council, the Australian Embassy, and the United States Embassy. Sponsors included the Nikon Corporation, Nikon Imaging Japan, Inc, Shiseido Co, Toppan Printing, and the Corporate Membership of the Tokyo Metropolitan Museum of Photography. The exhibit was produced in cooperation with Asahi Breweries, Kyoto Seika University, community center akta, The Westin Tokyo, and Tokyo FM. Community center akta and JaNP+ both work directly with local people living with HIV/AIDS and were included in production. These groups most likely assisted in the dissemination of information about the exhibit.

The museum itself is affectionately known as Shabi in Japanese (short for shashin bijutsukan), and opened in its present location in 1995 after five years at a temporary location. It is supported by the Tokyo Metropolitan Foundation for History and Culture (TMFHC), which also supports several other museums. Shabi specializes in collecting, preserving, researching, and restoring still and moving images; it is unique in that its collection includes the work of a number of both foreign and Japanese photographers and videographers – most other museums of photography in Japan focus on a single artist (Tokyo Metropolitan Foundation for History and Culture 2013); this suggests an international sensibility that may have factored into Shabi’s interest and ability to put on eclectic and sophisticated exhibits such as the “Love’s Body” series. The building has the capacity to put on three separate exhibits simultaneously, and the museum consistently puts on around twenty exhibits/events a year. Exhibits range from fine art photography exhibits to photojournalism exhibits. Exhibits may be comprised solely of photographs owned by Shabi, solely photographs owned by other parties, or a combination of both. In the case of “Love’s Body” for example, the curator selected photographs from Shabi’s archives and borrowed others from private collections and galleries abroad.

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80 These include the Teien Art Museum, the Museum of Contemporary Art, the Metropolitan Art Museum, the Edo-Tokyo Museum, the Open-Air Architectural Museum, the Tokyo Bunka Kaikan (a concert hall), Art Space, and the Tokyo Wonder Site.
Shabi is located in the Ebisu neighborhood of Tokyo. Ebisu is known for its upscale and “Western” atmosphere, which is due in part to the Yebisu brewery\textsuperscript{81}. When it began using German techniques and materials to produce beer in 1890, the brewery adopted the name Yebisu, one of the seven gods of fortune\textsuperscript{82}. The region became Ebisu after the beer production by this company, and Ebisu Station was built to transport Yebisu Beer (Pearce, Yamamote, and Ariga 1976). Ebisu and Sapporo beers are still brewed there, and a gleaming gold statue of Yebisu himself greets visitors to the Yebisu Beer Hall. In keeping with this region’s “Western” ties, Ebisu Garden Place was erected in 1994 and features vast brick walkways and western-style buildings. Considered a sophisticated place to spend the weekend hours, wealthy Tokyoeites walk their dogs through the square, stopping to let onlookers admire and pet their rare pooches. Concerts featuring foreign musicians are common. While visiting in summer 2011, a “Hawaiian Culture Festival” was in full swing: shops featured “Hawaiian” goods, Japanese children performed hula while their mothers (clad in tropical print dresses) looked on, and signs advertised a Jake Shimabukuro concert.

Given this atmosphere and the history of photography in Japan, it is not surprising that Ebisu was deemed an appropriate location for Shabi. The importation of photography materials, techniques, and systems of evaluation pre-date the importation of beer-brewing techniques, but not by much: the first camera passed through Japan in 1843, and the first one to remain in Japan came through the Satsuma domain in 1848 (Fraser 2011). The first photo studios were opened just prior to the Meiji Restoration in the early 1860s in the port towns of Yokohama, Nagasaki, and Osaka (Fraser 2011).

Both Sontag (2001) and Berger (1977) note that photography in general was first considered high technology rather than fine art, and the trajectory was similar in Japan. This is illustrated by the actual Japanese characters for photograph, \textit{写真} \textit{shashin}, which

\textsuperscript{81} The company opted to keep the archaic Yebisu, while the sound “ye” was converted to “e” in contemporary speech. Examples include the surnames “Ueda” and “Uehara”; emigrants who left Japan prior to the change may still spell their names “Uyeda” and “Uyehara,” respectively.

\textsuperscript{82} Ebisu is derived from Yebisu, one of the seven gods of fortune (Pearce, Yamamote, and Ariga 1976). He began as a fishing deity and protector of livelihoods, but morphed into a more general god of commerce around 1100. He is usually depicted as a portly figure wearing hakama, a kimono, and a folded hat who smiles broadly with a fish in one hand and a fishing pole in the other.
literally mean “reflect truth.” Further, a photographer was called 写真師 shashinshi in which the final character is the same as for doctors (医師 ishi) and teachers (教師 kyōshi) and indicates a technician or professional of sorts, someone with some level of skill mastery (Fraser 2011), rather than the contemporaneous 写真者 shashinsha, in which the final character simply means “person.” Essentially, photography came into Japan as the country moved towards becoming a modern nation-state through changes in government, technology, and art and developed along similar trajectories as it did in other countries in that fine art photography, photojournalism and amateur photography gradually became part of Japanese culture. Additionally photography as fine art is evaluated according to a rubric of aesthetics much like it is in other places.

The genre of the nude is a good example for our purposes here because Kasahara specializes in artwork related to bodies, and the 2010 exhibit was actually a continuation of a “Love’s Body” exhibit she put on in 1998 that featured nude images. Thus, a brief explanation of both the nude genre and Kasahara’s 1998 exhibit is necessary before analyzing the 2010 exhibit.

**Fine art Nudes in Painting and Photography**

The Nude as a genre was first established in painting and has been distinguished from “naked” in that the naked body is simply an unclothed body while the nude body is considered to be an unclothed body perfected by the artist through his or her work (Imai 1998). The nude body was almost always a female body, depicted as passive through lack of eye contact and body position, and thus easily consumable for a male viewership. Canvasses were also often smaller-than-life and therefore portrayed the subject as takeable simply based on size. At first, artists depicted goddesses (who could be considered non-human) rather than “real women” because of social conventions that would not allow for the painting of what could be construed as simply naked women (Imai 1998). Artists often argued that painting a nude was adherence to a “pure form,” and that such portrayals were study aids for painters and sculptors – although they did acknowledge that some depictions could be considered a form of erotica (Imai 1998).
However, as in any artistic genre, there is always a desire to push the boundaries, to redefine the form by breaking it in a measured way. Such breaks often result in criticism from artists as well as the community. Thus, as the painting of nude goddesses gave way to the painting of nude women, there were protests that such representations were vulgar and did not constitute art. Not only did the public find them inappropriate, but they were often not accepted in the art world at the time of their production because the images had not been “perfected” by the artist, and the images could simply be classed as “naked” (Kasahara 1998). Thus, they were considered transgressions to both the morals of the general public and the forms accepted in the art world.

Similar discussions also occurred in Japan after the genre was introduced there. Volk notes that some Japanese viewers argued that the painting of nudes was simply a case of men painting naked women, and that the activity was therefore detrimental to social morals, while others argued that the painting of nudes was a pure and perfect form (2010). The Ministry of Education opted to side with the former viewpoint and censored nudity from the waist down; paintings were then either physically covered with drapes to conceal such nudity, or artists complied by either painting in draperies or cropping nude paintings at the waist (Volk 2010). Further, Japanese artists who attempted to break the form also met with opposition. Focusing on Yorozu’s 1912 painting Nude Beauty, Volk illustrates how Yorozu embodied the contradictions inherent combining Japanese and Western painting styles as well as in pushing the boundaries of the genre: brushstrokes reminiscent of van Gogh, distortion similar to that of Matisse, powerful posturing (the nude is placed above the audience and forces eye contact with viewer), and content (inclusion of armpit hair and disconnection from the nude’s “natural” surroundings) simultaneously validate and break the form of the nude produced abroad and emulated domestically, drawing the ideals of style and genre into question in a single piece.

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83 Artists such as Goya, Manet, Degas, Toulouse-Lautrec, Courbet, and Renoir began breaking the form by painting a naked human female rather than a goddess (in the case of Goya), women who engaged the viewer directly in some way, such as through eye contact (as in the case of Manet), and women in everyday settings (in the case of the others) (Imai 1998).

84 The depiction of unclothed bodies was not introduced by Western artists, but the genre of the nude as it is known in the art world was.
Perhaps not surprisingly, the work was not appreciated at the time. Volk argues that part of the reason for this was that the set of ideals artists prior to Yorozu hoped to exemplify had not transferred linguistically or conceptually with the importation of the nude genre: “The ‘nude’ was a newly imported concept and set of aesthetic conventions and ideals, but the term *ratai* (裸体), which literally means ‘naked body,’ did not… distinguish between the nude and the naked. For many Japanese, the genre was indistinguishable from pornography (*shunga* 春画)” (2010:56).

This same issue of “fine art or vulgar photograph?” also came to the fore as nude photography developed as a genre. The existence of pornography illustrates the simple fact that photographing an unclothed body does not constitute art – or even if it can be considered art in some circles, it may not be considered fine art. As Kasahara states, “countless banal nudes” exist outside the art world and are produced by photographers who “simply pursue their own sexual fantasies or ‘abstract beauty’ [that reflect] nothing more than their own conceited idea of ‘beauty’” (Kasahara 1998:187). There are standards. They are necessary, as they are in any discipline, and these standards can only be broken effectively by artists and curators. Sometimes they cannot even be broken by these people; Kasahara reminded me during her interview that she could not select photographs owned by foreign galleries that showed genitalia or pubic hair because they would not make it past Japanese Customs (Field notes December 2010). Thus, relative acceptance of some nude photography in the fine art world does not mean that all such works are considered art by all critics, artists, communities, or governing bodies. This tension between producers and consumers, as well as other producers, it part of what drives trends; another factor is the recontextualization of extant works, and Kasahara’s exhibits are examples of how works can be recontextualized to push both social and aesthetic boundaries.
The 1998 “Love’s Body” Exhibit

Kasahara’s goal in producing the first “Love’s Body” exhibit was to further problematize the nude genre by bringing together a collection of photographs that highlight the relationships between the photographer and the nude subject, with particular focus on the balance of power between the two. She wanted to show that depictions of the nude body could be much more nuanced and illustrate the diversity of human bodies found in the real world, themes such as life, death, love, gender, and sexuality instead of just sex, and encourage people to consider having a more open understanding of, and relationship to, bodies (Kasahara 1998). This was accomplished by selecting nude photographs of both men and women, by men and women, in which the subject allows the photographer to capture his or her humanity and personhood on film by actively participating in the act of producing the photograph.

For example, the women Bellocq photographed at the turn of the twentieth century were not posed; rather they were relaxed and frank in their homes, comfortable with their choice to allow the photographer and his camera into their space. Female photographers such as Jean Fraser, Catherine Opie, and Kamikura Yoshiko invert the paternalistic nature of the nude genre by depicting women who can satisfy their sexual desires without the help of a male counterpart (Fraser); they invert the “ideal” definition of beauty and sexuality by photographing people with various body types, sexualities, and sexual practices including S&M (Opie) and the ordinariness of women who work in the sex industry (Kamikura). Male photographers such as Mapplethorpe inverted the gendered aspect of the nude by photographing the “beautiful male body,” and Otsuka Tsutomu attempted to transcend the gendered body altogether by producing images that cannot be defined as either male or female.

Through such re-contextualization of these photographs, Kasahara’s challenge to the nude genre goes beyond who photographs whom and in what manner by drawing attention to the relationship between the photographed and the photographer instead of

85 The main title “Love’s Body” was borrowed from Norman O. Brown’s 1996 poem. Brown’s poem, which discusses love’s body as liberty, nature, trinity, unity, person, representative, head, boundary, food, fire, fraction, resurrection, fulfillment, judgment, freedom, and nothing in the course of about 300 pages, was considered a good fit (Kasahara 1998).
simply the subject and the audience. Rather than the subject becoming simply a passive vehicle through which the ideals of the photographer are created and presented to an audience, the subject actively harnesses the talents of the photographer to assert their individuality and personhood vis-à-vis the photographer in a cooperative act that culminates in the production of a visual challenge to the audience as well. The act of production and the balance of power between the photographed and the photographer that this entails are highlighted simultaneously. Some critics have referred to this as “reinstating the naked” (Imai 1998) or as working toward an “anti-nude” (Kasahara 1998). Regardless of what it is called, this challenge highlights the emphasis on the power the photographed and photographer have in relation to one another, to the audience, and to their own senses of self-assuredness and confidence about their bodies – whether the body is the physical, lived body or a “body of work.” As sociologist Ueno Chizuko states in reference to the works of Okada Hiroko and Ito Tari, “the subject, here, is our relationship with our body, and that relationship, itself runs fluid, transforms, dissolves” (1998:177). It is this relationship that comes across so clearly in both the 1998 and the 2010 exhibits.

**The 2010 “Love’s Body” Exhibit**

“When I saw these works [by William Yang], the flood of my own past memories just wouldn’t stop... so what is the message from those who were lost to those of us who are still here? The clearest is that ‘there is something we can do.’ Now there are even medicines that can decrease the viral count in the blood to the point its negligible... but if we turn our eyes away [from HIV], then the same thing happens now that happened then. That’s what became apparent to me with this exhibit.” (NHK Online Rainbow 2010)

“Love’s Body” helped the correspondent quoted above link past memories to current realities of HIV. What did s/he see to facilitate that? Entering the gallery, the

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86 It seems that the nude genre has been stretched to include a wider and wider range of unclothed subjects. Therefore it seems that re-labeling might be useful. Perhaps the original nude genre could be called the Objective Nude due to the objectification of female goddesses as examples of “pure form;” the first nude pieces of actual women could be called Profane Nudes because of the reactions they provoked. With regard to “reinstituting the naked” or the “anti-nude” other labels are possible. Since the term “naked” lacks artistic nuance and the photographs exhibited are still within the context of “art depicting the unclothed,” and the focus on relationships, it seems appropriate to refer to such portrayals as another subset of the nude genre; perhaps the Reflexive Nude would suffice.
viewers were first met with three photographs by AA Bronson. Two self portraits depict him hanging by his feet, nude, his back to the viewer; these were positioned to either side of an image of a bearded man cradling a diaper-clad newborn on his bare chest. Visitors were directed left, where they viewed William Yang’s series, “Allan,” which captures Yang’s former lover’s everyday life with HIV and finally his death from AIDS-related complications. They were then met with Gupta’s full-color, vibrant shots of PLWHA in the streets of India. Next are Hujar’s black-and-white portraits and scenery shots – of sixteen photographs, ten are portraits. Of those ten, five are nudes. Following these were Wojnarowicz’s composite pieces, one of which features the three death pictures he took of Hujar, overwritten with hand-written text about the prejudice PLWHA were experiencing in the late 1980s and early 1990s. On the opposite wall were sixteen black-and-white photographs by Guibert; they include two self-portraits, a shot of Michel Foucault, and two of other men. The remaining photographs featured places. Rounding the corner, the viewer was met with a large screen onto which a video by Akira the Hustler (Cho Yukio) was looped. No one speaks in the video. Couples and families interact, and occasionally a screen pops up and reads “But don’t forget. For all that, the world is filled with love.” Cho also contributed three sculptures, two of which are male couples holding hands; the third is of a man and woman walking a dog. The fact that they are joined together is highlighted by red paint and red string, which eerily resembles blood. On the wall behind Cho’s work, was Gonzales-Torres’ string of lights and black-and-white series of benches.

With this second “Love’s Body” exhibit, Kasahara sought to problematize the portrayal of bodies in fine art, and to challenge the viewership to consider what it means to have a healthy, loving, and loved body. This time, she sought to redefine “sex, disease, death, race, culture, politics, isolation, families, and interpersonal relationships and life itself” by challenging the very image of AIDS (Kasahara 2010:167) that often overwhelms the general public. Noting in her essay that the portrayal of an AIDS patient as a gay man wasting away dominated the (western) media, and that even well-meaning exhibits such as those by Nicholas Nixon (who photographed a gay man living with HIV as he progressed to AIDS) were heavily criticized as “stereotypical” by AIDS activists (Kasahara 2010), Kasahara combines the work of Yang, Bronson, Hujar, Wojnarowicz,
Guibert, Gonzales-Torres, Gupta, and Cho to focus on what it means to *live with HIV* – rather than simply to die of AIDS. Rather than viewing photographs of nude subjects (which constitute only a fraction of the exhibit), the viewers are exposed to the artfully crafted emotions of the photographers and the photographed through each piece. In other words, a form of metaphorical, dually-constructed, emotional nudity is presented. In the case that no other people are depicted, the viewers are exposed to the raw emotions of the photographer vis-à-vis their surroundings.

Based on community engagement, which I describe below, this exhibit was relatively popular and well-attended. As the commentator above noted, visitors considered their past and future actions with regard to HIV/AIDS – possibly through the exhibit itself, and possibly through the lectures and supplementary events that were put on at the same time. In other words, the exhibit engendered direct engagement with HIV/AIDS. In addition, rather than the dark, hushed silence that hung over the “Access to Life” exhibit, the “Love’s Body” exhibition space was light, people spoke normally and moved comfortably as they went from photograph to photograph, and there seemed to be an over-all positive feel to the beginning and end of the exhibit – despite the fact that some images portrayed death, rage, anger and fear. This allowed for some discussion about the serious topics being broached by the exhibit. Indeed, as Kasahara hoped, the exhibit did allow participants changes to talk about sex and sexuality, life, death and the body. Her goal to “present works that are powerful enough to… influence aspects of art and photography while reappraising and redefining their meaning” also seems to have been met, and she mentioned that she was satisfied with the response from the art world (Kasahara 2010).

**The “Love’s Body” Print Materials**

Exposure for most audience members began with print materials about the exhibit, such as brochures and fliers, and the first thing I noticed was that the English title and the Japanese title are not the same. Although the English title is “Love’s Body: Art in the Age of AIDS”, no reference to HIV, AIDS, or art appears in the Japanese title. Rather, the Japanese title translates to: “Love’s Body Expressed through Life and Sex.” This was intentional; the curator stated that HIV has such a negative connotation in Japanese that
perhaps people wouldn’t come. She states she used *sei* (性), or sex, instead to ensure interest (Field notes December 2010). Is it possible to get a Japanese audience to come to an exhibit that touches on HIV/AIDS only if they’re tricked into it and HIV/AIDS is slipped into the English title?

That does not seem to be the case. Interestingly, it seems as though the Japanese and English titles supplemented each other, and in most PR on the exhibit written in Japanese, the authors titled their columns in ways that indicated the exhibit was indeed an art exhibit dealing with HIV/AIDS, regardless of what was in the Japanese exhibit title. For example, the Yomiuri Newspaper titled an article on the exhibit “Photographs that face Eizu: Love’s Body: *sei to sei wo meguru hyōgen*” (Maeda 2010); a g-laddxx (a blog for gay men) entry was titled “Love’s Body: *sei to sei wo meguru hyōgen*: From the viewpoint of living with AIDS” (g-laddxx 2010); and a writer for the Shibuya Keizai Newspaper actually put the title (Love’s Body) at the end and created his own Japanese title, effectively re-naming the project “An Exhibit by Eight Gay Artists who faced *Eizu*: Love’s Body” (Shibuya Keizai 2010). This “double title” may be considered a rather ingenious marketing strategy that provided PR outlets a linguistic tool kit they could use to shape their headlines to fit their audiences. To put it differently, this “double title” is an example of indirect engagement with HIV/AIDS similar to the use of the term *eizu* as outlined in Chapter 1: the vagaries allow the viewer to make their own associations. But in the case of the double title, the associations are guided by the curator rather than left up to the viewer as is the case with the term *eizu*.

In addition, news of this exhibit traveled extensively. Newspapers from Nagano, Fukui, Yamagata, and Yamanashi (among other places) carried the story in addition to the Asahi, the Yomiuri, and the Nikkei (Japan’s largest papers). In addition, columnists in weeklies and bloggers also commented extensively on the exhibit and yielded over 200 pages of data. This may be due in part to the participation of community center akta and JaNP+, which promote safe sex and sexual health, and support PLWHA, respectively.

This discrepancy between the English and Japanese titles seems to have had an overall positive effect in that people could focus on the key words they felt to be most important, and this may have influenced attendance. However, there are some more
subtle discrepancies between what was in the title and what was in the photographs – or, perhaps more specifically, what was not included that could have been. I discuss these points below.

**Three Points of Analysis for “Love’s Body”**

Although the differences in English and Japanese titles may have assisted the dissemination of information about the exhibit, it is crucial to realize that the content of the exhibit is actually much narrower in scope than either the English or Japanese titles imply. For example, “Art in the Age of AIDS” should leave the exhibit wide open to include art from all over the world, from the early 1980s to the present, should be able to include any number of types of experiences with HIV/AIDS, and should highlight various types of artwork. In her essay, Kasahara asserts that “Everybody who is confronted by these works can relate to them as personal problems, compare them to their own lives and repeatedly question something that they received from them” (Kasahara 2010:168). However, upon careful examination of the artists and their subjects, it is clear that the exhibit has a significantly narrower focus than the titles imply, and as such it is unlikely that “everybody” can relate to these works.

First, the works of a very specific type of artist were selected for this exhibit. The artists are/were gay men, trained to some degree in the West, either lived with HIV or had partners or friends who lived with HIV, and/or produced work during the HIV epidemic in the 1980s and 1990s (largely in the US). Excepting Gupta’s recent work in Delhi and Cho Yukio’s work in Tokyo, from this standpoint it seems that much of the exhibit is actually “Art in the age of AIDS according to gay artists in urban centers in the West in the 1980s and 1990s.” Put more simply, the art shown in this exhibit fits the fine arts parameters agreed upon by museum officials and art critics of wealthy nations. Perhaps it would suffice to call it G-8 aesthetics.

Second, the places and people hardest hit by HIV/AIDS are not included in this exhibit. Whereas medical care and ARVs are comparatively easier to obtain in the wealthy nations portrayed, this is not the case in developing nations where people still continue to waste away as a result of AIDS-related complications and the percentage of people living with HIV and dying of AIDS is much higher than in those countries
portrayed. Failure to include artists and photography from African, South East Asian and South American countries is to either ignore the problem that exists there or ignore the fact that photographs have been taken to portray it. This is a grievous omission.

Third, rather than highlight sexuality per se, this exhibit highlighted a very specific sexuality by presenting a largely gay-centered body of work. For example, lonely ten of the forty-eight photographs that feature people included females. In doing so, the exhibit privileged males and male sexuality over other forms of sex and gender, and focused on the gay experience in urban areas. This parallels safer sex messages that tend to focus on the use of condoms rather than on female condoms, gloves, or dental dams for women, and the tendency to leave out intersex and transgender issues altogether. Considering the large percentage of people world-wide who contract HIV through heterosexual contact (Center for Disease Control 2013), and the increase in heterosexually contracted cases in various parts of Japan (Nagano Prefecture 2012), this focus is misleading. Therefore, to title this exhibit sei to sei wo meguru hyogen, and to equate sei or sex with male-male sex is to perpetuate the phallic-centered discussion of sex that pervasive in Japan and elsewhere in general, and the fascination with the gay-HIV link specifically.

In addition to these points, it is important to recognize that the title “Art in the Age of AIDS is not a Kasahara original. It was first used for an HIV/AIDS exhibit in 1994 in Canberra by Ted Gott, which featured a range of artwork from around the world (Gelber 1995). Three things are significant: the difference in timing of Gott’s and Kasahara’s exhibits, the curators’ personal engagements with PLWHA, and the contents of each exhibit. Gott was involved with the art community in Australia and knew the artists in his show – unlike Kasahara, who states openly that she does not know anyone with HIV (Kasahara 2010). This suggests that the epidemic was felt more personally by Gott, who perhaps engaged with HIV on a more emotional (rather than strictly aesthetic) level. Second, HAART had not been developed at the time of Gott’s exhibit, so the number of people who contracted HIV, progressed to AIDS, and died was high compared

87 Of these, five stand and face the camera, two are reclining, two are nude, and one is an infant.
88 The first recorded use of this phrase is in an article of Opera News in 1992 and refers to musician William Parker’s performances post-diagnosis.
to now – at least in the case of the western world, where patients theoretically have better access to medications. Dying of AIDS rather than living with HIV was still very prevalent, even in wealthy nations; this made the emphasis on AIDS in a western setting more timely. Now, however, things have changed. Medications, epidemiological trends, and transmission rates are all different, and people who have lived with HIV for decades have different problems, different lived realities, and different bodies than those who are suffering from AIDS. Kasahara’s exhibit does not consider these differences. This discrepancy leaves viewers to wonder, exactly what is the “age of AIDS”? Are we still in it? Has it passed? Is this “age” defined differently around the world? Answers to these questions have to be sought outside the exhibit. Finally, Gott’s frame is larger, and he did include a wider range of artists and artwork than Kasahara did. A different title, perhaps an original one with less baggage, would have allowed Kasahara to side-step these issues.

Returning to the concept of memes, what images are being circulated in this exhibit? First, the artists are all men. Of the works included, the vast majority of the images are by and of non-Japanese men. Of those, the majority are of or by men who are or were openly gay. Some of these works are explicitly about HIV/AIDS, such as Yang’s series of his former lover. Others are tied to HIV through the experiences of the artist (such as those lost to AIDS or who lost friends to AIDS), through inclusion in the exhibit and proximity to works depicting HIV/AIDS, or through the English subtitle of the exhibit, “Art in the Age of AIDS.” What this boils down to is, as I argued above, an image of PLWHA as foreign gay men. Epidemiologically speaking, this image matched reality in the United States in the 1980s. However, the patterns have changed such that risk groups in the United States now are centered on ethnic minorities and injection drug use rather than gender and sexuality. To put it succinctly, foreign (predominantly western) gay men’s experiences are directly linked to HIV/AIDS through subject matter (Yang), artists’ personal experiences with living with HIV/AIDS (Hujar and Wojnarowicz), or the English subtitle (Bronson, Guibert, and Gupta); however, HIV is no longer predominantly prevalent in gay men in these places, so the overall image or meme illustrates past but not current HIV/AIDS realities.
Furthermore, Cho Yukio’s works represent the only Japanese contribution in this exhibit. He, too, focuses mostly on men: the video includes a male couple, and two of the three sets of figures are also male couples. Like some of the other artists featured, Cho’s work is not explicitly about HIV/AIDS. Rather, the work’s connection to it is indirect and dependent both on placement in the exhibit and association with the English subtitle – recall that HIV/AIDS is not a part of the Japanese title. The link between HIV/AIDS and gay Japanese men matches the current epidemiological pattern in Japan. So, although the image here links gay Japanese men and HIV, and that matches the epidemiological data, the reference is indirect. What this means for the exhibit as a whole is that audience members are basically faced with direct images of gay foreign men with HIV/AIDS from the past and current but indirect images of gay Japanese men with HIV/AIDS. I would argue that given the focus on non-Japanese artists and the vague link between Japanese men and HIV/AIDS, it is possible that the dominant, take-away meme is that PLWHA are foreign gay men.

In addition, the universality Kasahara asserts seems to be more a product of her discipline, less than an inherent characteristic of the art she has selected. It seems unlikely that everybody, even all PLWHA, would indeed find meaning in every piece. For example, to what degree would intravenous drug users, women who exchange sex for financial security, and people from the global south identify with Kasahara’s “Art in the Age of AIDS”? I myself struggled to understand the significance of Gonzales-Torres’ work and its place in the exhibit, and had to read about him online in order to understand what his work meant and why it was included. Although it is possible that most people could probably relate to at least one photograph in the exhibit, and that experiencing the exhibit did push some social boundaries for visitors, it is unlikely that this was an exhibit “everybody” would appreciate or understand.

In other words, “Love’s Body: Art in the Age of AIDS” excelled at portraying HIV as an important social issue germane to the local population, engaging the community in innovative ways, and focusing on male-male sex which is indeed the predominant mode of HIV infection in Japan. Viewed in the context of her previous exhibit, Kasahara does offer a powerful critique of the “normal” body and an alternative
through her representation of living with HIV. All this was done in spite of the fact that being at a photography museum restricted the art she selected mainly to photographs, the discipline itself restricted the art she selected to pieces that were well-known and accepted in the fine art world, and practical restrictions such as importation laws reduced the number of choices she had.

However, the cost of re-contextualizing these works as “Art in the Age of AIDS” is 1) artists who exemplify G-8 aesthetics were privileged; 2) art and the HIV/AIDS epidemic in minorities in wealthy nations were prioritized over art from African and South American majorities, and 3) male sexuality, particularly foreign, urban gay men’s sexuality, was highlighted and linked to HIV. As such, the memes described in Chapter 2 that link HIV, AIDS, gay, and foreign are writ large for the Japanese audience to see, even though other sexualities, bodies, HIV transmission routes, and types of HIV/AIDS-related art in Japan and elsewhere. However, every single one of these costs could have been minimized (or at least explained) by using a different title.

Thus, while the stories highlighted in the “Love’s Body” exhibit represent important pieces of HIV/AIDS art history, particularly with regard to gay rights in the United States and the epidemics in urban centers such as New York, Sydney, Delhi, and Tokyo, they do not live up to the large title, “Art in the Age of AIDS” and the global focus that that title seems to imply. Rather, to title this exhibit, this piece of HIV/AIDS history as “Art in the Age of AIDS” and to equate that large title with this particular artist demographic at this point in time is to privilege the work and experiences of artists trained in relatively wealthy nations over those of African or South American artists where the epidemic has been most devastating in terms of sheer number of lives lost and populations affected, and results in the misconception that either HIV/AIDS is not a problem in these places, there is no worthy art in these places, or the problems or the art in those places are simply not on the same scale as they are in wealthy nations.
Access to Life

命をつなぐ（inochi wo tsunagu89）

Access to Life is a temporary, traveling exhibit that contains photographs of people living with HIV/AIDS from Haiti, India, Mali, Peru, Russia, Rwanda, South Africa, Swaziland and Vietnam. The exhibit began in Washington DC in 2008 and has been to Paris, Madrid, Oslo, Rome, Oakland, Tokyo and Seoul since. It was shown in the Asahi building in Yūrakuchō (Ginza area) from September 5 to 22, 2010. Admission in Tokyo was free. Approximately 3,000 people viewed the exhibit, or roughly 176 people per day. The opening was attended by about 300 people, including then-Prime Minister Kan Naoto, several other politicians and bureaucrats, members from the medical community, and a few members of the general public. Additional events that accompanied the main exhibit included a forum with the cast of RENT, a lecture by Carol Nyirenda who serves as the National Coordinator for Community Initiative for Tuberculosis, AIDS, and Malaria, and a talk by Mori Riyo who was Miss Universe 2007. Media focus for the event was limited to the Tokyo area (JCIE 2010 personal communication).

The two main organizers are The Global Fund to Stop HIV, Tuberculosis and Malaria (hereafter The Global Fund) and Magnum Photos. Every time the exhibit visits a new country, a different suite of local, supporting organizations assists in its production. For the Tokyo exhibit, local organizers included Japan Center for International Exchange (JCIE), Friends of the Global Fund Japan, and The Asahi Shimbun (a newspaper). Supporting Organizations include the Ministry of Foreign Affairs (MOFA) and the Ministry of Health, Labor and Welfare (MHLW). Takeda Pharmaceuticals and ANA acted as special sponsors. Local collaborating organizations included GCAP Japan, STAND UP TAKE ACTION, Japan AIDS and Society Association (JASA), and Japanese Network of People living with HIV/AIDS (JaNP+). Non-Japanese sponsors listed in the Japanese brochure included (RED), Hewlett Packard, Chevron, Human Energy, Friends of the Global Fund, The Ford Foundation, and the Rockefeller Foundation.

89 The literal translation of this is “Connect to life.”
The primary goal in bringing this exhibit to Japan, as explained by JCIE representative Ms. Itoh, was to convince the Japanese government, then-Prime Minister Kan in particular, to continue to contribute to the Global Fund so that people in developing countries could continue to have access to ARVs (Field notes December 2010). Other goals included promoting the Global Fund and educating Japanese people about anti-retrovirals (ARVs). Kan pledged financial support, so the primary goal was met; other goals may have been met to various degrees, but these are more difficult to ascertain.

Although it is beyond the scope of this chapter to discuss every organization that sponsored this exhibit and its corresponding events, it is important to consider the main players in order to understand how the exhibit was produced and consumed in Japan. To this end, I briefly describe The Global Fund, Magnum Photos, and JCIE in an effort to illustrate the basic outline of the project in Japan.

**The Global Fund to Fight AIDS, Tuberculosis and Malaria**

The Global Fund is an international, collaborative venture begun by the G-8 in 2002 to direct finances for HIV/AIDS, tuberculosis and malaria relief into areas of intense need. Stakeholders include representatives from local governments, the public and private sectors, civil society, and nongovernmental organizations. Mostly large-scale donors such as governments and foundations supply funds. Organizations apply for funding to support campaigns to combat HIV/AIDS, tuberculosis and malaria, which the Fund terms “three of the world’s most devastating diseases.” Applications must be goal-oriented to be funded, and future funding is allocated based on past successes – a strategy the Global Fund refers to as “performance-based funding.” The goal is to rely on “local ownership and planning to ensure that new resources are directed to programs on the frontline of this global effort to reach those most in need” (Access to Life 2013). High-profile supporters include Bill and Melinda Gates and U2’s Bono. By 2009, six hundred grants had been awarded in 144 countries totaling US $18.4 billion: so far, programs supported by the Global Fund have provided 3.3 million people with antiretroviral treatment, 8.6 million people with treatment for TB, and 230 million insecticide treated
nets to families for the prevention of malaria (The Global Fund 2013), which Bono has equated to saving nearly 8 million lives (The Global Fund and Bono 2012).

Government donations comprise the vast majority of financial support, which is why Former Prime Minister Kan (who served from June 2010 until August 2011) and other politicians were considered the target audience. Incidentally, Kan was the Minster of Health and Welfare when Japanese people who had been infected with HIV through medical treatment with tainted blood sued the government and pharmaceutical industries responsible (Yamamoto et al. 2006). In 1996, he made a public statement attesting to the fact that the government was at fault for allowing importation and continued use of non-sterile blood products and apologized to yōseisha directly – a course of action that earned him a great amount of respect and trust from the general public at the time. Kan’s position as Prime Minister during the exhibit was likely advantageous to meeting the exhibit goals: in fact, Kan agreed to open the exhibit and the Global Fund was successful in securing support from the Japanese government. Standing alongside Bill Gates in January 2012, he discussed the plan to provide the Global Fund with $340 million for 2012, part of the $800 million he pledged as the “Kan Commitment” in 2010 (JCIE 2011).

Magnum Photos
Magnum Photos was founded in 1947 at the Museum of Modern Art in New York with its goal being to “chronicle the world and interpret its people, events, issues, and personalities with empathy” (Magnum Photos 2013). Founding fathers include Robert Capa, Henri Cartier-Bresson, George Rodger, and David Seymour. Magnum Photos celebrated its 60th anniversary in 2007, the same year that it joined with The Global Fund to illustrate the effects of ARVs on those living with HIV/AIDS. Magnum currently has offices in New York, London, Paris and Tokyo and provides images to the

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90 Kan is anti-nuclear. After 3/11 he closed Hamaoka and halted the production of fourteen new reactors. McNeil’s interviewees hint he was removed from power because of this stance (personal communication 2012)
91 This museum itself opened in 1929.
92 Capa photographed the D-Day Invasion.
93 Cartier-Bresson was a French photographer who participated in the French resistance.
94 Rodger photographed the Blitz and the liberation of Bergen-Belsen.
95 Seymour worked in American Intelligence and lost his parents to the Nazis.

**JCIE**

The Japan Center for International Exchange (JCIE) was one of the major local supporters of the Access to Life exhibit. JCIE was founded in 1970 as “an independent, nonprofit, and nonpartisan organization dedicated to strengthening Japan’s role in international networks of dialog and cooperation” (JCIE 2013a). It is financed through private donations and grants, and it in turn funds several programs aimed at promoting Japanese engagement in internationalization and strengthening Japanese civil society (JCIE 2013b). HIV/AIDS projects include the Levi Strauss Foundation Advised Fund, which was sponsored by the American jean company and provided $1.1 million to 133 NGOs working on HIV/AIDS in Japan from 1997 to 2004 (JCIE 2013c), and Friends of the Global Fund, which has worked to encourage the Japanese government to continue to support international efforts to combat HIV/AIDS, tuberculosis, and malaria since 2004. They have also sponsored domestic HIV/AIDS conferences. JCIE played an essential role in providing local support for the exhibit, including locating a venue, translating materials, and organizing PR releases.

**The Venue and Ginza**

“Access to Life” was exhibited in the Asahi Building in the Ginza/Hirō area of Tokyo. It was chosen for its convenient location: it is near government offices and several embassies. However, this area has also been a seat of wealth since the late 1500s when Tokugawa Ieyasu standardized coinage and established a mint (Waley 1984). Ginza literally means “silver mint.” It has also been considered a fairly Westernized section of Tokyo since the Meiji Restoration. Fires destroyed large parts of Ginza in the 1870s, which led the government to experiment with western architecture, namely brick buildings and willow-lined arcades there (Richie and Simmons 2010) (Waley 1984). The first train ran from the port in Yokohama to nearby Shinbashi (Waley 1984). Japan’s first sidewalks and gas lights were built in Ginza, and these were followed by newspaper offices and telegraph poles in the 1880s, the Hattori clock tower in 1894, and an
increasing number of shops that sold western suits, hats, glasses and western comestibles (Waley 1984). “Strolling through Ginza” became a pastime in the Taisho era (1912-1926) and the early Showa period (1926-1989), and beer halls, dance halls, milk halls and cafes proliferated (Waley 1984). Department stores flourished, and shops such as Shiseido, Fujiya, and Morinaga sold western sweets, desserts, coffee, and tea (Waley 1984). Now the area is known for its upscale department stores such as Hankyu, Matsuya, Matsuzakaya, and Mitsukoshi as well as the presence of foreign and domestic designers including Chanel, Cartier, Coach, Gucci, Hermes, Mikimoto, Prada, Sony, and Tiffany’s. As I discuss below, the main goal of “Access to Life” was to get a government-level donation; thus Ginza, given this wealth and proximity to power, was an ideal location for a photojournalism exhibit on the efficacy of ARVs.

**Photojournalism, Representing Self, and Representing Other**

As discussed briefly above, photography in Japan began to develop around the time of the Meiji Restoration (1868). As in other places, fine art photography, photojournalism, portraiture, and amateur photography all developed as photography became more accessible and its various uses were realized. Fraser notes that as technology and know-how were imported, they were often “Japanified” (Fraser 2011). For example, fine art photography at first mimicked woodblock prints and ink painting (Fraser 2011), but styles and contents of photographs, regardless of the genre, all reflected the relationship between a particular self and a specific other.

As Berger states, “We never look at just one thing; we are always looking at the relation between things and ourselves” (1977:9). Thus, who produced a photograph for what audience is a factor in photography in general. A simple framework for this, which is not specific to any country or genre, consists of four possibilities: 1) self-produced (or commissioned) for private or semi-private consumption, 2) self-produced for marketing/consumption by others, 3) produced about others for self-consumption, and 4) produced by others for consumption by others. For example, many wealthy Japanese

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96 Another way to put this is 1) objectifying the self so that one can consume the self (such as self-portraiture hung at home), 2) objectifying the self so that one can be consumed by others (such self-portraiture that is circulated through gift, trade, or sale), 3) objectifying others or “them” to be consumed by
people in port cities such as Yokohama had portraits taken in western clothing, which demonstrated their status and social position to themselves and their acquaintances. Other photographs of Japanese were clearly intended for foreign audiences and illustrate the second category: for example, the first photographs of the Meiji emperor to be circulated to foreign heads of state in 1872, in which he wore Japanese court clothing, were replaced with photographs of him clothed in Prussian military suit and seated on a western chair in 1873 so that he would be considered “modern” (Fraser 2011). Moreover, photographs showing “traditional” Japan – such women in kimonos and scenes of rural enclaves – were also produced and sold to foreign audiences (Fraser 2011). In this way, Japan was cast as a modern nation with delicate traditions at the turn of the 20th century.

The development of photojournalism in general, with the goals of documenting and distributing photographic evidence of events shortly after they occurred, magnified the us/them relationships inherent in creating visual representations. For example, Collins and Lutz assert that National Geographic packages both local and foreign stories specifically for upper-middle class American consumption in a manner that reaffirms readers’ senses of self while ostensibly teaching them about the world (1993). Efforts such as these fall into category three, and can become extreme, even nationalistic, during wartime. For example, historian John Dower illustrates how WWII war propaganda put out by the US government simultaneously portrayed Americans as heroic saviors and the Japanese as treacherous apes; likewise, propaganda put out by the Japanese government portrayed Japanese as courageously standing up to American bullies, who were depicted as devils and monsters (1986). Gordon and Okihiro discuss how wartime images that did not support these stark dichotomies, such as many of Dorthea Lange’s photographs of the interned Japanese Americans, were shelved97 (2006). Furthermore, Fraser notes that WWII colonial propaganda in Nippon Magazine and Front, focusing on “the benevolent Japanese,” were based on German and Russian publications respectively making the point that not just images and themes but techniques also circulated (Fraser 2011).

“us” (such as Dorthea Lange’s photographs of Manzanar), and 4) objectification of others by others, possibly for both emic and etic audiences (such as Toyo Miyatake’s photographs of Manzanar).

97 Ansel Adams’ photographs of Manzanar were published in 1944, but his photographs did not tend to portray the Japanese as imprisoned or unhappy in their settings as Lange’s sometimes did; this is an important distinction because, the argument follows, such portrayals may have caused Americans to question the interment and see themselves as aggressors.
Finally, examples of photographs by others for others, category four, include post-WWII photographs of Emperor Hirohito and Ise Shrine taken by the US occupying forces and distributed to the Japanese. Such photographs were used to demystify the emperor and the Imperial shrine through casual portrayal of McArthur in contrast to the emperor, and by subjecting the interior of the shrine to the public gaze (Fraser 2011).

In each of these cases, the producer of the photographs was simultaneously making a precise statement about both the self and particular Others. One place that this precarious relationship can be clearly observed is in museum exhibits. Not only are photographs given specific contexts through captions and placement (Alpers 1991), interpretation at at least three levels is possible because the producer of the piece, the museum curators and supporting staff, and the viewers each interpret the photograph (Baxandall 1991). Moreover, both Berger and Ogura further note that contextualization and re-contextualization open up pieces to a multitude of interpretations by multitudes of people (Berger 1977) (Ogura 1998). Take for example the photographs of the mushroom cloud above Hiroshima from August 1945. Such pictures have been used to describe “what happened to us” at the Peace Museum in Hiroshima, “what we did” on the cover of John Hersey’s book, and something that should not be repeated in materials by international anti-nuclear groups; they have also been interpreted by the photographers that took them, numerous curators and editors, and members of the global community in different ways because of these various contextualizations – although some tropes are more common amongst various groups than others.

The same is true for HIV/AIDS-related photography. Whereas fine art photography featuring PLWHA was often produced by people close to the epidemic, done in honor of individual lives in relatively wealthy nations, and made according to specific aesthetic rubrics, photojournalism photography of PLWHA usually strives to document particular aspects of the illness for specific audiences with a specific goal in mind. For example, Bleiker and Kay assert much of the photography of HIV/AIDS used in campaigns “hinges on the assumption that images of suffering can invoke compassion

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98 Ironically, the Emperor had to be paraded and introduced around after being restored into power (Fujitani 1996) and Ise Shrine had been a popular shrine, open to the public, before being closed with the restoration.
in viewers, and that this compassion can become a catalyst for positive change” (2007). They cite Ed Hooper’s 1986 photo of a Ugandan woman and her child as an example of a photograph circulated to encourage people to feel sympathy for people dying AIDS-related deaths in African nations. The trope is “humanist photography,” which is meant to appeal to the sympathies of the viewers; but it also draws a stark distinction between the viewer who is assumed to be able to help financially and the person portrayed who is supposedly unable to help themselves. The us/them distinction is clear. The plea for change depends on it. This is the trope that characterizes photos used in “Access to Life.”

The “Access to Life” Photographs

“Even if you have a picture, if you have a caption, you still don’t know what you’re looking at. If you don’t have an explanation, you can’t understand... not in the case of eizu. What is the context? What is the story? The difficulty of portraying something as complicated as eizu in photographs stuck with me,” Ms. Itoh shared. She elaborated, stating that the balance of what to photograph, what to exhibit, is really difficult. “The ‘rosy picture’ of HIV/AIDS where if you get ARVs, you’re fine... [On one hand] it’s convincing, it’s a reason to provide funding – it matters. But it’s not the whole story...” (JCIE representative Ms. Itoh, December 2010).

So exactly what does the exhibit include? Recall from the profile that the exhibit is comprised of photographs of thirty people living with AIDS (not just HIV) in Haiti, India, Mali, Peru, Russia, Rwanda, South Africa, Swaziland, and Vietnam taken by eight photographers99. The photographs are before-and-after in nature, portraying each individual prior to and four months after beginning ARV therapy. Color as well as black-and-white photographs are included. The context and bodily comportment of each individual in each photo varies. However, the general trend was to portray people before medication as weak and without hope, which was accomplished by photographing them sitting or supine, gazing blankly away from the camera, often alone, and often in black and white. The “after” photographs generally portray progress through photographing

99 The photographers are Jonas Bendiksen, Jim Goldberg, Pablo Pellegrin, Eli Reed, Alex Majoli, Gilles Peress, Larry Towell – who photographed in both South Africa and Swaziland – and Steve McCurry, respectively.
individuals outside, engaged in work and socialization, with smiling or engaged faces, and often in color.

However, not all the “after” images were positive. Some individuals had died; in these cases, their homes or family members were photographed instead. The complicated parts of their lives – whether to disclose their status to family and friends, for example – was portrayed through the presentation of photographs in which the individuals grimaced or appeared concernedly meditative. In fact, the Global Fund does not want to paint an entirely positive picture. Ms. Itoh states, “The rosy picture… is the last thing the Global Fund wants. They commissioned Magnum to show the reality. But we always have two messages, and that is difficult for the general public to understand…” Here, we begin to see the precarity with which the photographed, the photographers, and the exhibit organizers deal: if all the pictures are positive, help no longer seems to be needed, but if all the pictures are negative, the cause seems hopeless. Some balance is required.

“Access to Life” Print Materials

Unlike the “Love’s Body” exhibit discussed above, “Access to Life” was not nearly as well advertised because the target audience was mostly politicians. However, the brochure and the accompanying materials, such as captions at the exhibit, had to be translated. In fact, this was considered one of the most difficult tasks by the JCIE support staff: “One of the biggest problems was translation,” said Ms. Itoh. JCIE worked with JaNP+ and the Japanese Foundation for AIDS Prevention (JFAP) to create a glossary of terms for Magnum to use. Ms. Itoh highlighted three main translation issues: 1) medical language, 2) “subculture” language such as how to discuss transgender issues and sex workers sensitively when “many Japanese don’t know anything about these issues,” and 3) the language of development – for example, the fact that “health care workers” does not necessarily refer to physicians or nurses in developing countries and can refer to unpaid volunteers or traditional healers as well. “That is the area we have to be very careful to use the accurate expressions to reflect the developing countries situations that Japanese people don’t know very well. But it has to be short or people won’t read it,” Ms. Itoh commented. In other words, organizers struggled to make unfamiliar words, terms, and situations understandable to the viewers while at the same time making such
explanations short so they would read what was provided. Again, a very careful balance was required.

It is important to note that supporting organizations such as JCIE, JaNP+ and JFAP played strictly supporting roles and did not have any control over the actual content of the exhibit beyond helping with translation, nor did they have input on where things were placed. These were decided by Magnum Photos, which was commissioned by the Global Fund.

**Three points of analysis for “Access to Life”**

As with “Love’s Body,” the title “Access to Life” is arguably problematic; unlike “Love’s Body,” however, the problem does not stem from a gap between the title and the contents. For this exhibit, the title and the contents have the same pitfalls. For example, consider “Access to Life” and the focus on providing ARVs. Both the English “Access to Life” and the Japanese “inochi wo tsunagu” imply that the people in the photos do not have life without medications, or without the help of donor countries; in contrast, it subtly implies that the donor country citizens are “connected to life” via their affluence. In many ways this is true, and even echoes the political-economic theories in medical anthropology in general, which illustrate that access to healthcare is a factor in overall health (Farmer 1992; Farmer 1997; Farmer 2001a). The emphasis on money = access to medication = access to health = access to life is the sound byte that The Global Fund and Magnum Photos uses to – very effectively – demonstrate that donations for medications save lives, and it may be one of the reasons they are so successful in securing funds.

However, this is a simple assumption that frames the HIV/AIDS epidemic as just a lack of medicine when the real picture is much more complicated. Focus on money and pharmaceuticals is made at the expense of acknowledging other factors that enable improvement in people living with HIV such as nutrition, social support, education and employment. Access to medication is not enough; even if people have medications, it has been established that people are more likely to die from AIDS when they do not have access to these other resources (Biehl and Eskerod 2007). That the organizers are at least vaguely aware of these factors is evident in print materials, in the photographs themselves, and the descriptions written by photographers. In fact, it is unfortunate that a more
cohesive narrative based on the photographers’ explanations was not available, because many of them do indeed comment on these very factors. Notes from several of them decorated the walls of the exhibit, for example, and included statements such as, “AIDS is only part of the problem,” “poverty and location prevent people from getting care,” and “people are afraid to disclose their status and risk losing friends, family support.” Unfortunately, the power of these nuanced voices is lost when they are not organized or given focus.

Moreover, other titles would have been possible. In fact, there are possibilities drawing on the goals that are clearly articulated on the Global Fund website and in the brochure, where it is stated that “the best photographers in the world… capture the complex changes that take place when people who are faced with death suddenly get a new chance at life.” “A new chance at life” seems more all-encompassing than the current title, although the “new chance” alluded to in these sources still emphasizes the “life-changing impact of the drugs” over individual strength and/or social support.

Second, although grants must be written by in-country organizations, the visual representation of the grantee countries is entrusted to professional photographers who are from the countries reviewing, not writing, the grants. This is illustrated in the comments by Global Fund Executive Director Michel Kazatchkine when he states “It’s the countries that are in the driving seat. The countries decide on their programs, they decide on their budgets, they decide on how the money will be channeled. What we ask in return are the results.” (The Global Fund 2011).

Compare this to the fact that ten years ago, the language PLWHA used to apply for grants had been interpreted as pathetic (kawaišō) and thus unconvincing. For example, Ms. Itoh described the victimized tone of grants written by PHWHA prior to 2000: “We are discriminated against, poor, we are kawaišō’ – [they were] full of that kind of attitude.” However, around 2000, around the time that the Global Fund was forming, many NGOs began forming and collaborating. “As their [PLWHA grant writers’] knowledge increased and they began to write about the problems associated with HIV

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100 The Access to Life website now includes such narratives.
more objectively, they were more empowered and their proposals were more convincing.” She said she herself learned how empathize for the people writing as they learned how to write grant proposals. Put another way, country representatives had to learn how to use grant-ese, had to discipline themselves according to granting agency standards, in order for their suffering to be validated so that they could receive funds to alleviate it.

It is ironic that the written experiences in grant form were deemed pathetic and thus unconvincing while funding agencies utilize hopeless images of these very people to secure funds. Perhaps the Global Fund, which touts its policies to support grants for local people by local people, should follow the same guidelines for photography as it does for grants and ask local people to photograph themselves. On a disciplinary level, reliance on professional photographers is reminiscent of Ruth Benedict’s efforts to educate Americans about the Japanese in the 1940s. She was commissioned to teach her fellow Americans about the Japanese people through the analysis of texts and Japanese-American experiences in much the same way that the Global Fund is teaching governments about PLWHA using Magnum Photos photography. This reliance seems unnecessary since photography of and by PLWHA exists around the world – including in Japan. For example, the photography of Tenanesh Kifyalew, a young girl in Addis Ababa who was instructed in photography and eventually died from AIDS, used photography to document her life – playing with family members, toys, et cetera – in addition to her difficulties in living with HIV/AIDS (Bleiker and Kay 2007). In addition, Kikuchi Osamu’s photographs of JaNP+ founder Hasegawa Hiroshi and the narrative that accompanies them illustrates how both the photographer and the photographed have come to live with HIV as something that is part of life in Japan (Kikuchi 2008). In such photographs, HIV is one part of life and not necessarily the defining characteristic of it. Perhaps the Global Fund could work with local photographers in future iterations of their exhibits rather than relying on outsiders to document the narratives of those in need. The system as it stands demonstrates the tendency for donor countries to expect recipient countries to become acculturated through grant writing and to accept outside representation, or photographs, as “results.” Are donor countries and organizations
expected to become culturally literate in equal measure, or is the same colonial framework at work?

Third, a common HIV/AIDS meme can be distilled from this exhibit: HIV/AIDS as a problem of the poor, foreign Other who struggles with drugs and prostitution. Again, there is truth in the meme: HIV tends to occur most often in minority populations, and this is facilitated by drug use and unprotected sex with multiple partners. However, what is difficult to see with an exhibit like “Access to Life” is that this same pattern occurs within wealthy nations and not just in relatively poor ones. Put differently, when the unit of analysis is the world (as it is with Access to Life) poor nations are viewed as having more problems with HIV; but when the unit of analysis is a particular country, poor citizens are viewed as more likely to live with HIV. Thus, the “Access to Life” exhibit on one hand fosters direct engagement with HIV/AIDS as a problem for wealthy nations like Japan as a donor, but allows Japanese people to ignore problems with intravenous drugs (as illustrated by the opening anecdote in the Introduction), the consequences of limited sex education programs (discussed in Chapter 2), and rising rates of HIV infection domestically. HIV/AIDS remains “far away” and someone else’s problem.

To summarize, “Access to Life” has been extremely successful at utilizing the existing trope of the passive, lifeless image of an HIV/AIDS victim pre ARVs and the smiling, vibrant PLWHA after beginning treatment to convince wealthy nations to provide financial and medical support. Indeed, these campaigns have been successful in garnering funds, delivering ARVs to those who would otherwise not get them, and improving the quality of life of thousands – if not millions – living with HIV. This could not continue if politicians, like Kan, decided not to donate and not to be part of this multi-million dollar deal.

However, there are costs for utilizing these representations, such as the perpetuation of assumptions like the perception that access to ARVs is equivalent to being granted life, the perception that only professional photographers are capable of capturing images that would encourage donation, and the perception that HIV/AIDS is a foreign problem of people completely unlike “us.” Notably, the memes that are writ large and circulated here are ones described in Chapter 2: HIV is associated with being foreign,
poor, and ethnically and socially different from the audience. These memes are common internationally and survive in Japan because they fit what Japanese people want to believe about HIV/AIDS: that it is a problem of the global south. This is far easier than admitting that HIV/AIDS rates are rising in the very city where the exhibit took place. To do so would be to acknowledge the precarity that HIV/AIDS is causing in Japanese society.

“Our Lives, Society, and Future: The Brilliance of Life”

「私たちの命・社会・未来: 命の輝き」

(watashi tachi no inochi, shakai, mirai: inochi no kagayaki)

The final exhibit I discuss is very different from the two discussed above. The first two took place in Tokyo, in the Kantō region of Japan. As temporary exhibits sponsored to varying degrees by private organizations, they were able to put on exhibits that packed a punch, making bold statements about social issues related to HIV/AIDS. However, they did not have to stand the test of time, or worry about the local government shutting down the facility. This final exhibit, “Our Lives, Society and the Future,” is a permanent exhibit in Osaka, in the Kansai region of Japan. The organizers of the exhibit are supported by local governments. Therefore, the relationships between the curators and the local government offices clearly shape the goals, content and target audience of the exhibit, which are also strongly tied to where the museum is located. Below I provide a profile of the exhibit, the local history of the area, and some of the NGOs and NPOs that support it.

Liberty Osaka Human Rights Museum

The Liberty Osaka Human Rights Museum (hereafter, “Liberty Osaka” or “Liberty”) caters to school groups and members of the local community. About 50,000 people visit a year (172 people a day, for the 290 days the museum is open). School groups are free; otherwise, entrance is 300 yen for general admission and 150 yen for students and senior citizens. The museum has worked to engage the public since it
opened in 1995 and over a million people have visited (Yoshimura 2012). During my research period, it was supported by the Osaka Municipal government\textsuperscript{101}. Like Shabi in Ebisu, Liberty collects and preserves documents so that it can produce original exhibits based on its holdings and pieces it borrows from other institutions. In 1999, the museum staff re-structured its curriculum to include tours, lectures, and educational kits specifically for elementary education following the Japanese Ministry of Education’s focus on museums as educational sites (Yoshimura 2012). Through these activities, the museum worked for the “public good,” often by attempting to foster relationships with and dialogues between the people they portray, the museum staff, and the general public.

Although Liberty Osaka first opened as a museum in 1995, it began in 1985 as a research facility charged with collecting and preserving predominantly local documents related to human rights (Yoshimura 2012). It has a permanent exhibition space in addition to a gallery for temporary exhibits. The main exhibit was refurbished in 2001, 2005, and 2011. Despite some degree of continuity within the exhibit over time, the titles, divisions, contents, and goals changed with each remodel, as I will discuss below. The basic point of the current exhibit is to encourage visitors to engage with the idea that Japanese society is diverse; to varying degrees, it has focused on perceptions of differences as possible roots of discrimination.

Liberty capitalizes on its location in Naniwa, an area associated with burakumin (discussed below), to discuss the diversity of the local population which includes not only this minority group, but also permanent (zainichi) Korean residents of Japan\textsuperscript{102}, the Ainu, Uchinanchu\textsuperscript{103}, sexual minorities, homeless people, disabled people, and sufferers of illnesses that include Hansen’s Disease, Minamata Disease,\textsuperscript{104} and HIV. A second goal of

\textsuperscript{101} The museum lost municipal funding in 2013.
\textsuperscript{102} Zainichi Koreans are descendents of Koreans who were forced to enter to Japan as laborers during the 20\textsuperscript{th} century or others who came willingly as citizens from colonial Korea. They are not recognized as Japanese because they refuse to take Japanese names. Some may speak no Korean or hide their Korean ancestry, becoming culturally Japanese. Others opt to embrace both cultures to varying degrees.
\textsuperscript{103} People from the Ryūkyū Islands, which was a separate kingdom prior to annexation by the Japanese. Okinawa is in the Ryūkyū Islands.
\textsuperscript{104} Minamata Disease is a condition caused by methyl mercury poisoning. Methyl mercury causes neural dysfunction, mental impairment, birth defects, and other health conditions. It is called Minamata Disease because people in Minamata, Japan began suffering from this illness in the 1960s when Chisso, a chemical company dumped waste into the ocean next to Minamata that poisoned the local fisheries (Walker 2010).
the museum is to acquaint viewers with the history of Osaka, particularly with regard to industry and trade. This seems to be an effort to show the contradiction inherent in treasuring goods and traditions considered essentially Japanese, such as taiko drumming, while discriminating against those who produce such items of material culture. This connection is not made overtly, but rather is suggested through the proximal placement of narratives and material culture items related to leather producers.

**Naniwa, the leather trade, and outcasts**

Historian Tsukada Takashi asserts that while Tokyo was (and is) a major political seat, Osaka was (and remains) a major economic center (2012). By the middle of the seventeenth century, the three districts that comprise contemporary Osaka had been formed (Tsukada 2012). The city was divided somewhat according to production centers and status groups, as was the case in Tokyo. However, it has been argued that, although these geographic regions can be noted and studied, people moved about and there was constant inter-status interaction (Tsukada 2012).

The Watanabe and Naniwa areas of Osaka, where Liberty is now located, were well-known for leather production; Watanabe Village was the center of western Japan’s trade in cow and horse skins, supplying both the domestic and Korean markets (Tsukada 2012). Although this was a lucrative trade and leather goods were in high demand, tanners and other people who handled animals carcasses and deceased humans were labeled *eta* (穢多) meaning “very polluted” or *hinin* (非人) meaning “subhuman” prior to the Meiji Restoration in 1868; it has been argued that they formed a sort of class of “untouchables” similar to dalit in India, although this comparison is contested because contemporary scholars are finding that the groups may have more differences than similarities (Amos 2011:32). While the contemporary term used to describe the supposed descendents of these people is *burakumin* (部落民) or *buraku*, meaning “hamlet people,” the origins of *eta*, *hinin*, and *burakumin* and whether or not it is acceptable to simply link

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105 Also note the difference between being marked by status according to job (*hinin* or *eta*) versus place (*burakumin*). This may signify the ways in which stigmatization can be shifted from a object (blood or a dead animal or human) to a person through his/her contact with that object, and finally to a place where a job is carried out or people who carry out the job live. Such shifts also occur in instances of illness, and examples such as Hansen’s Disease, Minamata Disease, and HIV/AIDS come to mind regarding Japan.
these terms and these people, is also contested (Amos 2011). What is germane to our
discussion here is that both self- and government-identified burakumin have been living
in Naniwa for some time, the region is famous for leather, the production of leather and
leather goods has a history of being considered an “unclean” profession, and people
associated with the trade became a minority who were often considered polluted and
discriminated against. In Naniwa today, there are several statues in the area that depict
people playing or making drums, which is what much of the leather produced here was
used for.

According to Amos, Naniwa has been the center of buraku activism and identity
politics since the 1960s (2011), with people fighting for social and economic equality, as
well as for recognition of the stigma and discrimination they still face, particularly when
searching for jobs or spouses. These very visible efforts resulted in the construction of the
Buraku Liberation League Archive, which grew into the Liberty Osaka Human Rights
for Human Rights Education (1995-2004) as an impetus for reframing the struggles of
burakumin as pushing for ‘human rights culture’ (jiken bunka 人権文化) (2011:149).

In addition, the museum was constructed so that rather than simply going to the
museum to view “human rights culture,” the viewers experience human rights culture by
walking through Naniwa and taking in the sculptures and surrounding environs (Amos
2011). Statues line the streets from the train station to the museum, and even the seats at
bus stops are fashioned to look like drums.

**MERs**<sup>107</sup> *(Medical Care and Human Rights Network) and Memorial Quilt
Japan*<sup>108</sup>

Because Liberty houses displays featuring several minority groups, curators have
worked with a number of support organizations in order to ensure that the information
and representations are fair and accurate. In the case of the section on HIV, the museum

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<sup>106</sup> The irony that people who made drums, which are often used in sacred spaces such as temples and
shrines, were considered unclean while their products were not deserves further exploration.

<sup>107</sup> 「特定非営利活動法人ネットワーク医療人権」 Tokutei hitei katsudou houjin netto waku iryou to
jiken; Ma-zu for short.

<sup>108</sup> 「メモリアル・キルト・ジャパン」 memoriaru kiruto japan
consulted with an NPO called MERS. MERS began in 2000 in the wake of the trials against the Ministry of Health (now the Ministry of Health, Labor and Welfare) regarding the infection of patients with HIV and other blood-borne illnesses through medical treatment \((yakugai eizu)\) cases. Its goals are to prevent infection through treatment, discourage stigmatization and discrimination against those infected, and assist in the realization of a society free from discrimination (API-Net 2013). Among other projects, MERS staff produced three volumes of transcripts (amounting to several hundred pages) regarding the \(yakugai\) cases from the perspectives of the patients, their families, and the physicians. They also put on seminars, do community education projects, put out a newsletter for PLWHA, and organize support networks for hemophiliacs. Many of their efforts focus on \(yakugai\) cases, and MERS’ focus on this is reflected in Liberty’s presentation of HIV/AIDS.

The HIV/AIDS display also currently features AIDS Bears and Quilts\(^{109}\). For this aspect of the exhibit, staff worked with members of Memorial Quilt Japan, which is an off-shoot of the NAMES Project started by Cleve Jones in San Francisco. This organization has a tiny office in Osaka, and the quilts of several Japanese people who have been lost to AIDS complications are kept there. They are used in exhibits when possible.

Although these two groups helped to formulate the print materials and display items for the exhibit, they played only advisory roles; like sponsors and consulting NGOs/NPOs for the other two exhibits, they did not have ultimate control over what was included. However, unlike with the other groups, the relationship between Liberty staff and the group leaders is long-term. During interviews, both curatorial staff and NGO/NPO staff referred respectfully to one another by name.

\(^{109}\) Some quilts were made for and used by patients while they were still alive; others were made after a person’s death. Those made after death often feature favorite clothing or items they often used or carried and were never meant to be used as a blanket. AIDS Bears were first made in the early 1980s and given to patients in need of comfort – at the start of the epidemic, people were afraid to visit or touch patients dying from AIDS. The bears were often decorated with personal items in the same way memorial quilts are.

The 2005 exhibit was comprised of 4 “corners” that reinforced the premise that the overall themes were human rights and discrimination. Entering the first room, visitors faced Corner 1, “Human Rights Right Now”110. Viewers could read general information about human rights in Japan and internationally, including examples about the right to work and study. These concepts were then spatially and linguistically linked to Corner 2, “My Values and Discrimination111,” which occupied the same room, where visitors’ values were portrayed as possible roots of discrimination. A girl who spent her life on a respirator served as an example. Put simply, the assertion was made that people (including the visitors) discriminate against those who hold different values or live life differently than the visitor/viewer.

Moving to the next room, viewers faced the “others” that exist in Japan in Corner 3, “The Assertions and Lifestyles of Those who are Discriminated Against112.” This section contained documents and display items for the following groups: Zainichi Koreans, Uchinanchu, Ainu, Women, Sexual Minorities, Disabled Persons, HIV positive people and AIDS Patients, Hansen's Disease Patients, the homeless, Hisabetsu Burakumin, Victims of Environmental Pollution, and Minamata Disease Patients. Although the exhibit clearly described each group, the overall feeling was that these people were still outsiders rather than members of society. The exhibit came to an end at Corner 4, “Discrimination, Human Rights, and Me113,” which featured a video. A video booth, which was part of the first exhibit and remains as part of the current exhibit, is tucked away in the space before completing the circuit and returning to the lobby.

110 Jinken no genzai (「人権の現在」).
111 Watashi no kachikan to sabetsu (「私の価値観と差別」).
112 Sabetsu wo uketeiru hito no shuchō to seikatsu (「差別を受けている人の主張と生活」).
113 Watashi ni totte sabetsu to jinken (「私にとっての差別と人権」).

The exhibit was significantly refashioned at the close of 2010 and re-opened in spring of 2011. Corners 1 and 2 became Zone 1, “The Brilliance of Life.” Upon entering, viewers first face a large video screen with images from nature and everyday life streaming before them, highlighted with words like “nature,” “society,” and “values.” A mural is to the immediate left: “inochi,” or life, is spelled out in pink paper scraps on a cotton cloud in the center, and surrounded by cartoon-drawn figures connected with yellow yarn on a blue-scrap background. The wall nearest the entryway, which is to viewers’ backs as they approach the video screen, is a large display entitled “Living Hand in Hand with Nature” and is filled with snapshots from the natural world, such as insects, animals, and scenic views. In addition to these, this room includes sections on Life on a Respirator, HIV/AIDS, Diverse Families and Sexualities, Domestic Violence, Bullying, and Victims of Crimes. Gone are the references to human rights and discrimination: these terms, along with the use of the active “I” that was present in the previous iteration, are whitewashed from the exhibit.

Over the video, viewers hear the sound of an infant crying. Going around the corner to the main area of Zone One, it becomes apparent that the infant’s cries are part of an interactive display on birth. Children see egg and sperm meet on a video screen, view a sonogram of a fetus in utero, and are finally invited to climb through a “birth canal” to be “born” – and hear the cries of a new baby. This is in the center of the room, with separate displays on the surrounding walls. The section on the diversity of family types is on the left. It includes cartoon pictures of single mothers, single fathers, blended families, children raised by grandparents, and parents of the same sex; however, there is little for people to interact with here, and captions are comparatively brief. It is likely that, with the absence of an interactive component, children would simply walk by the pictures and head for the “birth canal.” The same is true for the sections on domestic violence and bullying, also on the left and just next to section on diverse families. To the right are displays on life with a respirator, assumptions about roles based on gender and other

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114 Inochi kagayaki (「いのち・輝き」).
factors, and a display on HIV/AIDS (discussed in detail below). Before moving to Zone Two, the audience is faced with questions about how morals and values are formed and how stereotypes can lead to discrimination.

Zone Two is entitled “Living Together, Building Society”\(^\text{115}\) and includes displays on various ethnic and social minorities, such as Koreans, Ainu, Okinawan-Ryūkyūans, the homeless, burakumin, and people with Hansen’s Disease (leprosy patients were once institutionalized but are now living in society). Each area includes video displays and items from “everyday life” – for example, the Ainu display includes a model of a pre-Meiji Ainu kitchen and clothing made with Ainu designs. There is also a section dedicated to the history of Osaka. This zone occupies the same space that occupied Corner 3, so some of the exhibits resemble the previous iteration.

Zone Three is entitled “Dreams and the Future”\(^\text{116}\) and includes displays on the industries that have long been central to Osaka’s economic livelihood – including leatherwork and lacquer ware. This is by far the most noticeable difference in terms of theme. At the end of this exhibit is a small photographic display of people who suffer from Minamata Disease. The display contains no explanation of the pictures, but there is a flier that viewers can take to read about the disease in general, which is common for many sections of the exhibit. Just before exiting, there are desks where visitors can watch additional videos of people speaking about their experiences as Ainu, HIV+, single mothers, among others.

**HIV/AIDS at Liberty**

How HIV/AIDS has been represented has of course evolved with the museum. In the 2005 exhibit, PLWHA were placed in the “discriminated against” section (making them an “other”). Additionally, PLWHA were indirectly linked to sex through placement near the sexual minorities display in 2005, although most of the materials on HIV/AIDS focused on yakugai eizu court cases. Framing HIV as a human rights issue involving patients wronged by the State, and indirectly linking it to sex via proximity to sexual minorities may have been less controversial than discussing it explicitly as a sexually

\(^\text{115}\) Tomo ni ikiru, shakai wo tsukuru (「共に生きる・社会をつくる」).
\(^\text{116}\) Yume, mirai (「夢・未来」).
transmitted infection, particularly since the memory of yakugai cases was still relatively fresh (such cases came to a close in 1999). Moreover, the first major wave of cases in Japan was comprised predominantly of such cases, not sexually transmitted cases. However, the display was problematic in that it may have implied that “normal” people, those outside the minority groups listed, do not get HIV; it could have also reinforced the prevailing opinion that HIV was no longer a threat once the trials finished.

Curators set out to address some of these problems for the 2011 display. The contents were radically changed to be both more interactive and more balanced towards the biological realities of HIV (which I discuss below). But they also chose to move the HIV/AIDS display, which served to re-contextualize it. By moving the display to Zone One (“The Brilliance of Life”) and alongside panels that aim to emphasize the diversity and importance of life in Japan from what had been Corner 2 (“People who Face Discrimination”), it was dissociated from “others” (such as Ainu and other minorities) and from issues of sexuality and gender. These displays were also moved to Zone One, but they are located on the opposite side of the room and are separated by the interactive display on birth. This move to re-contextualize HIV/AIDS, family, and sexual diversity into “The Brilliance of Life” signifies a purposeful effort to show that these issues do not diminish one’s will and ability to live and to contribute to society as an everyday Japanese citizen. This separation also signifies a separation between those who are perceived to be visually recognizable as physically embodying difference (ethnic minorities, lepers, Minamata patients, the homeless, the physically challenged, and burakumin) and those who do not.

Re-contextualizing the HIV/AIDS display also entailed scaling it down space-wise as curators worked to make the display more readable and more interactive. One way they did this was to discuss HIV transmission and the progression to AIDS in question-answer form. For example, commonly posed questions were displayed on the wall, and viewers lifted tabs to read the answers. Other documents outlined the increased rates of HIV in Japan, whether or not someone will progress quickly from HIV to AIDS, and whether or not particular behaviors lead to transmission of HIV.
The display items, which used to focus on the class-actions *yakugai eizu* suits against the government, now focus on the art and personal belongings of one man who contracted HIV through treatment for hemophilia. Iwasaki Takayoshi’s photograph, some of his artwork, and personal effects such as his glasses, train pass, and quilt, are all displayed. These items give a more personal feel to the display, showing that Iwasaki was not so different from the viewers. He went to school, studied, drew, and commuted on the train every day, just like many other students. Further, inclusion of Iwasaki’s quilt and other material items was considered to be a major improvement to the display by one of the curators, Ms. Hazama (Field notes 2011). For the first time, the display also included information about the meaning behind red ribbons, AIDS Bears, and AIDS Quilts. Along with Iwasaki’s quilt, a yellow bear is also displayed, with the heading, “Learning about the importance of life through memorial quilts.” Thus, the overall focus has shifted from showing social suffering via the lawsuits, to examining the loss of an individual who is supposed to represent those lost to AIDS complications.

Curators and staff noted that the inclusion of such items improved the exhibit but worried that the position and content of the new display might have weakened the message about HIV/AIDS to the point that viewers would consider it a past issue (Field notes 2011). The display emphasizes that it is not easy to get HIV by listing the ways one cannot contract it, and the display no longer includes extensive information about the court cases. In other words, the museum staff tried to move away from the us/them pattern prevalent in the previous iteration of the exhibit, but then worried they had weakened the display too much by integrating it. And while HIV/AIDS is no longer spatially linked to sexual minorities, it is still strongly linked to *yakugai eizu*, which the public tends to feel is finished; thus, they may assume they are safe from HIV. Moreover, focusing on an individual lost to AIDS may mean that the prevalence of HIV/AIDS and other sexually transmitted infections is lost on the viewers, which may compound effect. This is particularly a problem in Osaka, which has one of the highest rates of incidence of HIV in Japan.

Because “Brilliance” is a permanent exhibit that has gone through several iterations and has been sponsored by the Osaka municipal government, HIV/AIDS has
been represented in different ways. The operative meme in the current exhibit is HIV/AIDS as an iatrogenic issue. While this is important because a large number of Japanese people infected through medical care require ongoing care and face discrimination, iatrogenic infection is no longer a major mode of transmission. Furthermore, direct discussion of HIV as a sexually transmitted infection is difficult because of the museum’s position as an elementary school education site. Thus, though audience members engage with HIV/AIDS directly as a domestic issue, it can still be misinterpreted as an issue that does not affect the general public.

**Liberty Osaka Displays as Sites of Conflict**

Overall, the changes to both the permanent exhibit and each of the displays can been seen in both positive and negative ways. On one hand, the exhibit is brighter, more interactive, and encompasses the history of Osaka. The new approach highlights diversity at the individual and family level first, then moves to show diversity at the societal level, using Osaka as an example. Further, Ms. Hazama pointed out that the reading level is aimed at 5th grade elementary students, and kanji\textsuperscript{117} are written with the readings in hiragana above them so that all the text is readable by almost every type of viewer (Field notes December 2010).

However, although there are some welcome additions in terms of domestic violence and bullying, most of the displays lost space and some (including the section on women) were dropped altogether. Furthermore, materials glossed over many of the complexities inherent in discussion discrimination of and human rights. Most importantly, the direct messages of the importance of human rights and the difficulties faced by those who experience discrimination in Japan were removed, and thus the main thrust of Liberty’s permanent exhibit was vastly weakened. Put simply, a museum that focuses on human rights sadly became less, not more, able to present human rights issues directly in its most recent iteration.

\textsuperscript{117} Recall from Chapter 1 that the Japanese written language is comprised of Chinese characters (kanji), a syllabic alphabet for domestic words (hiragana), and a syllabic alphabet for foreign words (katakana). Sometimes Japanese is converted into English letters (romaji).
Curator Yoshimura Tomohiro describes his opinion of what happened succinctly in a publication of the *Rekishigaku Kenkyu*, known in English as The Journal of Historical Studies. In his essay, Yoshimura states that the changes were a result of political and economic issues such as 1) Mayor Hashimoto\(^{118}\) Toru’s assertion that the 2005 iteration was difficult to understand and must be reconstructed to cater to elementary school children; 2) the severe funding cuts Hashimoto’s administration gave the museum, which cannot support itself on publication or entrance revenues; 3) the time limits placed on the curators to re-do the exhibit; 4) the inability of the staff to press their views for fear the museum would simply be allowed to close; and 5) the lack of a common understanding about the goals of the museum exhibit, the social duties of curators, and the role of curators in collaborating with schools amongst the museum staff (Yoshimura 2012). Liberty has faced criticism regarding various components of its exhibits before, but it was this particular combination of factors – a new mayor with several fiscally and ideologically conservative goals paired with a curatorial staff that was struggling to define its ever-changing roles in a set time frame and new budget – that led to the weakening of this exhibit on a scale that had not happened with prior exhibits.

For example, in response to the 1995 exhibit, the argument was made that trying to show the universal experience of “discrimination” that various groups faced actually obfuscated the significance of each group and left viewers with only a general feeling that some people in Japan faced discrimination (Yoshimura 2012). Thus, for the 2005 exhibit, efforts were made to show the significance of each group by highlighting each one. In response to the 2005 exhibit, some people commented that there were too many documents to read and not enough visuals or interactive components, although what they read was interesting (Yoshimura 2012: 37). Also, it was said that the 2005 exhibit failed to obviously touch on issues of the human rights violations that occurred at the hands of Japanese outside Japan. Regarding this, Yoshimura states that this very problem is a failure of the museum, and cites three instances in which such events/exhibits were

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\(^{118}\) Hashimoto is an ultraconservative politician who considers Tokyo Governor Ishihara as his mentor. He is known for trying to conserve funds by combining the Osaka City and Prefectural governments; he is also known for using a heavy hand with teachers who refuse to stand during the national anthem (Kimigayo) and public servants who oppose his ideas (or just have tattoos). They are often fired. He is considered a dictator among some circles.
cancelled – two of which had been set to occur in 2008\textsuperscript{119} (Yoshimura 2012). Although Yoshimura does not make this link directly, it difficult to believe that it is purely coincidental that these events were cancelled the year that Hashimoto took office.

On a more positive note, others compared the museum to peace museums that depict past transgressions, such as the Hiroshima Peace Museum or various Holocaust museums. One scholar said that seeing Liberty’s permanent exhibit, he could understand the importance of creating exhibits that engage both the representees’ consciousness and the representors’ logic (Yoshimura 2012). The simplest ways to see that the curatorial staff attempted to demystify discrimination is to notice that the second iteration greatly expanded the exhibit and led to the inclusion of discrimination in the title.

Given the conservative nature of the municipal government, it is perhaps not shocking that the government’s involvement in the yakugai cases is weakened compared to the former iteration; that HIV as a sexually transmitted illness is touched upon but constrained by what is deemed appropriate for a 5\textsuperscript{th} grade audience; and that HIV/AIDS activism needed to be tempered by adding personal effects and artwork. Mr. Yoshimura explicitly states that no group is solely responsible for the changes:

“I definitely do not want to pass the buck or push all the blame onto Cultural Affairs[from the city and prefectural offices]for the contents’ lack of direct connection to discrimination and human rights, or the loss of the curators’ opinions in the exhibit. On the contrary, it is because so many people, including myself, endeavored to keep the museum going, considering it natural to shoulder our individual, professional responsibilities as museum administrators. Following that, we analyzed the museum’s situation calmly, groping towards the solution, while also realizing that, more so than before, from here on we must be more clear about our stance as curators in participating in the [production of] exhibits.” (Yoshimura 2012:36)\textsuperscript{120}.

\textsuperscript{119} For example, one of these included war atrocities committed by the Japanese at Hainan during WWII.
\textsuperscript{120} 「ただ、学芸員の意思が反映されたテーマが大幅に減少し、差別・人権問題に直接かかわらない内容が多分盛り込まれたことの原因を文化財行政に押し付けたり、責任転嫁したりする意図は筆者にはまったくない。むしろ、多くの人々が当館の存続のために尽力してくださいましたのであるから、展示の責任はやはり筆者にもあり、当館の運営にかかわる職員のひとりとして職責
However, the financial power that the municipal government had over Liberty cannot be ignored. Although exhibits at Liberty have been shaped by the discipline of historian-curators, they have also been subjected to the socio-economic rules of local government. Further, what makes this exhibit different from the others, what Yoshimura clearly points out, is that it is the *continued efforts* of the staff and others to act individually and do their jobs to fight for the continuance of the museum collectively that has shaped the exhibit over time. In other words, keeping a permanent exhibit going requires the constant effort of all players to re-assess the exhibit and their roles in it. Sponsoring organizations may continue to support the exhibit, but the players within those organizations change. Therefore, the goals change. The exhibit is then a product of dynamic tensions between organizers and supporters, people who are variously disciplined and who possess different levels of authority at different times and in changeable circumstances.

Yoshimura is perhaps unable to openly criticize Hashimoto’s regime, and it is important to acknowledge that politically and economically, the museum did not have the upper hand: the municipal government did. Hashimoto, in his typical dictatorlial fashion, was careful not to give museum staff the time or the open atmosphere required to discuss how to make the changes he demanded. He did not give them what they felt was adequate time to do the renovations he requested. His committee cut the museum staff by half, effective after the renovations were complete. Moreover, he threatened to close various museums in Osaka in general. In other words, the staff felt pressured to simply conform or lose their jobs – or the museum entirely. I argue that these factors, combined with Hashimoto’s ultra-nationalist views that directly oppose Japanese diversity, made it difficult for the whole exhibit, and the HIV/AIDS exhibit in particular, to be formulated any other way in 2010-11. The government set the parameters, and the curators, working as best they could within the time, budgetary, and thematic constraints placed on them and, afraid for their jobs and the fate of the museum, followed the local government’s
lead. The result was that the permanent exhibit at Liberty Osaka Human Rights Museum currently does not address human rights directly at all.\footnote{In fact, in summer 2012 Hashimoto opted to cut funding to Liberty Osaka from spring 2013 “on the grounds that the museum displays are ‘limited to discrimination and human rights’ and fail to present children with an image of the future full of ‘hopes and dreams;” (Morris-Suzuki 2012). In response, the museum curators retorted that they hope to abolish discrimination and abolish human rights \textit{so that children can} have hopes and dreams (Liberty Osaka Human Rights Museum 2012) and are thus seeking private support.}

**Discussion: Disciplinarity and Precarity**

“The work of a curator is... curious. There is the work of art. And yet, it is but one profile of the work, singled out in the curator’s eye. Why this particular artwork, not that one? One artwork is placed beside another. Why do these two works share the same space? ... In the gaps between the artworks you can feel the curator’s intent, can almost see the curator, working behind the scenes.

‘What is it you would like me to see?’ – we always feel prompted to ask. Naturally, if we did ask, the curator would act surprised, would laugh and say, ‘You, the viewer, are free to find any message you would like.’

Nonetheless, in this space where we are expected to exercise our freedom, the curator has been brutally deliberate in imposing his or her (in this case, her) choices. We can only be here and respond.

At the same time, the curator may not be completely clear about her own intentions. We feel our way forward through a darkness she has measured with her sensibilities. The curator follows her intuition, suffers indecision and perplexity, even deviates from course. As a consequence of these dilemmas, she inadvertently gives us messages she is not even aware of.” (Ueno 1998:173).

Messages we are not aware of. Sociologist Ueno Chizuko penned these comments in response to the 1998 iteration of “Love’s Body,” and they are germane here because of her attention to the connection between embodied disciplinarity and unintended messages. Similar to my arguments in Chapters 1 and 2, where I make a case for studying the significance of the vagaries of the term \textit{eizu}, the difficulties in spreading non-viral information, and gaps in learning networks, I argue that the unintended messages of
exhibits like the ones discussed here are worthy of our attention because they contribute to HIV/AIDS-related social precarity in important ways.

The discussion of the three exhibits above in terms of disciplinary gazes, representation of Others, the importance of location, and issues of directness and indirectness helps us to understand the goals, contexts of production, and messages – both intended an unintended – of each. Although all three are well-intentioned and promote awareness of HIV/AIDS, they inadvertently perpetuate memes such as HIV/AIDS as a problem of foreign, gay men (“Love’s Body”), or foreign Others who are poor, promiscuous, drug addicted, or criminals (“Access to Life”). HIV/AIDS only touches Japanese lives when contextualized as an iatrogenic issue (“Brilliance”) or when a work featuring Japanese gay men is placed in an “AIDS Exhibit” – which is only demarcated as such by a foreign language (not Japanese) title (“Love’s Body”). In other words, direct engagements with HIV/AIDS in Japan are truly direct only when the focus is an Other. When Japanese people are included, the tendency is still to avoid direct associations with current risk groups, regardless of differences in the rationale or location.

Perhaps the most important factor for this is the disciplinarity and the resulting goals of the organizers. Each of these exhibits was put on for a specific purpose through which they addressed HIV/AIDS. For example, “Love’s Body” was meant as a critique to the nude genre; “Access to Life” is a call for national-level donations; “Brilliance” is meant to show diversity in Osaka. Therefore, in all of these exhibits, HIV/AIDS was framed differently and people living with it were subjected to different gazes; these ways of seeing, via the organization and display of the selected photographs, were then presented to different sections of the Japanese public. In other words, not just the images but the ways of seeing the images were transmitted to the various audiences.

Foucault’s concept of the “medical gaze,” in which biomedical practitioners focus on disease rather than a patient, can be extended and used to describe the disciplined gazes of all these organizers. Beginning with “Access to Life,” it appears that granting organizations are utilizing the same reductionism common to biomedicine, in which they focus on access to medicine as access to health – at least in terms of their museum exhibits. Before-and-after photographs, like before-and-after x-rays, are used to illustrate
the relationship between treatment and health. All other factors are invisible. This reductive gaze is blind to the fact that a reliance on photography of suffering taken by western professionals in non-western settings, along with the expectation that local people write grants following western formulas, is inherently colonialist. Further, such stipulations imply that either local people are not considered to be disciplined in a way that they can contribute photographically, or they are not disciplined in a way international funding agencies recognize, or “Access to Life” organizers are not disciplined in a way that makes such local participation possible. Surely this is not the case and adjustments can be made.

With regard to “Love’s Body,” the gaze is an aesthetic rather than medical one. The basic premise for this exhibit, or any fine art exhibit, is that the pieces included must be fine art – something that is defined partially through forms and partially by how forms are broken. When forms are “broken well,” genres are pushed forward; but the evaluation of these breaks is often from the perspective of by sensibilities that are hard to define. When fine art curators embody the discipline, they choose artwork to fit an exhibit using his or her “sensibilities,” as Ueno points out above. But what they do not choose also tells us something about a curator’s aesthetic gaze. Again, it seems that either Kasahara’s disciplinarity prevented her from selecting fine art photographs from artists in the global south, or global south photographers are not disciplined in a way that the fine art world recognizes.

While curators at Liberty Osaka attempted to facilitate a holistic, human rights-centered gaze, their interpretations were shaped by the political gaze of the city government. Although the staff struggled to present Japan in general and Osaka specifically as diverse, capable of facing adversity, and vibrant in terms of activism, this perspective was “disciplined out” of them in the face of Hashimoto’s “One Osaka” agenda though threats of lost funds, lost jobs and museum closure. Liberty Osaka became a miniature panopticon in which the “political gaze” disciplined the staff to the point that messages about diversity, adversity, and activism were silenced and democratic participation disappeared. Management by the City under such an administration does indeed appear prison-like.
Conclusions

Finally, the bottom line is that these exhibits encourage direct engagement with HIV/AIDS in Japan. By focusing on HIV/AIDS in public setting, these exhibits force the issue. Considering the rising rates of the disease and the difficulty in broaching the topic, the organizers of the exhibits deserve credit for their efforts to improve awareness. However, within these exhibits, it is apparent that grappling with the presence of HIV/AIDS in Japan is still dealt with indirectly. The goals and disciplinarity of the organizers work such that viewers are encouraged to see HIV/AIDS as a problem of foreign others (who are usually poor, drug addicted, promiscuous, and/or gay) or minority groups such as hemophiliacs domestically. Therefore, the overwhelming, unintended message is that “HIV has nothing to do with me.” So, organizers who aim to alleviate the precarity associated with rising HIV rates domestically and in response to the epidemic abroad through these exhibits may actually, inadvertently, contribute to precarity through the display of images that lead the Japanese public to believe HIV/AIDS is not their problem.

These issues can be alleviated by being reflexive about disciplinary gazes and acknowledging not only what is included, but what is left out and why. This would increase the chance that exhibits about sensitive subjects such as HIV/AIDS work to alleviate rather than foster precarity. Rather than inadvertently perpetuating stereotypes, the acknowledgement of frameworks would help curators avoid using them in exhibits, and contribute to their destabilization amongst the general public.

Museum curators and exhibit organizers are not the only ones who experience problems when trying to broach the topic of HIV/AIDS in meaningful ways. In the following chapter, I discuss how non-governmental organizations recognize the difficulty in balancing messages about preventing HIV and living healthily with it in such a way that people recognize it as a grave enough threat to their personal health that they use condoms, but not to the degree that they will discriminate against those who have it.
Chapter 4: Illness in the Time of NGOs and Socialized Medicine: Navigating HIV/AIDS Resources

Today I delivered letters requesting interviews to various organizations in Tokyo. I tried to deliver one to Place Tokyo. Tried. Looking for Place Tokyo... the whole experience was just very odd. I couldn’t even find the building at first. With map in hand, I walked around the neighborhood. None of the buildings looked remotely like a professional office. I’m usually good with maps, so I got frustrated. Finally, I called a friend who lives in the neighborhood to see just how turned around I was. It turns out I wasn’t turned around at all! I was in the right place after all – the seemingly residential building in front of me really was the place. I was taken aback because it was clearly an apartment building with no signs of any type of office. But, shrugging it off, I went up to the second floor to look for the office. I couldn’t hear many signs of occupancy and there were no signs on the doors or on the mailboxes downstairs. The door bearing the number from the website was deathly still, and there was no answer when I knocked. I found myself examining the electric meters outside each door and only two of the five on the floor were quietly whirring away. Maybe I should check these? Maybe the website was wrong? No one answered at the first door. A housewife and two little kids answered at the second place. Knowing this was definitely not Place Tokyo, I excused myself, waved goodbye to the little boys who were looking after me with great big curious eyes, and admitted defeat. An hour later, I was on the bus to Nagano. I like to do these things in person, but maybe email is better in this case?! (Field notes, November 20, 2010)

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My e-mail request to meet the director of Place Tokyo had been promptly accepted, and I headed over. They sent directions in the email, noting that they had recently moved and were still updating their website to reflect the changes. I felt much less like an idiot.

Searching for the new office actually felt almost the same. There were no landmarks, no signs of any kind. I still felt like I was lost in some Murakami novel, and any moment some woman with her voice turned down or a man wearing a sheepskin would lead me into the secret lair of this organization. But this time, I was sure I could
find it. And I did. It was in an old apartment building not so different from the place I’d first visited. But this time, there was a small nameplate at the door – Place Tokyo. I rang the bell and was greeted at the door – just like I would be if I went to a friend’s home. “Please come in,” a middle-aged woman said warmly, gesturing to the slippers on the step above the entry way.

As I sat in this warm, home-like space, I marveled at how large the operation seems online with how tiny it is in terms of physical space. But I also thought about how much easier it must be to come to a place like this to talk about something as sensitive as HIV. The building is not on a main road. There are no big signs announcing what they do. The space is not clinical. There are rooms that can be closed, a kitchen area where people can have tea and snacks, and a balcony where people can go to get fresh air or a smoke. This home-office is the base of the first and most prolific HIV support organization in Japan. (Field notes, December 9, 2010)

The above anecdotes from my field notes illustrate my difficulty in finding Place Tokyo, one of the most active and influential support groups for HIV in Japan. Upon first perusal, it seems like a typical “lost in the field” type story where the researcher just does not know where she is going. At first, that is all I thought it was, too – simply a strange, frustrating experience. However, the more I looked through my data, the more I realized that this experience encapsulates the contradictions inherent in doing HIV support work in Japan – being “out of the way” and discrete to protect privacy on one hand but hard to find on the other, for example. It also symbolizes the intense efforts of navigation required by yōseisha to utilize the available resources, and for the support organizations to secure resources, craft messages for both HIV- and HIV+ groups, distribute/find information, and serve as counseling and support centers for the people who depend on them.

In this chapter, I break from the format of the first three chapters in which I discussed HIV in terms of what and how non-yōseisha know, learn, and exhibit information about HIV/AIDS. In the previous chapter, I noted that yōseisha and support organizations that specialize in HIV are asked to contribute to exhibits – exhibits that are largely put on by people who are not living with HIV/AIDS. But from this chapter on, I
shift the focus to how yōseisha experience HIV through the resources that are available to them. This begins the second half of this dissertation, in which I focus on what and how yōseisha and those who work closely with them know, learn, and present information about HIV/AIDS.

As stated above, this chapter is about navigation. I begin by focusing on visibility by comparing the messages about HIV at a rural test center and a blood donation site; in this section I draw from HIV testing guidelines drawn up by the CDC (1999; 2006), Bell’s (2007) work on testing globally, and Robertson’s (2012) research on blood donation in Japan. I argue that the visibility of HIV at donation clinics paired with its relative invisibility with regard to testing sites leaves the public confused about HIV prevalence in the community and where they should go for testing. Next, I discuss the relationship between disclosure and treatment by highlighting the experiences of a yōseisha, Mr. E, who has worked as a long-time volunteer at his hospital. I draw from Etzioni’s (1999), Jeffe’s (2000), and Seki and colleagues’ (2009) research on disclosure to contextualize Mr. E’s experiences and illustrate the difficulties of disclosure in medical settings. I suggest that despite having a socialized medical system, disclosure even in medical settings in Japan can lead to stigma and rejection of patients. Following this, I discuss how support organizations (often termed the third sector) aim to fill the gaps left by the private and public sectors using Place Tokyo as an example. However, I show that yōseisha still face problems in accessing these resources, and support organizations likewise struggle to secure financial support to keep resources available. For this section, I draw on Devine’s (2003), work on NGOs, Hammar’s (2007) work on HIV NGOs in Papua New Guinea, and Takao’s (2001) explanations of NGOs in Japan, among others. Through this discussion, I illustrate how accessing resources is difficult, not necessarily because of an individual’s desire or lack thereof to use them – although this is sometimes the case – but because of contradictions about what is visible, disclosed, and connected – and how comfortable people are in general with dealing with HIV in Japan.

Following previous chapters, I continue to frame HIV/AIDS responses as being direct or indirect and comment about how they therefore contribute to or alleviate precarity. So far, I have generally argued that indirectness alleviates social precarity (fear
of HIV/AIDS and what it means to society) at the expense of contributing to the precarity of the HIV/AIDS epidemic (engendering the spread of HIV by avoiding the issue) and that directness alleviates the spread of HIV but contributes to social precarity by forcing people to confront HIV and related issues. In this chapter I show that directness can also contribute to precarity particularly with regard to making test centers visible and disclosing HIV status, which puts yōseisha at risk for being stigmatized as they seek to mitigate the effects of HIV in daily life. Moreover, the purposeful use of vague, indirect terms can be helpful even though I argued that the opposite is true for the term eizu. Thus, I argue that the Japanese tendency to be indirect can contribute to or alleviate various forms of precarity and therefore cannot be classed as simply harmful or beneficial.

Furthermore, Butler has described how precarity is the result of having to trust and rely on unknown others (2004). This is definitely the case with regard to locating and utilizing resources at clinics, hospitals, and even support organizations. These organizations form systems aimed at optimizing usage -- which requires disclosure -- while attempting to protect privacy, and yōseisha rely on them for help. But these two factors, optimizing usage and protecting privacy, are often at odds with one another, something that comes to the fore when we trace the “expected” journey of someone living with HIV as they attempt to find support and get treatment. Finally, it is not only the yōseisha who must navigate the care landscape: organizations also must make policies based on what participants find most ethical, what is financially feasible, and what various people in the population need. Getting care and providing it, then, are not as simple as the system implies because everything is in flux and mutually dependent.

In the following pages, I describe the basic turn of events for people who find they are HIV+. The ideal course is a simple one: a person is tested at a clinic that is specified as an HIV testing site, referred to a hospital that has a team of HIV specialists, begins treatment, and visits whichever support groups s/he feels comfortable with. Yet each of these steps is much more complicated than this simple protocol implies. I begin with the testing.
(In) Visibility of HIV Testing Sites and HIV Messages at Blood Donation Centers

The first HIV tests were developed in 1985 in the United States with the initial goal being to protect the blood supply there (Centers for Disease Control 2006)\textsuperscript{122}. There are now a number of ways to be tested, and home tests are now beginning to emerge. Innovations such as targeted testing are also beginning to take off in some urban areas in the U.S., such as in clubs frequented by high-risk populations (Barnes W et al. 2010; Schulden et al. 2008)\textsuperscript{123}. However, most HIV tests still take place in medical settings and are conducted by medical staff. Of these tests, there are two types, anonymous testing and confidential testing (Center for Disease Control 1999; 2006). Anonymous testing generally takes place at a clinic that specializes in STIs and/or HIV, and as the name implies, no names are taken. Confidential testing generally takes place at health care facilities that deal with a range of health care issues and tend to be familiar to the person seeking the test – such as a family practice clinic or hospital. I will discuss disclosure more fully in the section that follows this one; however, for now it is important to consider that seeking any test requires some form of disclosure. For example, taking a confidential test involves making a medical record of one’s test – positive or not. However, simply visiting the facility does not disclose one’s purpose in going there. Even though the information is supposedly “confidential,” this information may be obtained by people in the medical field or even by third parties (again discussed below). This is the opposite of anonymous sites, where medical records are not tied to individuals by name or personal records, but visiting the site can lead people to discern one’s concern about the possibility of an STI of HIV infection.

Since testing requires some form of disclosure about one’s possible or actual status regarding infection, whether verbal or otherwise, people may fear stigma. As Bell and colleagues note, stigma and discrimination can come from other visitors or even staff

\textsuperscript{122} I will return to the significance of this “protection” later in the chapter.

\textsuperscript{123} Barnes et al illustrated that HIV incidence rates amongst MSM at one site was fifteen percent with only forty percent having prior knowledge of their status (2010), while Schudlen et al found rates amongst transgendered people to be twelve percent with no individuals having prior knowledge of their HIV status (2008). The CDC reports similar statistics from data from five U.S. cities: fourteen percent of MSM between 18-24 years old surveyed tested positive for HIV, and eighty percent had no prior knowledge of their status (Centers for Disease Control 2006).
who work in medical settings (2007); Kangashe and Rwebangila note that lack of privacy, for example, was a major complaint at a clinic in Tanzania (2011). As my examples below show, sometimes testing sites go to great lengths to ensure privacy as well as anonymity or confidentiality.

Of course, in order to be tested for HIV, one must actually feel the need to be tested. As discussed in previous chapters, general knowledge about and awareness of HIV/AIDS is low in Japan. This translates to reduced motivation to get tested, low testing rates, and lack of knowledge about where to get tested. Even Misa, an interviewee we met in Chapter 2 who is relatively knowledgeable about HIV/AIDS, was not aware of where she could get an HIV test in her rural hometown. Part of the reason for this is the way that anonymous HIV test sites are obscured to protect the privacy of those who come. However, it is possible that obscuring the test sites also obscures HIV from the general consciousness of the public. Consider my experience taking an anonymous test:

Every month, the prefectural newsletter comes to my house. This month [June 2011], there was a full-page advertisement about getting tested for HIV. There was a blurb about the rates increasing here and how the test is free and anonymous. Figuring it was time for me to see for myself how this worked, I made an appointment over the telephone, following the directions on the page. I asked for a particular time, and they gave me a patient number. The woman gave me directions to one of the health clinics in town and told me to call this same number when I was in the parking lot on the day of the test.

I arrived at the test site a few minutes early and took in the building. It was a health center near a university, and people came and left in a steady stream. I called the number I had called to set up the test. The woman on the other end said a nurse would meet me at the door and show me to the right room, and hung up. A few moments later, a white-clad, uniformed nurse approached me and led me to the second floor of the building. She showed me into a room down the hall, asking if I spoke Japanese. I said yes. She looked relieved. She gave me a form to fill out (where was I from, how old was I, did I have a reason to think I had HIV?)
When I was done, the nurse pulled out a binder and explained each step of the HIV test and the window period\textsuperscript{124}. She spoke slowly and purposefully, and paused at various places to allow me to ask questions. She explained what would happen after a positive or negative result (offers for counseling and referral to a hospital in the case of a positive test, virtually nothing for a negative test). The nurse asked if I wanted to be tested for Chlamydia as well – and said that although I’d have to wait for a week for my HIV test results, the Chlamydia test would be ready shortly after I took it because they processed them in-house. I agreed to both tests, thinking I might as well get the “full” experience.

With the explanations finished, she took my blood. I noticed she did not wear gloves, which I thought was odd for a health care professional who tested for infectious diseases. She gave me the test kit for Chlamydia. She took me to a tiny room adjacent to the test room that was filled with brochures on sexually transmitted infections, told me to help myself to whatever I wanted, and left me to my own devices. I took one of each brochure, then went to the bathroom to take my self-test.

After sliding what remained of the test kit through a small window in the bathroom, I sat on a cushy bench in the middle of the hall to wait for my Chlamydia test results. I read, and watched people come and go as they would in any government or community office. A whole group of elderly housewives came in, seemingly for a class on food and nutrition. They smiled and bowed their heads to me as they went into another room at the end of the hall, the one closest to the stairs. While I waited, not a single person went through the doors I’d been taken through for my test – except the nurse, who came out to invite me back into the room one more time. She gave me a slip of paper with my results and asked if I had questions. I’d have to call back a week later and give them both my patient number and the date and time of my test to get the HIV results. I thanked her and stepped back into the hall.

\textsuperscript{124} The window period is the time between infection and the time the infection will show up on a test. It is about three months. Essentially, an HIV test shows your status at three months before the test date; it is therefore possible to test negative even if you are infected.
There were no signs, no indications of what went on behind those doors. The people who smiled and nodded at me had no idea why I was there, but were courteous and kind. Strangely, no one seemed to notice the room I had been in for 20-30 minutes. It was like that space was just invisible to them. (Field notes, July 14, 2011.)

So what can we take away from this experience? The clinic took great pains to ensure the privacy of people seeking testing, and this went far beyond not asking for a name. The space was carefully controlled. Similarly to a successful clinic in South Africa that catered to a wide variety of patients with multiple types of health issues rather than advertise its HIV services (Bell et al. 2007), the test was in a regular health facility that caters to the public, with municipal employees and citizens coming and going to do everyday things. There were no signs about the test or visible indicators of where to go if that was the purpose of your visit: the staff quite literally guided you from the door. If I had not seen the advertisement or looked up where to get the test, I would never have known HIV tests were available there; without the nurse, I would not have known where to go even if I had found out. The place appeared to be as anonymous as the test.

Additionally, my visit seemed to be timed so as not to coincide with anyone else who wanted a test. I met and spoke with the nurse who tested me and no one else – apparently it was her job to man the hotline, too. I found myself wondering how many people could possibly be tested this way, given that I was there for about an hour, and they only offered testing on specific dates and times. I mentally compared this site to other testing sites, such as one in Honolulu in which people sit in a packed room waiting their turn to be tested for various sexually transmitted infections; this place was also much different than the busy clinic in which patients voiced complaints about privacy in Tanzania (Kagashe and Rwebangila 2011). The assumption at work here seemed to be that they expected few people to come for the test – even though this prefecture has one of the highest rates of HIV per capita. I wondered how the set-up would be different if they expected a larger turn-out. Although this was probably not a conscious choice, the lack of visibility of the HIV testing site probably played a part in making this ultra-private system viable.

To summarize, the anonymous testing site provided ample privacy through minimizing contact with staff and other people seeking testing, as well as through an anonymity of place through creating a nondescript space in a health center. As I stated,
there was no way for other visitors to the building to know why I was there, but there was also no way for visitors to find out about such testing available around the center. Overall, the testing space felt invisible. I felt invisible. While privacy functions to protect people from discrimination and blame, it can also lead people to turn inward. Such an experience could lead a positive person to feel that they are alone and isolated, as the place and space implies, which would contribute to feelings of shame, self-blame, and depression.

So what about confidential test sites? Most confidential tests are done on patients who either have an existing condition in which HIV would complicate treatment, or a condition that suggests HIV or AIDS. One common example is prenatal screening for pregnant women. In the U.S., for example, the CDC began recommending that all pregnant women be screened for HIV, and seeking medical attention is considered consent for an HIV test (Centers for Disease Control 2006). It may come as a shock to women to find that they have been screened for HIV – and to find that they are positive (Bell et al. 2007).

Japanese physicians follow similar guidelines as those outlined by the CDC, and all pregnant women in Japan are tested as a matter of course. Generally no attention is drawn to the test. When I myself was tested during a prenatal exam, my doctor gave me two pieces of paper, one with my HIV test results and one with every other test on it. She handed me the most detailed one first and reviewed the results. Then she handed me the HIV test result, saying, “And of course this is negative, too.” Barely taking a breath, she went on to talk about diet and target weight gain. And, notably, there was nothing about HIV visible in the clinic; the same is true for most hospitals.

This is probably how most women experience HIV tests in Japan, as something routine at pregnancy and nothing to worry about. And for the majority of Japanese women, this is true. Women have much higher test rates than men, and comprise a small fraction of new HIV and AIDS cases every year. In this way, Japanese women represent a public health ideal for managing infectious disease: mandatory testing, few positive cases, and immediate care for those who do test positive.
However, there is one more increasingly common reason for confidential HIV tests to be done in Japan. Sometimes someone, usually a man, comes to the hospital after feeling ill for quite some time. He has a suite of symptoms and health problems that persist or return quickly even after treatment. He has not thought about HIV, he just knows he feels terrible and is becoming weak. When he cannot endure it anymore, he goes to the hospital. When doctors examine him, they ask, “Will you take an HIV test?” The patient is shocked but agrees. The test is positive and, due to the CD4 count and the symptoms, the doctors diagnose the patient as having not just HIV but as progressed to AIDS. In Japanese, this is called *ikinari eizu*, or, “suddenly, AIDS.” *Ikinari eizu* is a problem that occurs when there is a general lack of awareness about HIV/AIDS, when people fear getting tested because of the stigma of the test or a positive result, when people feel that HIV/AIDS is someone else’s problem, or when there is a combination of these factors.

It is important to note that the visibility of HIV testing at health facilities – whether at anonymous or confidential sites – is limited. If other means of making testing visible were utilized, this might not be problematic. But as it stands, it is difficult for the public to see that testing is there and that it is important both for personal and public health. This “invisibility” of the HIV testing site and information about testing is more pronounced when compared to the visibility of the blood donation centers and the encounters with messages about HIV one has there.

When the technology for blood transfusions was developed for general use in the United States following WWII, campaigns for blood donation began (Blood Centers of the Pacific 2013). Americans were encouraged to think of blood donations as a “gift” or as a civic responsibility (Blood Centers of the Pacific 2013), but these concepts are far from universal. Japanese people in particular have been more reticent than Americans about donating blood and organs as well as receiving them on several grounds: reasons range from hesitancy to “give away” a part of the body, to aversions of mixing one’s blood or tissue with someone else’s, to distrust of the medical system in general (Lock 2002). Robertson further notes that ideas of the strengthening or weakening of the “Japanese Race” through “mixing blood” have waxed and waned, and that one way tacit
blood donation rules in Japan differ from those in other countries is the importance of the perceived “purity” of Japanese blood (Robertson 2012).

In fact, the possible dangers of receiving blood products from persons unknown as part of medical treatment were made clear when connections were first made between HIV infections in hemophiliacs in the U.S. and treatment with Factor VIII, which aids in clotting. Infections were not limited to the U.S., however; Factor VIII manufactured in the U.S. was also used in Japan. The Ministry of Health, Labor and Welfare reported that 1,432 hemophiliac patients contracted HIV after using imported, unheated blood products that had been prescribed by their physicians between 1983 and 1988 (Seki et al. 2002). This is about 40 percent of the hemophiliac population in Japan. The use of these products had been approved by the Ministry, despite the purported connection between such products and HIV infection of American hemophiliacs and the exclusive use of heated blood products in the U.S. starting in 1985. Two class-action lawsuits were leveled against the Japanese government and the pharmaceutical companies that made the product, which the plaintiffs won (Seki et al. 2002). These scandals have tied HIV to blood, blood donation, and blood transfusions in the minds of the public, although heat treatment technologies and donations by Japanese for Japanese have helped improve the image of treatments involving blood for some\(^{125}\).

In addition, Yamamoto and colleagues have noted a steady increase in the detection of HIV tainted blood in donations since the start of the epidemic in Japan (2006). Because it is well-advertised that blood donation centers test donations for HIV and other pathogens, and due to the fears of testing or the lack of knowledge about where to go, this increase in HIV in donated blood may signify people’s attempts to find out their status without going through anonymous or confidential testing channels – hence the messages about HIV in the donation center, and attitudes towards a foreign woman’s presence there below:

\(^{125}\) While most HIV-blood donation issues have been due to HIV+ individuals making donations that were ultimately used to treat HIV- patients, Chinese people who were paid to give blood have become infected with HIV through the use of unhygienic collection practices (Erwin 2006).
I decided to donate blood this month [March 2011], and see what sort of information they have about HIV there. I went to the local donation center, and the first thing I noticed was a big sign by the door that read, “Please do not donate blood to find out your HIV status." Apparently, I did not even have to walk through the door to get the first message about HIV.

The first few steps were similar to those you would take donating to the Red Cross in the U.S. I answered all the survey questions, and had my blood pressure checked and my blood typed. They were also doing elective screens for cholesterol and general blood chemistry exams, so one of the technicians took some blood for those tests. She sent me to the lobby to drink 2-3 cups of fluids.

A nurse called me back into the donation room. There were twelve large reclining chairs, like dentist chairs, arranged in a circle so that they all faced inward. When I sat down, every chair was occupied and I was one of only four women. The nurse who called me in checked my name and chart, and started talking to me as she worked. Swabbing my inner elbow with Betadine, she asked how long I had been in Japan (eight years). She placed water bottles in my hands (apparently they were cold) and asked what I did for work (teacher and researcher). She tied the band and inserted the needle as I told her I was married and my husband was a researcher, too. As we talked about studying abroad, English education, and trips her daughter had taken, I was keenly aware that every person around me was observing me without watching me – and that the nurses talked to no one but me. It was like we engaged in a conspiracy to demonstrate I was a ‘good foreigner,’ worthy of contributing my blood to the bank that supplied it to Japanese people in need. Donation went surprisingly quickly, and she sent me back out to the lobby for more beverages.

Before leaving, the office staff brought me a clear plastic file with Hello Kitty and Kenketsu-chan – Mr. Blood Donation, who has two drops of blood for ears. Inside was a

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126 In 2013, the neighborhood notification file came to my house (it is a file with monthly notifications that get passed from house to house). One of the fliers was for blood donation – a blood donation van was going to be in our neighborhood by the train station. Again, the message “Refrain from donating blood to find out your HIV status” was included. When I looked up the Prefectural Red Cross office online, they have this on a banner on their site in big letters.
flier about where to get information about HIV from the Japan Foundation for AIDS Prevention.

From the very start, the two things that make the HIV testing site anonymous – no visible connection to HIV in any way, and maximum anonymity for the person being tested – were completely reversed at the donation site. Not only did the nurse call me by name as a way of checking to ensure she had the right donor, she asked me very specific questions about myself (my schooling, my job, my family) during the act of donation. Whereas I was an anonymous foreigner, the nurse was an anonymous nurse, and there was no “audience” whatsoever at the health office HIV test site, I played a very stereotyped role at the donation center, one that was facilitated and encouraged by the nurse and was seemingly for the benefit of the other donors. Although the Japanese donors did not receive nearly the same amount of attention I did, their names were still verbally verified as they sat down, and they were all seated in a circle with their faces clearly visible to one another. Given the rural setting of the donation center in combination with this set-up, I would not have been surprised to hear one donor call out to another in recognition. Donors and practitioners were both highly visible in this very public setting.

Furthermore, the signs and information regarding HIV/AIDS were presented for the benefit of all donors (and recipients) in a way that could not be ignored. One could hardly help the large signs by the door, the questions on the survey that included a question about HIV status, and the leaflets literally enveloped by Kenketsu-chan. Unlike the test center, messages about HIV were everywhere and directed at everyone. Through these signs we were told not to use donation as a proxy for a test, and through the leaflets, we learned where we could go to get tested.

**Summarizing (in)visibility**

The stark contrast regarding the visibility of the donors, the blood donation center, and the center’s engagement with HIV compared to the invisibility of these at the municipal testing site can be explained in a few ways. First, the connection between blood and HIV was made clear and very public with the lawsuit against the Japanese government in the 1990s. It was the activism on the part of patients infected through
blood treatment that shamed the Japanese Ministry of Health (now the Ministry of Health, Labor and Welfare) for knowingly using tainted blood products after they had been pulled from use in the United States (Seki et al. 2002). Many middle-aged and elderly Japanese remember this. The pronounced messages about not donating blood to find out one’s HIV status probably serve not only to warn those who may try to avoid test centers, but also to assure the public that efforts are being made to ensure that donated blood is “clean” and safe.

Additionally, increasing rates of HIV in this particular region may have lead to the local emphasis on disseminating information about HIV at blood donation centers. Public health officials I spoke with readily acknowledged HIV as a growing concern and noted that education about it is difficult because local views about sex and sex education tend to be conservative. To circumvent that, the incidence rates for HIV have been uploaded onto the prefectural website, and messages stressing “HIV is our problem” have circulated in newsletters. Further, given that 70 percent of blood donors are male, and men are less likely than women to be tested for HIV, this seems like an effective method for drawing attention to HIV in a specific group. Therefore, it is possible to view the messages at the donation site as aimed at fostering awareness as well as attempts to protect the blood supply.

Furthermore, it is important to consider the vast difference in the two actions described above. While getting tested for HIV is considered something private that one does for oneself, donating blood is a public action done for others. Although being tested and knowing one’s status are helpful to society – a large percentage of people who have HIV are unaware of their status and may transmit it to others – it is regarded as a private matter. On many fronts, this is justified. HIV status is about one’s body and assumptions are made about HIV status, sexuality, health, and the ability to perform gender roles (this is discussed in Chapter 6). These assumptions cause fear, which leads to discrimination and blame. Therefore, HIV status is definitely a private matter that

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127 Even though it seems as though I was expected to be more “public” than the Japanese donors in the center, playing “good foreigner” is something that is fairly common, particularly in rural areas like this one. But because blood was the focus, the feelings of the audience were much more palpable than they usually are.
requires a certain level of protection. However, if being tested and knowing one’s HIV status were promoted as beneficial to society and messages about it were disseminated more broadly, like those about blood donation are, perhaps there would be less stigma surrounding testing.

The question remains, however, why HIV information is not prominently displayed in test sites, given that many of them (anonymous or confidential) are housed in health centers that do not cater solely to testing for HIV. Although the intent is to create a safe environment in which testing is completely anonymous, it seems that erasing HIV at places that offer testing and making test sites “invisible” may be contributing to awareness problems as well as confusion and apprehension about where to get tested – especially when the most common place to see statements and fliers about HIV is a place where one cannot be tested. Perhaps if posters for HIV testing were common at ALL health facilities, even ones where testing is not conducted, then awareness would increase and privacy would be retained. In any case, this invisibility of HIV test sites and visibility of HIV messages at donation centers, combined with other factors such as difficulties in teaching about HIV in classrooms, is contributing to the public’s lack of awareness or confusion about the prevalence of HIV in the community, the importance of getting tested, and the proper place to seek a test. Thus, access to testing resources is not as clear as it first appears.

According to the examples above, it becomes clear that the presence of HIV – and the perception of it as dangerous – is blatant at blood donation sites but not at HIV test sites. The invisibility of HIV test centers, while providing a measure of privacy for visitors, may inadvertently foster the mistaken beliefs that there are no testing sites or that HIV is not a problem. It also contributes to the very practical issue that testing sites can be rather difficult to find. Put simply, invisibility provides privacy but limits awareness and complicates access. Lack of awareness may contribute to precarity in the form of low testing rates, but alleviate social precarity (fear of HIV) through avoidance of the condition. On the other hand, the visibility of HIV messages at places where you cannot be tested, such as blood donation sites, may increase awareness of HIV as a problem. However, privacy is not guaranteed and donation sites may not be able to tell people
where to go for testing and/or counseling. To put it simply, advertising about testing is limited, but advertising about where NOT to go for “testing” is blatant. In the absence of clear messages about where to test, messages about not donating blood to find out one’s HIV status may contribute to fear of HIV and apprehension about getting tested and encourage a cycle of avoidance that results in an increase of HIV/AIDS cases due to fear of engaging with HIV.

**HIV Disclosures in Medical Settings**

The issues of privacy and disclosure discussed above continue to factor into finding and accessing medical care – particularly when PLWHA are required to disclose their status to access the resources they need. But before proceeding with disclosures about HIV in Japan, I provide some context for medical disclosures in general.

Patient disclosure is often focused on a patient disclosing something about his/her health to a loved one. With regard to HIV, for example, Olley et al’s research provides a common example: they found that in South Africa, non-disclosure of HIV status to sexual partners was most common in men who are married but have multiple sex partners, do not use condoms, and tend to use alcohol prior to sex (2004). They report that the tendency not to disclose could be a factor in the rise of HIV incidence from 5 to 12 percent amongst married heterosexuals there (Olley, Seedat, and Stein 2004).

However, disclosure goes far beyond informing partners about pertinent health information. As Etzioni points out, the increased tendency to record health information and to store it electronically has increased the number of potential viewers and the potential for such information to be misused exponentially (1999). His examples include both “authorized” and “unauthorized” uses of electronic records that include insurance companies’ access to full patient records rather than abstracts, disclosure of health status by health insurance companies to present or future employers, and the sale of patient records to HMOs or malpractice lawyers (Etzioni 1999). Once a condition is recorded, disclosure of some type is inevitable – no matter how confidential the information.

There is also the issue of direct and indirect person-to-person disclosure in medical settings. For example, Bell and colleagues note that patients around the world have said that indirect disclosure may occur through purchasing infant formula (because HIV+ women are directed not to breastfeed), buying or taking particular medications,
visiting specific clinics, and displaying physical symptoms and may subsequently lead to people discerning their HIV status (2007). Further, people may be required to disclose their status on visa or job applications, research trials, or ARV programs (Bell et al. 2007). Fear of being “found out” in the community is strong in many places.

However, having to disclose one’s status in medical settings may be no less frightening, even though medical staff are supposedly there to help. “Disapproving and poorly trained health care providers may treat some people with HIV as victims and others as dangerous people” (Bell et al. 2007:114). This fear, or the fear of being turned away, may lead people who know their status to fail to disclose it to health care providers who do not have access to that information. For example, Jeffe found that only 69 percent of HIV+ respondents surveyed disclosed their status to all medical staff that they visited, and some health care providers did admit they refused HIV+ patients if they knew their status (Jeffe 2000).

In Japan, the issue of who discloses what to whom is further complicated in that it has been common for medical practitioners to disclose a patient’s terminal diagnosis only to family members – and not to the patient (Long 2005; Elwyn et al. 1998). This caused a number of problems when HIV reached Japan. First of all, in the case of patients infected through blood products, the physicians who prescribed the treatment bore some responsibility for these infections, which is not the case with other illnesses like cancer. Not only were they criminally liable according to Japanese law, but they were also overcome by feelings of guilt and hopelessness because, at the time, treatment and resources for patients were almost non-existent (Seki et al. 2009). This resulted in cases in which physicians placed the burden of disclosure to the patient on family members, cases in which physicians accidentally disclosed to a family member when a patient had already been told but wanted to keep it secret, cases in which patients or families found out indirectly through charts or symptoms or medications, and even cases in which physicians failed to disclose HIV diagnoses to patients or families at all – even when asked directly (Seki et al. 2009). In fact, in a 1998 survey of surviving patients infected through medical care, less than half had been told their status by their doctors; furthermore, failure to disclose has led to at least fifty known cases of mother-to-child transmission of HIV due to hemophiliac husbands unknowingly transmitting the virus to
their wives and unborn children (Seki et al. 2009). One more fact that makes this non-disclosure particularly striking is that quarantine laws in the 1980s in Japan allowed physicians to disclose the names of patients likely to spread HIV (several foreign prostitutes were named), and also allowed officials to quarantine or bar HIV+ foreigners from entering Japan (Miller 2002; McCall 1993). This double standard – public disclosure of HIV status for foreigners and sex workers and non-disclosure for Japanese hemophiliacs – illustrates the fear and denial that existed with regard to HIV in the upper echelons of the Japanese government and the medical community at the height of the epidemic there.

Given this background, it is not difficult to imagine that HIV disclosure in Japan is still a complicated matter. As we will see in the examples below, issues of disclosure are not limited to patient-doctor-family relationships. Mr. E, a retired accountant who had known his HIV status for nineteen years at the time of the interview and who often volunteers in the hospital to work with newly diagnosed *yōseisha*, is an ideal person to speak about the difficulties of accessing treatment and care due to his personal and volunteer experiences with HIV. Through his experiences, it becomes clear that in addition to all the types of disclosures listed above, disclosure between patients and institutions is also an issue – one that complicates *yoseisha* abilities to get medical care.

Below I assess current issues in HIV disclosure in Japan beginning with a positive test.

Upon receiving a positive diagnosis, some basic counseling is provided for the new *yōseisha* onsite, and they are directed to a hospital where they can receive medical treatment. It is important to note that *yōseisha* cannot just go to any hospital – it has to be one that is designated to treat HIV and AIDS patients. They must also register their HIV status in order to access the care at these hospitals. The rationale for this is that HIV/AIDS patients need to be overseen by an infectious disease specialist who is specifically trained to treat HIV because of the complications they can face regarding opportunistic infections and the medication needed for these subsequent conditions. In other words, *yōseisha* can no longer be treated by “regular” doctors. They must be seen by an HIV care team. And not every hospital has one. However, each prefecture is required to have at least one hospital where *yōseisha* can be treated. Thus, just where a
yōseisha can go for care is extremely limited – especially if they find they need care for a condition that is not HIV-related.

Japan’s socialized medical system is organized such that every citizen and resident, including foreign residents, pay into the health insurance system and are covered for most procedures and tests. Put in place about fifty years ago, it is a sliding scale system in which people pay according to their income, and gradations of “disability” (numbered 1 to 8, with 1 being the highest level of disability) exist for various conditions. These conditions are documented by a medical professional and registered at the city office so that the person is able to access treatment and medications at a payment level corresponding with the severity of their condition. HIV and AIDS interventions are part of this system. Therefore, to access treatment and get medication, yōseisha must officially register their status:

“The biggest problem for me when I was diagnosed was that my hospital said I had to be independent and do all my paperwork myself. Usually there is a medical social worker who would do the paperwork for you, and go get the health booklet from City Hall in your place. But they had, like, one coordinator for 250 patients so I had to go there myself to get the booklet [and register]. And all these people came to stare at me. I was so shocked…” (Mr. E August 7, 2011.)

This was Mr. E’s experience in 1992, a time when HIV and AIDS cases were rapidly increasing in Japan but resources for yōseisha were not well established. However, even now people still fear the paperwork process because of experiences like Mr. E’s: he had to figure out the paperwork himself, and became the focus of unwanted and discriminatory attention when he turned it in. His privacy, which was guaranteed at the test site, was no longer protected when he went to register – the staff who were in place

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128 This is a literal translation from the Japanese word shōgai (障害). Because of the nuances this carries in English, I will henceforth refer to it as “condition.” However, the choice of the word shōgai perhaps says much about the way the Japanese consider people who, for whatever reason, do not fit what is considered to be the physical or mental norm.
129 Japanese are issued health booklets if they have a chronic condition or are pregnant. The booklet given to pregnant women becomes the baby’s basic health record after it is born. Some basic health information is recorded at every doctor visit.
to help yōseisha were, at the time, overworked and could not protect him from discrimination at the city office.

Once the paperwork is in, claiming benefits and using insurance cards for treatment and medication can be equally frightening, and the fear is not limited to experiences that may occur at the city office. More than likely, people are most afraid of what will happen if their place of employment realizes they have HIV:

“Some people are afraid to use their national health insurance for coverage because they are afraid their company will find out. And it’s expensive! It costs $2600 per month without insurance. I pay about $120 for three months’ worth because I have a level 3 condition. But not all hospitals have it set up to get it that way." 

Because insurance often goes through one’s place of work, there is a fear that the company will find out and the person will suffer from discrimination or lose his/her job, but failure to register and get benefits is financially prohibitive for most people, so they feel that they have no choice but to risk it if they want the medication. In addition, yōseisha sometimes say that filling the prescription is difficult because the pharmacist will know what they have and this further impinges on their privacy. This does not seem to bother Mr. E, who gets his prescription filled at the hospital where he has been going for a number of years. But this is a difficult step for yōseisha because their diagnoses and conditions are being constantly written into their lives through insurance policies, health booklets, and prescriptions. At each step, someone has to process their paperwork and requests for medicine, leaving them feeling vulnerable. At each step, they have to rely on anonymous others to keep their private information private.

In addition, although resources have improved since Mr. E was diagnosed, there are still a lot of people who need help, and yōseisha are pushed to take responsibility for their own health. This means that after they disclose to medical professionals and city officials, they are encouraged to develop a knowledge base about HIV and to fully make it their own:

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130 All comments from Mr. E in this section are from August 7, 2011 unless otherwise noted.
“Yōseisha have to learn a lot so that we’re able to talk to the doctors. At first the coordinator or social worker will go with you to help you understand. But you have to do some learning by yourself, because there are always new patients who need help and those staffers just can’t handle the volume. You have to become an educated patient.”

Many yōseisha state that they did not know anything about HIV before being diagnosed, and that part of their fear stemmed from thinking they would die right away. Once they learn more about their illness, how to manage it, how to rely on the system to get treatment and medications, and to what degree they feel the need to rely on others, they often come to realize what they need to do individually to keep their health, and to personalize their illness experience. There are things they have to learn through experience with their bodies:

“I didn’t pay attention to health at all before being diagnosed, but now I manage my health carefully. For many PLWHA, the way they take care of health is to keep from showing symptoms [of AIDS]. So managing health becomes a strict regimen. You have to keep yourself healthy so you don’t get sick. My hospitals don’t manage symptoms and side effects, so I do that by making my own food. I also take supplements for my skin.... I make sure not to get too stressed, and sometimes I drink with friends. The important thing about managing health is, don’t let stress build up, and don’t do things that stress you out. I make sure I sleep well, too. But it’s important to remember that being infected is not the same as being sick. Unfortunately, people often think that [they’re sick] when they find out they’re infected...

The hardest thing is taking medicines consistently. It’s important because you can build up a resistance if you miss doses or you’re late. So it’s especially hard when traveling. You also have to pay attention to what you eat. I can’t eat food with lots of garlic with the medications I take. I did that once, and I threw up. Then I found out from a friend who also takes it, but has a different doctor, that that can happen with that medicine and garlic. And also, if you throw up less than an hour after you take the

131 PLWHA often have skin problems that are caused by the virus or the ARVs. Skin color and texture can change, and it can also become photosensitive.
medications, you have to take them again... then it becomes a problem of getting more doses when you need your prescription filled.”

Like many of the interviewees introduced in Chapter 1, Mr. E has his own view of health and how to keep himself healthy. He eats well by cooking at home, takes supplements he finds appropriate, avoids stress, sleeps well, and goes out with friends. These are things he knows the hospital and medical staff cannot do for him; he needed to learn about his illness and his body in order to establish a health regimen that worked for him. Also note that even though he has lived with HIV and taken medication for several years, he still finds it to be a challenge because anti-retrovirals (ARVs) must be taken according to schedule without fail: missing or delaying a dose can cause the medication to become ineffective. Once a medication becomes ineffective, a new medication must be prescribed, but not all patients can tolerate all ARVs. Finding a new drug regimen can be a matter of trial and error, and thus takes time, patience, and perseverance as one balances the positive effects of the medications and the side effects. Furthermore, side effects that are related to what a yōseisha eats, drinks, or otherwise consumes, are often discovered by yōseisha themselves and not by medical staff. In order to feel their best, yōseisha have to be highly aware of their bodies, and how their health regimens might influence how their medications work, and they have to be able to relate this to their health care providers when necessary. This may include asking for more medication if it is lost through vomiting or other side effects or illnesses like influenza.

On the surface, these steps seem to be more about realizing the personal aspects of HIV than about disclosure. However, learning about one’s body is key to learning how and when to disclose these issues at medical facilities. Building such awareness may also help yōseisha discern when to seek medical attention and when they can avoid visits to facilities that may mean having to disclose to a new practitioner or institution. It also gives them the strength to point out problems with, or hypocrisy about, disclosure in the medical system. For example, Mr. E complained that medical staff often did not wear gloves during procedures, and that this was dangerous to patients:

“We are taught to protect others [using condoms] but what about these professionals who don’t wear gloves? It’s ignorance...and ignorance is sin.”
He felt that it was hypocritical for medical staff to tell people to wear condoms to protect themselves and others but to fail to wear gloves to protect patients who may be immune-compromised. After all, patients probably do not know the health status of their practitioner, even though the practitioner knows the status of the patient in front of him or her. In this way, disclosure and treatment are unequal. Mr. E further reasoned that protecting patients and the general public was already done by wearing masks when one is ill. Thus, if yōseisha were told to protect others by using condoms, why wouldn’t health professionals protect others by wearing gloves? In the case of the use of surgical gloves during procedures, practitioners may feel that they are demonstrating their comfort with their patients and view it as a non-discriminatory gesture; on the contrary, however, some patients feel that when practitioners fail to use gloves, they have failed to consider that the practitioner could transfer pathogens to the patient.

Despite this issue, most yōseisha had positive things to say about their HIV specialists and how they were currently treated by them. Perhaps of even greater concern, then, is the care that is necessary when yōseisha require treatments that are not related specifically to their HIV status. This could be anything from a common cold to surgery. Given that many yōseisha are now living longer lives thanks to improved treatment regimens, this is becoming a more and more pressing concern, particularly in wealthy nations such as Japan. One of the big problems facing yōseisha is that even when they disclose their status to medical professionals outside their usual circle of specialists, this does not mean they automatically get access to care:

“Most of the problems I have are not with HIV specialists. Basically, I have no problem with getting care from my regular doctor. It’s with other medical professionals... if something happens, even if I get a cold, it’s hard. They can’t even give me cold medicine! They don’t know what I can or can’t have, so consulting with my HIV specialist is, in the end, necessary... although [in terms of acceptance] dentists are usually good because they deal with blood and have patients with hepatitis.”

132 Hepatitis is also blood borne and common in Japan.
In my case, recently, I found out I need eye surgery. In all of Tokyo, Yokohama and Kawasaki, only about five eye clinics will accept HIV+ patients. The hard thing is that all clinics at first say it’s fine, but when [I go there and ] they find out I need surgery... well... they don’t say ‘no’ clearly. They just say, ‘well, here that may be hard...’ And it's not like they show some kind of disgust on their face or anything. It’s just an unspoken ‘No thank you’ that you can feel. For me, I really hate that. If they feel that ‘no thank you’ attitude, they can just say it. It’s better than this half-baked ambiguity. Because it’s hard for me to decide what to do then. I’d be really thankful if they’d just say ‘no’ clearly so I could be on my way and ask somewhere else. But unfortunately, it’s part of the Japanese way.”

Whereas the gloves/no gloves issue appears to signify a misunderstood gesture of goodwill or a lack of self-awareness that medical staff can spread illnesses, from Mr. E’s narrative it seems that fear and anxiety about treating yōseisha is much stronger and much more palpable to yōseisha when they consult with specialists who have no specific training in HIV. This echoes Jeffe’s results in which some practitioners (non-specialists) refused to treat HIV patients in North America (2000). Physicians do not want to discriminate against such patients, but they are afraid to treat them – either because they feel they lack the necessary training to work with HIV or because they harbor fears about the illness; this leads to the “half-baked ambiguity” Mr. E describes above in which practitioners do not give a straight “yes” or “no” answer when asked if they are willing to perform specific procedures in Japan. Although Mr. E says he understands this fear and wishes such practitioners would say “no” clearly so that he would know what to do, this hesitancy to treat patients with HIV when the risk of transmission is relatively low illustrates the degree to which stigma and lack of training regarding HIV still remains in the medical community, despite major advances in treatment. For yōseisha, this means that disclosure does not guarantee care.

Even when a willing specialist is found, the transfer of medical records can be problematic. In this case, rules intended to protect patient information and privacy make

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133 I found that it was not uncommon for non-specialists to say that they had no experience with HIV and had no idea how to handle an HIV+ patient, other than to tell them to go somewhere else.
life more difficult for yōseisha. Many medical institutions have rules about which facilities and individuals are allowed to receive copies of the medical records established there. For example, if the consulting hospital and the yōseisha’s “home” hospital are in the same group, records can simply be transferred automatically. But when patients themselves want access to their records or want to have files transferred to a facility outside the hospital group, such transfers can be denied: medical facilities, it seems, cannot simply disclose to one another even if the patient wants that to happen. This means the burden of disclosure is often borne by patients. Mr. E faced this issue several times:

“They won’t release my information to other hospitals [hospitals outside his hospital’s group] if I have to go somewhere else or want a second opinion. On top of that, I can’t even take my own files out of the hospital in these cases. So any time I go to a new place, I have to start all over. I have to tell them my status. They have to do all these tests again. It takes time and money. The only time it can be transferred electronically is if it’s a hospital in the same group. But it’s my chart. It’s my privacy. I should be able to take my own information! It’s NOT the hospital’s privacy, it’s mine!”

Mr. E is rightfully incensed over the issue of who is allowed to access his information. Although this restriction of patient charts and history is said to be due to patient privacy and patient rights, Mr. E notes that he is not the one being protected in this case. Instead, it seems to him that the hospitals are the ones making money from the policy because he has to re-do tests and paperwork. Moreover, he has to disclose his status verbally rather than simply allow the consulting teams to read his chart. In his eyes, it is the hospital, not the patient, who benefits from the rules:

“Take, for example, the protection of personal information. I think this is totally strange. They ‘protect’ things that aren’t necessary to protect. Rather, [the practice is] used to hide things. They control information to the point of hiding information. Rather [than being protected], patients get stuck by the hospitals.”

The expression being “stuck by the hospitals” is telling because it indicates the lack of choices yōseisha have about where to get care in relation to the general public, as
well as the difficulties of accessing their own information. Like the testing centers described above, patient privacy was meant to ensure the protection of patients from stigmatization and blame. But the ways in which the rules are instituted and operate, as we can see from Mr. E’s example, sometimes effectively block patients from getting information – even when the information they seek is the corpus of information hospitals have constructed about their own bodies.

Restrictions are not just in place for patient records, either. There are further rules about how yōseisha engage in public speaking and what yōseisha are allowed to disclose about the hospitals where they receive care:

“You can speak as an everyday person wherever you want. But you cannot speak as a patient or representative of a certain hospital without permission. So even if you volunteer [at the hospital] to speak publically, people are restricted about how they speak and where... if you act as an individual, you can do whatever you want. But if you try to work through the hospital, you can’t do anything.”

This point was further clarified by Abbey, an HIV counselor from AIDS Network Yokohama:

“The patient isn’t free. She should be free to speak out about anything, but she’s gonna have to have the alliance [with the hospital]... and not just the hospital staff, but also the related hospitals and their top officials... [the thinking is that] they have to decide if it is ok for ‘their’ hospital patient to go out there and speak out? Because that is going to reflect on all of them. So she is not really free to speak out without the hospital’s and the hospital group’s permission... So as a patient from a specific hospital group, you can do volunteer work in hospitals that make up that group... It’s kind of like a denomination... if you’re Methodist, you don’t preach at Catholic, Quaker, Episcopal or Jewish places of worship... ” (Abbey Frew, October 23, 2011).

Most of the yōseisha I spoke with avoided these rules by not disclosing where they are treated and who treats them when speaking in public or during interviews. And rather than being bothered by restrictions about public speaking, some articulated speaking issues they faced at the hospital when they were newly diagnosed by noting that
non-disclosure rules make it very difficult to find other yōseisha to talk to – even if they are in the same hospital at the same time. In other words, they felt that the way the system was set up prevented them from making connections with other yōseisha. Rules designed to protect privacy made yōseisha feel isolated, alone, and constrained.

**Summarizing MedicalDisclosures**

To summarize, disclosure encompasses a number of relationships between patients and loved ones, patients and medical staff, patients and other patients, patients and institutions, and even between institutions. Once something about a person’s health is recorded, disclosure is inevitable, and privacy and disclosure at medical institutions or for medical purposes do not always favor patients – in this case, yōseisha. First, disclosure even in these places, which are supposed to be resources for them, can still open them up to discrimination. Second, disclosure does not always result in care – even though the medical system is a socialized one. Even in cases where care is accessed, failure by hospitals to disclose health information to other hospitals can cost yōseisha time and money and contribute to stress. Finally, medical management of yōseisha goes far beyond simply managing their HIV viral loads, medications, and side effects. Through rules of non-disclosure, medical institutions also manage yōseisha records and voices. Again, yōseisha, their records, and their narratives are “stuck by the hospitals” – although they do find some measure of freedom by connecting with fellow yōseisha. This often happens once they find support organizations outside the hospitals and clinics, were they learn to voice their concerns and find people to help them navigate the system of resources more smoothly. However, getting access to these networks can still be rather difficult.

To summarize, Mr. E’s experiences indicate that direct disclosure of his HIV status, which is necessary for him to get care, does not ensure that he will get care, avoid stigmatization, or that his directness will be matched by medical practitioners. In fact, direct disclosure may mean that he is subjected to the fears of medical specialists, who are unable to “say yes or no clearly” about whether or not they will treat him. Furthermore, taking direct steps to get care by visiting places that are known to treat HIV or by submitting prescriptions for ARVs can “out” a patient indirectly and expose them to stigmatization. And finally, rules about who can and cannot have direct access to
yōseisha information often work against the patient and in favor of medical institutions. In these situations, directness on the part of the patient is often met with indirectness on the part of medical staff and institutions, felt by Mr. E as an attitude of “no thank you.” Whereas the patient is trying to alleviate a health issue that may actually be tangential to his HIV status, the practitioner or institution is attempting to alleviate their own fear and discomfort, or felt precarity, that is prompted by the patient’s request for care. Because of the status and power of the practitioner or institution, the patient is left feeling frustrated and powerless when turned down for care with a sharp breath and the comment that their request “might be hard,” or asked to submit to testing s/he’s already had because institutions cannot or will not share information – even with the patient in question.

**Connecting with Support Networks**

Part of being healthy is being able to be social. Because of the shock and changes to their lives, yōseisha need a social support network of people that extends beyond the medical establishments and the social circles they already have – a social network that provides a safe space to air questions and concerns, get reliable information, and find people who have faced the same fears and challenges. Medical professionals are aware of this, and sometimes recommend support networks such as NGOs, NPOs, or CBOs\(^{134}\) (often referred to as the “third sector”). To understand the inner-workings of such organizations and how yōseisha connect to them, I provide some basic information on the third sector in general and in Japan specifically, as well as information on HIV/AIDS-related organizations. I then highlight the experiences of a telephone counselor, a yōseisha who works as a counselor in a hospital, and the research of one of the most prominent HIV/AIDS CBOs in Japan – Place Tokyo.

NGOs, NPOs, and CBOs are generally considered part of the third sector, a sector that attempts to make up for the gaps in services left by the public (government) and private (business) sectors (Bell et al. 2007). As Devine notes, one of the major paradoxes of such organizations is that although they strive to be independent, they are

\(^{134}\) NGO – nongovernmental organization; NPO – nonprofit organization; CBO – community-based organization. In the American context, CBOs are groups that started out with a specific goal to benefit the community or society. Examples include the American Lung Association or the March of Dimes, which were originally formed to alleviate TB and polio, respectively. Because such groups can be classes of NPOs or NGOs, the term CBO is not as commonly used.
financially dependent on government or private sponsors that often demand some measure of control over what such organizations do (2003). Seckinelgin goes so far as to say that NGOs are simply “service delivery tools” for sponsors and often reflect the sponsors’ goals rather than those of the general public or the organization per se (2006:359). Although the extent to which sponsors control NGOs and other such groups varies, organizations in the third sector are inextricably tied to both the private and public sectors.

In fact, finding terms to describe all the groups involved (NPOs, NGOs, and CBOs) is difficult because of these relationships with actors in other sectors, because the terms mean different things in different places, and because there is some amount of overlap even with these distinctions. Moreover, even when groups ascribe these labels to themselves, other organizations may re-label them otherwise: “The reason why private organizations for the promotion of international cooperation or the protection of the environment are often called NGOs rather NPOs [in Japan] is that the UN and UN agencies have referred to them as such when inviting them to participate in UN conferences,” (Takao 2001:296). Takao further argues that, although it can be analytically useful to consider how NGOs are often categorized as service organizations that deal with either international or domestic development concerns or human rights while NPOs are often viewed as self-help groups in Japan, “the two are overlapping in practice” (2001:296). Therefore, rather than enter this terminology quagmire, I refer to “support organizations” in this section because it can refer to organizations with varying levels of government or private sponsorship/management. Where pertinent, I also explain why certain groups prefer a particular label.

Support organizations that work specifically with HIV/AIDS often work to reduce HIV transmission or increase care for PLWHA in any number of ways, and at a number of levels. As we saw in Chapter 3, international organizations such as The Global Fund and UNAIDS tend to focus on HIV/AIDS in the global south – in African nations and developing countries in southeast Asia and the south Pacific – as a foreign problem that requires aid from wealthy countries like Japan to solve through donation for medications. Other organizations – or the combined efforts of several organizations – focus on
national-level epidemics, usually focusing on either prevention or care. For example, Umeh and Ejike assert that combined campaigns to spread awareness and encourage discourse about HIV/AIDS has resulted in decreases in prevalence of the virus in Nigeria at a time when government efforts were said to be weak (2004). In a similar vein, The Japan Foundation for AIDS Prevention (JFAP) works closely with the Japanese Ministry of Health, Labor and Welfare to work on HIV/AIDS domestically. However, as in many countries, some of the most focused, on-the-ground support is shouldered by prefectoral and municipal governments or locally-organized support organizations. In Japan, for example, Yokohama City sponsors AIDS Network Yokohama (a counseling center), and one of the most active support networks in Tokyo is akta, a community space that provides information about safe sex, sexual and gender diversity, and condoms. Finally, some organizations attempt to function on multiple levels, like Treatment Action Campaign (TAC) in South Africa. TAC was successful in challenging the intellectual property rights of pharmaceutical companies on the global level, fighting Mbeki’s HIV/AIDS strategies at the national level, and mobilizing local people to push for care (Robins 2004). Place Tokyo, the CBO I highlight at the end of this section, functions similarly in terms of advocacy, outreach and research.

Instead of simply grouping these organizations based on their international/national/local status or their level of engagement with the public and private sectors, it can be useful to consider how they come about and who operates them for whom. Essentially, support organizations arise in four basic ways. First, “home grown” organizations develop to solve a particular problem locally and exist in a specific national or regional context. JaNP+, a Tokyo-based organization (but accessible online) is run for yōseisha by yōseisha, for example. Second, groups begin in one place for specific use in a separate location, such as Japan International Cooperation Agency (JICA), which started in Japan and operates mostly in developing nations. Third, organizations are formed collaboratively by delegates from various regions for use in a variety of locations, such as the Global Fund. Fourth, local groups take inspiration from groups in other countries or

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135 President Mbeki has been a controversial figure in HIV/AIDS prevention and care because he has been adamant that HIV does not cause AIDS, poverty does. His administration, because of this claim, has also advocated for alternative treatments to ARV therapy, many of which have been useless and some of which have been dangerous. For details, see Fassin’s *When Bodies Remember.*
locations and build their own organizations using other groups as models – or may even be loosely affiliated with the organization that provided inspiration. For example, Memorial Quilt Japan was organized locally based on the U.S.-based Names Project and is loosely affiliated with that group. Many of the larger HIV-related support organizations in Japan are of the fourth configuration.

**API-Net: Finding Appropriate Resources**

Many of the support organizations can be found online. API-NET, short for AIDS Prevention Information Network, is a type of one-stop HIV/AIDS website that is managed by JFAP and supplies and maintains reliable a wide range of information about HIV in Japan. From this page, one can access: 1) current epidemiological data for Japan and the world with links to UNAIDS, 2) educational manuals and pamphlets for the public, 3) an explanation of the meaning of the red ribbon, 4) a link to the JFAP page, 5) a Q&A section about HIV/AIDS, 6) testing and counseling information, 7) information about events, 8) links to current research, 9) a list of support organizations around the country involved, to various degrees, in HIV/AIDS activism.

This last item, a list of support organizations is a valuable resource. Using the information provided there, I contacted eleven groups\(^{136}\) out of the eighty listed, and spoke to representatives from six others\(^{137}\) in the course of doing participant observation at various events. Sometimes finding and contacting these groups was easy – a phone call, email, or letter led to meetings and interviews. But sometimes navigating the list led me to walk in circles in Tokyo neighborhoods such as when I tried to find Place Tokyo, which is related in the opening anecdote of this chapter. I called numbers that were no longer in service. I emailed group leaders for groups that no longer existed. Conversely, I was put in touch with people “in the know” who were not on the list at all. For example, when I told a friend I was having trouble reaching AIDS Poster Project (APP), I got an unexpected answer:

\(^{136}\) Fuchisonokai, HIV/EIZU Network Nagano, Japan HIV Center, Place Tokyo, JaNP+, AIDS Network Yokohama, PLANET, AIDS Poster Project, Bazaar Café Project, Memorial Quilt Japan, and Medical Care and Human Rights Network

\(^{137}\) Center for Health and Rights of Migrants, World AIDS Day in Nagoya, Japan AIDS Prevention Awareness Network, AIDS Bunka Forum in Yokohama, AIDS Bunka Forum in Kyoto, and AMDA
“APP is no longer a group, per se,” Tomoko told me over dinner. “They don’t have an office anymore. But if you want to talk to someone who worked there, I can introduce you to my friend. Hang on, I’ll call her now.” Tomoko pulled out her phone and dialed. After exchanging pleasantries with her friend, she told her briefly about my research, that I was going to be in Kyoto, and could she meet with me? “What day?” I gave a couple dates. “Nighttime OK?” I nodded. Tomoko made some notes on a sticky note from her purse while setting up my interview, thanked her friend, and hung up. She passed the sticky note across the table with a smile. “Just because the group isn’t really there doesn’t mean the people aren’t still around!”

I got a similar response when I tried HIV/EIZU Network Nagano via email:

“We don’t have office space anymore, but if someone contacts me, I can try to help them and put them in contact with people who will support them,” Mr. Uchiyama told me. I asked why they did not have office space anymore. “No critical mass and no financial support,” he said.

So what does this tell us? First, as interviewees mentioned in Chapter 2, finding helpful, reliable information amidst the sea of internet data is difficult – even if you are spending time to seriously research it. Second, even if people find a source like API-NET, the groups are dynamic and changing. Some may cease to exist while others spring up, as my conversations with Tomoko and Mr. Uchiyama indicate. The complexity of the ever-changing web of support groups is further illustrated by analyzing the groups lists from the site I catalogued in 2010 and again in 2012. The overall number of organizations listed dropped from eighty to seventy-two. Although this indicates a net loss of 8 organizations, it is actually a loss of sixteen and a gain of eight. But these numbers still hide the group dynamics. For example, some organizations appeared totally new\textsuperscript{138}. Some have been around for some time, but were just recently added to API-NET list\textsuperscript{139}. Some of the “new” groups were actually re-workings of old groups – for example, Rainbow Ring became akta. Other organizations may have ceased functioning as an entity, such as APP and HIV/EIZU Network Nagano, or have simply been removed from the page: JFAP removed itself from API-NET but is still operating. In addition, some

\textsuperscript{138} This includes secret base, PARTNERS, and Let’s Know AIDS in Toyama.

\textsuperscript{139} Such groups include nankr Okinawa which has existed since 2008, Yorokko which came to be in 2004, SHIP which was formed in 2002, and CREATIVOS which has been running since 1999.
groups splintered into multiple groups when goals or financials become an issue in the past. So even though they appear to be two totally separate entities on paper, they have a shared history. Finally, the list is not necessarily complete. For example, there is a group dedicated to sex education by and for sex workers that does not appear on the list, despite being very active in the Kansai region.

Given all these changes, someone who is searching for a specific type of organization in a specific location (a group for transgender/transsexual individuals, a gay-friendly group, or a group for sex workers, for example) may have difficulty in doing so – even if they do an online search. Although local health clinics often have lists of support groups in the area, people worried about testing or their status may not have visited these places yet. Support organizations can tell members of the general public about testing facilities and clinics and vice versa, but a person has to make a move and contact one or the other. Getting into the loop, so to speak, can be complicated. In much the same way that the difficulty of finding accurate information was discussed in Chapter 2, finding the appropriate support organization for a particular yōseisha requires them to be active and persistent.

**Hospital Volunteers and Hotline Staff**

The first support organization that a yōseisha may come into contact with may be at the clinic or hospital where they were tested or receive care. These are usually in-house groups designed to help patients in ways the paid staff, such as medical social workers, cannot. But just because resources exist, it does not mean that making a connection between the speaker and listener is easy. In cases where the individuals involved are very different, the experience may even end negatively. Mr. E volunteers at his own hospital, and describes his involvement this way:

“I work mostly with people who are already diagnosed as HIV+. I tell them that there is nothing that can cure HIV, but that with medication they can live for a long time. There are, of course, side effects which are sometimes bad. And people usually after a year or two are kind of OK. But the first few months, they can’t even take medicines properly...
I get the hardest cases. People who are the most mentally or emotionally unstable. Like people who use LSD or people who just do extreme things sexually. They’re not ‘normal’ even amongst the gay population. They’re extreme in terms of drug use, their sex lives, etc. They’re the people who are so far from the standard, the coordinators can’t help. For example, amongst gays, there are several different types of gay men. Maybe you know about this, but there are guys that go to Shinjuku and maybe meet and have sex with ten guys a day, in the public bathroom. Medical social workers just can’t hear that. Some of the men are showing symptoms of AIDS. But I can’t tell them, ‘You can’t do that!’ I have to tell them you can have sex, but you have to do it this way [referring to condoms]. I tell them that it’s a risk for them, too, because they can get all these other illnesses. Like one guy came in and he had everything. HIV, Hep B, syphilis, gonorrhea... patients like that, even the doctors don’t know where to start. Even I’m distant from them, so it’s hard... So the first step is me just listening to them, sometimes for three or four hours. I can’t say ‘you can’t do that’ to them or be judgmental. I just listen to them, connect to the positive parts of what they say, and try and use that to get them to come back to the hospital... The most extreme thing I’ve heard is a fantasy about filling a bathtub with excrement and then having a sex in it. When I first heard that, I’m sure my eyes opened wide. I felt sick. But then while he was talking, I thought, well, that’s another way to have sex...” (Mr. E August 11, 2011 and October 23, 2011.)

There are several things to learn from Mr. E’s comments above. As he states, all of his clients are HIV+ and many of them are what he describes as “extreme.” Because it is difficult for the medical social workers to listen to such cases (both in terms of time and content), the cases come to him and he finds ways to explain the system to the client and give them clear information about HIV so that they can protect themselves and others. Messages are tailored to the person with whom he is speaking. So first of all, patience and willingness to listen, to hear the story of the client, is essential. Being heard and supported is sometimes the most important thing.

Second, it is clear that there is a definite need for volunteers like Mr. E because of the skills they have in connecting with patients and the time they can spend with them. The patients Mr. E works with have such different lifestyles from the medical staff that
the staff do not know how to listen to extreme cases without being judgmental – which turns the patient off the staff and possibly off the treatment. In fact, it takes an incredible amount of time to work with an individual patient – sometimes up to four hours. This is time the medical staff most likely could not take if they wanted to. Third, we see how Mr. E realizes that he himself is “distant” from these extreme patients, but that he is able to keep an open mind about lifestyles, focus on what the patient needs to hear in terms of medical advice, and discern how to deliver it so that the patient will follow it – and return to the hospital for treatment. While this may be in part due to training, personality and life experiences also play roles in shaping how someone is able to listen. Abbey, a counselor from ANY, puts this very succinctly:

“You don’t have to accept it, you just have to know your listening limits... lots of people know what is required in their head, but they don’t feel it in their hearts. Everyone has their limits.” (Abbey Frew, October 23, 2011)

Each person’s ability to hear what another says is different. The listener does not have to agree with the speaker’s lifestyle, but has to be able to accept them as a person. Knowing when you cannot do this, even if you want to, is just as important as knowing when you can because how patients are treated influences the degree to which they accept medical care (Whyte, van der Geest, and Hardon 2002).

Another way to get initial help, yōseisha or not, is to call one of the numerous HIV hotlines run by support organizations. Entities such as ANY, Japan HIV Center, Place Tokyo, and Tokyo English Life Line all have HIV hotlines that are fairly easy to find and counselors can provide answers quickly when internet searches do not yield the desired results. Abbey, an ANY counselor, explains what it is like to answer the phones:

“About half of the people who call me, I eventually find out, have not done anything that would allow for transmission at all. I tell them they don’t need a test... I ask them if they know the difference between HIV and AIDS and they usually don’t... I explain all the infection routes to them... a lot of times telephone counseling is just to be able to give people a sense of safety because they don’t have anyone else to ask... I get calls from all over Japan, Australia, the US, and China... lots of people from Hiroshima,
Osaka... people want to make sure they don’t know the person who answers.” (Abbey Frew, October 23, 2011).

As Abbey says, many people just want someone to talk to, to confirm that their behaviors have not put them at risk for HIV. He gives them information so they can try to protect themselves in the future. Interestingly, he fields calls from all over the world, not just all over Japan. Oftentimes, people who call want to be absolutely sure that the person who answers is not an acquaintance. If the caller lives in a small town or has a wide social network, placing a call to a center across the country or across the world may make them feel safer than they would trying to find a testing center or a local support organization. In other words, people want to connect with another person, someone who can put them at ease and help them, but they want to make sure it is not a known person. In terms of providing a non-judgmental, informative listening ear, Abbey’s job is similar to Mr. E’s, and requires similar skills.

There is one last point to make about counseling in person, at the hospital, and over the telephone at support organizations: even though they know each other and can recommend places to go, they cannot always recommend places to go based on personal relationships or what they know about the staff at each place. Abbey explains:

“If someone calls me and tells me they are worried and they want a peer to talk to, I can’t tell them to go to x hospital, even though I know someone like Mr. E is there. I can’t connect them in that way because I’m an NPO counselor and Mr. E is a hospital counselor. It’s against protocol... It’s frustrating...” (Abbey Frew, October 23, 2011).

Abbey and Mr. E are friends, and they each know what kind of work the other does. But if someone calls Abbey and he feels that Mr. E would be a good person for the caller to meet, he is unable to recommend Mr. E and his hospital. Abbey can only recommend hospitals in a specific area if someone asks. On the other hand, Mr. E could tell a patient to visit the ANY office and talk with the staff there if they asked about organizations outside the hospital. This constrained ability to recommend resources illustrates the practical difficulties of connecting patients to available resources even when they exist and agents in the system know and respect one another. Organizations
with fewer governmental or institutional limitations, such as Place Tokyo, actively foster
the flow of information between groups and yōseisha rather than constrain it – but still
work to protect the privacy of individuals.

**CBO Profile: Place Tokyo**

As Japan’s first, most established and, arguably, most far-reaching HIV-related
support organization, Place Tokyo has been working to provide support for yōseisha for
nearly 20 years, and the organization actually pre-dates UNAIDS by two years. Ikegami
Chizuko started the organization in 1994 after spending several years in California and
Hawai’i. While in Hawai’i, she worked with sexologists such as Milton Diamond from
the University of Hawai’i and staff at the Life Foundation, which served as a model for
the formation of Place Tokyo. The organization began with the mission of the Life
Foundation, which is “To stop the spread of HIV and AIDS. To empower those
affected by HIV/AIDS and maximize their quality of life. To provide leadership and
advocacy in responding to the AIDS epidemic. To apply the skills and lessons learned
from the AIDS epidemic to other related areas of public health or concern” (The Life
Foundation 2013). The idea was to create an atmosphere that stymied stigma and
discrimination while also providing social support, testing, and information on medical
care and services. Thus, The Life Foundation created a comprehensive support system
that included telephone help lines, a buddy system, AIDS education programs, and
research (Ikegami 2011, volunteer training). These foci are clearly visible at Place Tokyo,
which offers telephone counseling and peer group meetings and events and also creates
educational materials and conducts research. Place Tokyo also emphasizes the
importance of fostering a positive environment with regard to HIV.

The importance of living positively was also carried over from the Life
Foundation to Place Tokyo, even if it is not so obvious at a glance. “Place” actually
stands for Positive Living And Community Empowerment. “Positive Living” refers to
“living as yourself;” “Community” refers to a group of people who collectively and
actively engage in activities to create a healthy environment and foster interest and

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140 The Life Foundation was started in 1983 by sexologists and epidemiologists who recognized HIV would
become a problem in Hawai’i due to the transience of the population and its relatively large gay population.
concern for others in daily life; “Empowerment” represents learning how to channel one’s inner power, whatever it is and in whatever way is best for an individual (Place Tokyo 2013). Ms. Ikegami further notes that empowerment starts at an individual level, but is necessary on the social level for social change. In this way, empowerment is considered multi-dimensional and interactive.

Interestingly, although the English acronym has this link, the name is not usually written in English. It is not written in katakana, either, which is the usual system for writing non-Japanese words in Japanese script. Ms. Ikegami explained that if English or katakana were used, it would limit the image of “place” to a single meaning: location (September 2011). But her intended meaning is much more nuanced than that, so it is written in hiragana: ぷれいす(pureisu). She asserts that the hiragana allows for a more flexible set of variables, including the networks, lifestyle, gatherings, and relaxation that are facilitated because of the presence of the organization as an entity (Place Tokyo 2013).

In other words, the focus is on being in relation to others rather than being in relation to a particular place. During an interview, she drew two small circles to represent “self help” and “public assistance,” and one large circle around them both for “community assistance.” She described the way Place Tokyo as a CBO works in concert with existing social institutions to facilitate this sense of being:

“Self help is looking for information and participating in self-help groups. Public assistance includes the government, medical institutions, social welfare, and law. Community assistance is where we are as a CBO. We give mutual support to the self and the public portions.” (December 10, 2009; September 19, 2010).

Ms. Ikegami sees the organization as being in and supporting each level – the personal, the public, and the community. Part of “positive living” is being yourself and finding help that suits your needs. Part of it is also connecting to others, helping others, and making a difference in a community by reaching out to others and contributing to knowledge production. And finally, empowerment comes with knowledge of one’s illness and how to manage it that comes from interacting with and learning the public assistance systems – and how to enact change in these systems when things are not working as well as they might.
As mentioned above, Ms. Ikegami worked closely with HIV activists and researchers in Hawai`i. She returned to Japan in 1991, thinking that Japan would need an organization like the Life Foundation. After rounding up like-minded friends and researchers, she started Place Tokyo in 1994 – the same year that the World AIDS Conference was held in Yokohama. This was the first time such a conference was held in Asia, and it was the first time that support organizations and yōseisha were invited to participate alongside medical researchers. These events also coincided with the increasing interest in the “third sector” in Japan during the 1980s and 90s as detailed by Takao (2001). Ms. Ikegami describes the timing and the start of the organization this way:

“Place Tokyo has been functioning as a research network since 1995. The World AIDS Conference was held in Yokohama in 1994. At that time, NGOs and CBOs played a really effective role, so the administration for the first time recognized that NGOs and CBOs also provide valuable input in HIV policies. And then, they also realized that if those groups want to do research, it should be considered. Up until then, ‘HIV/AIDS research’ was something that was only done by scientists and physicians. But there is research that really only CBOs are able to do.

The first real research that we did was an assessment based on HIV+ people’s input. For this research, of course we included someone who could act as an HIV representative and participate in the research team and checked everything from choosing the topics on. Until then, there had been no research like that. In particular, there was nothing but notifications from yōseisha through doctors who did this and that in their own offices. And we thought, is it OK to keep doing it like that? And how does how it’s done influence what kind of information is considered desirable? Maybe we should make sure the information given by the yōseisha benefits the yōseisha” (December 10, 2010).

To be effective, Place Tokyo had to engage with the institutions they view as part of “public assistance”, particularly people who work in medicine and medical research, social welfare, law, and politics. These members had dominated the production and dissemination of information about HIV/AIDS – not just in Japan, but around the world.
Furthermore, *yōseisha* had not been asked to participate in research directly. But attitudes had been changing prior to the 1994 meeting, and many *yōseisha* in various places had inserted themselves into the discussions about HIV because they were directly influenced by the research that was conducted, the laws that were made, and the social support systems that were or were not in place. They demanded that their opinions and voices be heard. For example, prior to this conference, the American group Act Up was largely responsible for pushing for the release of AZT and making it affordable, and The Names Project was started by San Francisco activist and PLWA Cleve Jones. These are just two examples among many.

Place Tokyo worked to become the nexus at which research and *yōseisha* connect, seeking ways to organize the opinions and voices of *yōseisha* so that research that was done “on them” was beneficial “to them.” To this end, they organized the first *yōseisha*-inclusive research to be done in Japan. Place Tokyo’s research trajectory is described by Ms. Ikegami in this way:

“As a result of this first project we determined that, as expected, the environment and protecting privacy are important, but the most important thing is giving a supportive message. We learned that if they are given negative messages about their treatment and lives, like ‘don’t come here for care,’ or you got this because you have ‘that kind of life,’ then they distrust the treatment. And things like that really reverberate through their daily lives and influence their quality of life while living with HIV... I think we put out a report on the 1995 project in 1997.

So then from 2000 the research group wanted to focus on what kind of supportive messages, what kind of proposals were needed, basically, and what kind of meaningful research NGOs and CBOs could do with *yōseisha* who wanted to participate. With a group of others, I worked as the leader for five years on finding out where the problems with prevention education were. Just getting information doesn’t connect to preventative behavior. What is obstructing preventative behavior with regard to sexually transmitted HIV in Japan? What is in the way? Does gender have an influence? If you separate male and female students and survey them, do you see different factors? [What we found was that] In the case of female students, they hesitate with regard to their male partners, and
find it difficult to strongly say for themselves that they want to use protection, or convince them to use it. It’s a relationship thing. In male students the same age, more than being a relationship thing, it’s that they’re not used to using them. They think they’re uncool or don’t feel good or destroy the mood. [So we want to tell them], if you’re not used to it, you should get used to it, right? About the relationship factors in the females, girls think that if they strongly assert themselves, it’s not ladylike or it leaves a bad impression, but we want to tell them, you’ve got the wrong impression. Boys don’t actually think that. But if the partners communicate beforehand, these misconceptions clear up, and they should think about that. If we change the image to make it positive, that preventative behaviors are cool, whether you’re male or female you can protect your sexual health – we want to spread that message widely. ‘It’s YOUR problem.’ They think it’s not their problem but someone else’s. But it is their problem. It’s ‘our’ problem, is what we want to say. This was really popular.

And now we have a gay working group. So what about gay couples? Amongst gay couples, what is the factor that obstructs prevention? We researched this in the same way. We found a lot of interesting things. Both issues [from above] come out, but it depends on the specific type of relationship and the roles each person plays in it.

What we’re working on now is care. We counsel the most yōseisha and manage the most care programs for yōseisha in Japan, so we’re doing research to find out, what is the most important thing for people we cater to? What do they need? This is the fifth year of that project. I think we’ll finish this year for now and then continue [with something new] next year.

So from getting the people who are affected involved, to focusing on prevention, and now care, that has been our trajectory.”

Not only has Place Tokyo been successful in re-engineering research on HIV to focus on issues important to yōseisha, it has also successfully included yōseisha in each step of the research process. Further, the research teams have been able to illustrate some of the differences that exist in various populations in Japan, such as differences regarding attitudes toward condom use amongst teenage boys and girls and same-sex partners, and
they have been trying to get that information to the public so that they themselves can realize how their misconceptions have shaped their health behaviors.

In addition to research and publication, other activities were simultaneously taking place to keep both yōseisha and the general public tuned in to HIV issues: peer support groups, newsletters, and telephone hotlines provided spaces for dialog about living with HIV. Research informed how these activities were executed, and activities shaped research. Essentially, Place Tokyo has grown from a group of people that collected and digested information for the public and for yōseisha prior to 1994 into an organization that does research alongside yōseisha that not only contributes to research but facilitates education, counseling, and improvement in the quality of life for people in the community. Thus, Place Tokyo functions at all the levels Ms. Ikegami described in her model, and this function is built into the name of the CBO. The integrated nature of the organization makes it relatively successful. But Ms. Ikegami says that despite all this work, there is still much to be done:

"Before HAART, before 1997, the process for people who contracted HIV was to get AIDS and die. But after 1997, it’s not like that. It has been possible to live as HIV+. So now it’s Living Together with HIV – for a long time. So then what is QOL? How are you planning to live your life with HIV? Creating a positive environment with your ups and downs, telling partners and friends, etcetera, becomes a big task. So with that in mind, what support and care are needed? That becomes a big issue, doesn’t it? And it’s not just a medical issue! What does it mean to LIVE? Questions like that keep coming…

There is medicine for HIV in Japan, but the social support is very weak. Like at work, it is really hard to say, ‘I have HIV.’ It has to be secret. The atmosphere is not supportive. They might get fired or have other problems. They’ll be thought of as a ‘bad guy,’ for example. And they experience self-stigmatization, too, so that is another reason they can’t be open. It’s just not a supportive atmosphere at all. The social system – we have a social system. What I mean by that is the medical system for disabled people. That’s a good thing, but as get into more and more rural areas, it is more and more difficult to use. The reason is that, when you apply, you have to say ‘I am positive.’ And you lose your privacy, and that is scary. So people don’t apply, and then if they don’t
apply, they can’t access the system even though it’s there. So it’s not fair. There is no atmosphere of privacy [in those places]. That’s why I always say that HIV is an environmental problem! Setting up the environment is important…” (December 10, 2010).

It is clear that, from Ikegami’s and Place Tokyo’s standpoint, socialized medicine is not enough. Improvements to medical technologies are not enough. What is necessary is social change, and for Japanese people to re-think what it means to live a good life. For this to happen, larger society has to be made aware of health-related issues like HIV, and yōseisha need to be included in research because it affects them directly. These are the things that Place Tokyo can do and can advocate for. Yet, for social change to happen, social support outside the existing support organizations is necessary, and that is weak. It is a classic catch-22: social change requires awareness, but awareness requires society to change. Although this is indeed happening little by little, the lack of awareness that still exists in Japan makes it difficult for the general public to accept yōseisha and interferes with the ability of these groups to garner the funds they need to provide the services they do and push for the changes they see as necessary:

“We’ve had problems getting financial support even before the economy was bad. We’re in the private sector. And we get donations from lots of foreign countries. Japanese companies are really cool to the idea of donating because it is about sickness. They always say it’s a medical issue. Or because it’s sexually transmitted, it’s a sex work problem. Their thinking is, ‘It’s your problem, why should we help you?’ Those are the two problems. It’s about sickness and sex. But if you say something is an environmental problem, it’s easy to get money. So that is one reason I say it’s an environmental problem!”

Thus, even though support organizations provide services that government offices cannot or will not provide – clear information about sex and STIs, telephone counseling, peer support, and research that improves care and treatment – support organizations compete for grants and rely on donations to survive. Put another way, the government now relies on the support network comprised of organizations like Place Tokyo to provide public health services that official public health offices do not, but the
organizations are expected to raise the funds themselves. One of the reasons for this is that stigma and discrimination, lack of awareness, and misconceptions of HIV/AIDS and yōseisha – issues discussed in Chapters 1-3 in regards to the general public, make it difficult for both yōseisha and HIV-related support organizations to persuade private and public sector actors to sponsor them.

There is also one final danger that has not become apparent yet, though many leaders such as Ms. Ikegami worry about: if their messages about living with HIV are successful, will people stop taking precautions to prevent it? Right now, they have two seemingly contradictory messages: protect yourself from HIV (for the general public) and you can live a normal life with HIV (for yōseisha). But what will happen if HIV becomes just another “treatable” illness like hepatitis? Living with HIV is not cheap and is still complicated to treat, so if more and more people require ARVs to live, it could cause a strain on health resources in Japan. No one is sure yet exactly how these mixed messages will influence the public if they do succeed in getting them out.

**Summarizing Support Network Access**

It is clear from the experiences of Mr. E and Abbey and the efforts of Place Tokyo that support organizations that supplement medical resources and comprise support networks are essential to improving the lives of yōseisha. Further, these organizations work to show how it is possible to live positively with HIV. However, it is equally clear that finding these organizations and accesses support networks can be difficult, finding people to listen can be difficult, and organizations themselves – regardless of how important or cutting-edge their research is – face problems gaining access to funds to keep them running. The networks themselves are in constant flux due to practical changes and constraints. Gaining access to networks that foster positive living, and the ability to circulate information about positive living is hard. These realities can be depressing, and Hammar (who conducts research in Papua New Guinea) has argued that the “living positively with HIV” message espoused by international groups is unrealistic because of the stigma, lack of access to resources, and sheer misery of having HIV – particularly in a poor, rural setting (2007). This is an important criticism because it illustrates the sharp contrast between the realities and ideals of living with HIV. People
do, in fact, die every day from AIDS, and in many instances these deaths are related to an inability to access care and/or escape discrimination.

Despite this relatively bleak assessment, it is worthwhile to pause and take stock of the impact that the network of international, national, and local organizations has had on the epidemic in Japan. Even though gaps and disconnects exist, the efforts of each of these groups has made a difference in people’s daily lives – even if that itself is difficult to gauge. The work of Ms. Ikegami and her CBO, which was inspired by the work of sexologists and activists in Hawai‘i, has vastly improved the lives of yōseisha in Japan through peer counseling alone – and hers is only one organization. In the wake of Place Tokyo, the AIDS conference in Yokohama and concerted efforts at all level of society, groups across the country have sprung up, and this is no small feat. In spite of the difficulties faced in Japan, Ms. Ikegami says, “I’ve learned that HIV is strong, but people are stronger.” While the difficulties Hammar discusses cannot be ignored, positive attitudes like Ms. Ikegami’s in the face of adversity are a cornerstone of effective HIV/AIDS support networks. Without hope for positive living, it truly would be impossible.

Again, the disconnect between supporting organizations and the difficulty in finding them online or in person foils attempts for new yōseisha to engage with them directly. Systems meant to protect privacy and patient’s rights can actually make it hard for them to seek social support, even when they take specific, direct actions to do so. However, community-based organizations such as Place Tokyo attempt to alleviate this by encouraging active engagement between researchers, medical practitioners, support groups, and yōseisha and carving out space for such engagement online, in print, and in Japanese neighborhoods. In the case of Place Tokyo, such engagement is even part of its name: it uses the hiragana name for Place, pureisu (ぷれいす), in a purposefully polyvalent way, ascribing specific meanings to it. Not only does it indicate the importance of a physical place or environment, it stands for “positive living and community empowerment,” with “positive living” including variables such as networks, lifestyle, social gatherings, and relaxation. Whereas the vagaries of the term eizu are
problematic because its polyvalency lacks parameters, the meanings of pureisu are many but structured by the organization.

Discussion

Navigating HIV testing, medical care, and support networks requires a lot of tenacity on the part of individuals. As discussed in each section above, accessing these resources is not easy because they are not always visible; disclosing one’s HIV status in medical institutions does not guarantee care and may actually open one up to stigmatization; and connecting to people who can help can take the time and effort to help sometimes must be done in a round-about way. In each of these situations, both engagement (seeking help) and failure to engage in the support network (ignoring a diagnosis or fearing a testing) can put a yōseisha in physical or emotional danger. Further, the degree to which yōseisha must depend on anonymous others to provide them with sound advice, provide for their medical needs, counsel them, and in some cases guide them to becoming a part of the support network itself – all while respecting their needs for privacy – makes living and coping with HIV a precarious situation indeed. Finally, the support system itself is precarious because it is in constant flux and actors depend on each other: society depends on all actors in the support network to care for patients, but the organizations depend on society for financial and community support to carry out these responsibilities.

When Ms. Ikegami envisioned Place Tokyo as a community organization that facilitates self-help and public assistance programs, she situated community as the mediating factor that could address precarity. I provide two final examples to show how this can function realistically in terms of testing and disclosure.

First, data on HIV testing rates, rates of HIV incidence, and prevalence of support organizations are often considered separately. But recently, hiv-support correlated testing and incidence rates to show that places like Tokyo and Osaka that have high incidence rates also have high testing rates (2012). This means that, unlike places that have low rates of testing, the incidence rates for Tokyo and Osaka are probably fairly accurate. In addition, these two places house the largest number of HIV-related support organizations. While it is difficult to hypothesize the extent to which these organizations have
influenced testing rates, they are most likely a factor. This becomes clearer when comparing the data of two other rural areas, Okinawa and Aomori. These prefectures have about the same population – roughly 1.3 million people. They have about the same number of clinics to get tested (six and seven, respectively). Okinawa’s HIV/AIDS incidence rate was five times higher than Aomori’s rate, but Okinawa’s testing rate is also seven times higher than Aomori’s testing rate. So we can say that Okinawa’s incidence rate is probably more accurate than Aomori’s, even though incidence there is higher. Interestingly, Okinawa has two NPOs that promote HIV testing, prevention, and care, while Aomori has zero. Again, although it is difficult to ascertain whether these groups are directly responsible for the high testing rates in Okinawa (or if the lack of such groups is a factor in low testing in Aomori), it seems reasonable to direct further attention to this line of reason considering the impact organizations like Place Tokyo have had, and the lack of visibility of testing information outlined above.

The second example revolves around disclosure and protection. Recall that Mr. E described practitioners who failed to wear gloves as hypocrites. In Japanese society, it is common to wear masks both to prevent the spread of an illness and to protect oneself from getting ill (Armstrong-Hough 2009). Many support organizations advocate the same type of thinking for condoms – to protect oneself as well as one’s partner (Ikegami 2011). However, because they told patients to wear condoms to protect themselves and others but failed to protect patients by wearing gloves, Mr. E got angry at the medical staff. To put it more simply, he got angry because in two cases (masks and condoms) the barrier was seen to function in both directions, but with gloves, they were only seen to function in one direction: the protection the doctor. Disclosure sometimes works similarly, unfortunately. Patients are expected to both disclose to medical staff in order to get care, and to not get upset when disclosure fails to result in care or when stigmatizing remarks are made. Further, gaps in disclosure between institutions that are costly to patients are considered protective to the institution. Disclosure, like gloves, is sometimes considered one-dimensional. However, research conducted by organizations like Place Tokyo, which actively seeks out participation by yōseiisha, brings these discrepancies to light and pushes for change in ways that professionals can understand. The condom message, for example, started with support organizations. That Mr. E’s medical team talks about it
shows that it has spread. It seems like it may just be a matter of time before the glove issue is remedied. Perhaps efforts to remedy some of the problems in institutional disclosure will follow.

Butler notes that precarity cannot be resolved by governments because the conditions they set up to ameliorate it merely perpetuate it by creating groups who can and cannot access social welfare and who then face more precarious lives (Butler 2009). However, precarity can be mitigated – particularly when the people who live most precariously are welcomed to give input on how to make their lives more stable.

Conclusions

In this chapter, I have argued that navigating the resources available to yōseisha is inherently precarious because the resources they need are difficult to find and, in some cases, are made “invisible” to protect privacy. I have also argued that disclosure is dangerous because it does not always result in care and can lead to stigmatization or rejection, even though it is considered necessary and commonplace in medical settings. And finally, I have argued that accessing support networks and finding the appropriate organizations for particular yōseisha is often anything but direct.

However, as yōseisha get more efficient at navigating the various resources of social and medical support, they begin to embody the system: they learn how to use it, how to become part of it, how to critique it, and in some cases how to make it better. At the same time, they are also learning how HIV is a part of them – how it changes them, and how it does not change them. In doing so, they incorporate HIV into their life stories and formulate narratives about living with HIV. Some even share these narratives as a method of educating the public. It is to these public narratives that I now turn.
Chapter 5: “Private” HIV/AIDS Narratives in “Public” Venues

I decided to participate in Place Tokyo’s Volunteer training, which they hold once a year. Over the course of several days, trainees grapple with issues from a range of topics including sexually transmitted infectious disease pathology and epidemiology, sex and gender, sexuality, medical ethics, human rights, and disease prevention, treatment, and care. One of the last things we did was listen to a yōseisha talk about his experiences with HIV and being a peer educator.

We were all seated when Mr. Y was escorted into the room. Immediately, I was drawn to his bright, energetic and friendly eyes. He looked at each of us carefully, purposefully, as he talked – and started off by saying that he knew several of us were “earnest note takers,” but for this session, he wanted us to just talk. I couldn’t help but think he was talking to me directly. I found myself nodding and placing my pen in my open notebook. I wrote only a few words during the whole time he spoke, but his voice, his words, had saturated my mind. Not wanting to forget the importance of what he said, I wrote down the words that remained in my mind after we finished training for the day:

“Not just the words, but the images of HIV are important. You know? In 1996, the image was you suffer, get thin, and die all alone. I thought I should get tested. I knew it was important. But because it was important, I avoided it, ran away from it. I wonder if you can understand that? Exactly because it was important I couldn’t do it.

But my stomach began to hurt, and I knew something was wrong. I had bloody diarrhea. You know – that stuff that they say looks like strawberry jam. I went to the hospital. They told me of all the g.i. tests I’d have to take and release forms I’d have to sign. HIV was on the list, and I thought, ‘Man! Here it is.’ They talked about the treatments I’d probably need. I screwed up the courage and said, ‘If I have HIV, what happens?’ And you know what the doctor said? ‘Well, we’ll use disposable kits.’ That’s when I started to learn about ‘this side’ and ‘that side.’ Things mean different things to different people.
Christmas Eve Day of 1996. I rode in the ambulance to another hospital. They did surgery on me. And I felt better right away. They sent me to hospice. That’s where I started thinking of the image of illness. There are a lot of people in hospice, you know? People with cancer and stuff you can’t cure. And there I was, I didn’t look so sick. I told them my liver was bad. So I was OK during the day, but really down at night. I called in the nurse once one night. Told her my back hurt. But really, what did I want? I wasn’t sure. Everything was complicated – friends, family. That nurse rubbed my back, listened to me try to decide: to tell or not to tell? ’You know, you don’t have to solve everything right now. Just one thing at a time.’ So I did that. One thing at a time. It got easier to sleep.

One day, I saw this guy in this the hall, going about his business. I was watching him. And he knew that. He looked over me and said, ’Hey Mr. Y, I take the blue pills, too.’ Blue pills. Those were my first drugs to fight HIV. You know, I knew the numbers, I’d heard how many people had HIV. But somehow I felt so alone until I heard him say that. Knowing someone is much different than just knowing the numbers. That’s the first time I felt I wasn’t alone.

One thing at a time.

I spent some time going to the gym. There was this foreign guy who was always on the bike next to me. ’Hey.’ ’Hey.’ We would chat a little. Even making new friends was hard! But one day we made plans to go get coffee afterwards. We went to a coffee shop and talked for a while. I was wearing a hat. When I looked down, I couldn’t see his face and he couldn’t really see mine. I found myself looking down into my cup, hands shaking, tears falling... and I told him in English, ’I am AIDS.’ I couldn’t stop the tears or the shaking, couldn’t let go of the cup.

He reached over and put his hands around mine. ’You’re going to spoil your coffee,’ he said quietly.

He took me back to his place, hugged me. He hugged me! I couldn’t believe it. We talked some more. When I went to leave, he said, ’Hey, what you said earlier. You made a grammatical mistake in English. You don’t say ’I am AIDS.’ You just have HIV.’
I just have HIV.

It’s hard for me to say I need help. But I started to go to Place Tokyo for counseling. I was there for two hours once. And suddenly I thought, ‘I have this much to talk about?!’ And then one day my peer group partner came in and said, ‘Man, this working overtime is going to kill me!’ What? You’re not going to die of AIDS? Another lesson.

You know, people live and die every day, with or without HIV.

When I first found out I was living with HIV, it was like, ninety-five percent of the pie. But then, over time, I considered it less and less a defining part of my identity. I’m not JUST living with HIV. Now it’s like five percent of that pie. It’s not that I think so much of living with HIV. It’s thinking that I’m living with something difficult. And most people do.

The important thing for peer support is that everyone is different. Not everyone can do peer support in the first place. And of the people who do, they have to choose what they need themselves, and what they want to say about their lives. The definition of peer is someone that has the same standpoint. But we are all different. We might have some things in common. But you have to remember your own standpoint, and learn how to find your own balance.”

This is the story I remember Mr. Y telling a group of strangers about his very personal story of coming to terms with living with HIV. Through the snippets of daily life he weaves together – the visits to the hospital, the time in hospice, his conversation with a friend at a cafe – the audience is drawn to him as an individual, as a person who can put a face to HIV. But what is not so obvious are the intense efforts made by the speaker, the organizing sponsor, and the audience to hear Mr. Y’s message in very specific ways: the narrative must be personal but allow the audience space for generalization; it must give details about life experiences, but protect the speaker’s identity; and it must be true to the narrator’s experience but be packaged to fit the organization’s and the audience members’ goals for participating. Moreover, the narrative must fit the time allotted and the atmosphere of the event. If these efforts are not made, then rather than an educational
opportunity, it becomes a disclosure that could open up Mr. Y to stigmatization and discrimination. In other words, although Mr. Y’s story above reads just like that, a story, careful analysis reveals it is also a very artfully constructed and performed illness narrative tailored to his needs, the sponsoring organization’s needs, and the audience’s ability to hear.

Illness narratives told in public or semi-public forums by yōseisha such as Mr. Y, despite their ostensibly private nature about coming to terms with HIV, are becoming a method of educating the public about HIV/AIDS in Japan. In addition, comparison between both written and spoken narratives like these reveals a consistent structure that, while perhaps important to yōseisha as they come to terms with their illness, is also utilized to engage the public. This structure, which gives shape to the way yōseisha tell their stories and the way that audiences hear them, along with individual yōseisha skills in and desires to perform such narratives, has become critical to the “Living Together” movement espoused by organizations such as Place Tokyo (introduced in Chapter 4).

In this chapter, I describe how successful narrators and event organizers balance several key factors to ensure certain levels of protection of the speaker while also fostering audience engagement. First, I contextualize the narrative above within academic discussions of narrative in medical anthropology and illness narrative in Japan specifically. Second, I discuss how public identities of yōseisha are managed through the controlled disclosure of key bits of information when relating their experiences with HIV to the audience at the AIDS Bunka Forums at Yokohama and Kyoto by drawing from Goffman’s (1959) concepts of self presentation as well as Ochs and Capps’ (1996) and Garro and Mattingly’s (2000) descriptions of how stories are told in particular ways, by particular people, in particular settings. Third, following Jurecic’s (2012) and Frank’s (1991) assertions that the audience may or may not be able to hear the narrative as it is told, I demonstrate how yōseisha narratives are fitted to particular audiences depending on the place, time, and atmosphere of the event using the PLANET Candle Parade in Kyoto as an example. Fourth, I illustrate how yōseisha fit their messages about HIV and their experiences living with HIV to specific sponsoring organizations – and vice versa – by comparing Mr. Y’s spoken narrative at the Place Tokyo volunteer training with the
multi-voiced written narrative published by Place Tokyo for the public. This is not so different from Cain’s (1991) research on how participants at Alcoholics Anonymous (AA) learn how to shape their narratives by listening to the narratives of those who preceded them at meetings. It is important to clarify that I use Mr. Y’s narrative in two ways: first, in its (relative) entirety to illustrate the power of the narrative performed as a whole; and second, in small pieces to reveal its framework and how this framework and the basic components are similar to those found in written accounts. Finally, utilizing Yano’s (2002) description of kata141, I discuss how all these factors – strategic disclosure, controlled settings, and a general narrative structure – constitute a flexible kata (or a way) of performing public HIV narratives that can be adapted to fit the individuals, the sponsoring organization, and the audience involved. Considering that learning to tell a story is a cultural matter (Mattingly and Garro 2000), and that culture is dynamic, I argue that yōseisha and support organizations are shaped by and shape Japanese narrative culture through the construction and use of these narratives. Further, I assert that this kata that they utilize mitigates precarity by simultaneously providing some safeguards for yōseisha and engendering positive audience engagement. Finally, I argue that these narratives constitute direct engagement with HIV/AIDS on the part of yōseisha; but, perhaps more importantly, they encourage active engagement amongst members of the general public as well. Moreover, despite being forms of direct engagement, personal identifiers are carefully guarded, making them a unique form of public illness narrative.

**Narratives and Illness Narratives**

Ochs and Capps describe narrative as a method of making sense of experience through the ordering of events that may seem disparate; it is also a “resource for socializing emotions, attitude, and identities, developing personal relationships, and constituting membership in a community” (1996:20). They further assert that narrative and self are inseparable because narratives are born out of and give shape to experience (Ochs and Capps 1996). In other words, experience shapes narrative; but being able to order events through narrative allows a person to assign meaning to an experience, serves

141 Kata is a Japanese term for patterned form or way. It is often used in art to define a method of execution. In her work on enka (a style of Japanese music), Yano describes kata as the “ground where industry, singer, song, performance and listener interact” (2002:91).
as a mode of self-expression, and functions as an assertion or sign of one’s position in a community.

Narratives have been a source of anthropological data since the discipline was formed, but just how they are used has, of course, changed along with the discipline. Take, for example, W.H.R. Rivers’ use of narratives (ethnographic data) to argue that the medical systems of others were not random but rather had internal logic in the early 20th century (Rivers 1924). Narratives were – and still are – considered ways of “finding out” for the listener. But gradually, it has become well-known that narratives are not inert for the speaker and, from a medical and medical anthropological point of view, may even be beneficial with regard to health. The recognition of the therapeutic (for the patient) and educational (for the practitioner-researcher) benefits of narrative began with Freud, and can now be seen in the work of psychiatrist-anthropologists Allan Young and Arthur Kleinman (Mattingly and Garro 2000). Thus, narrative is commonly viewed by medical anthropologists as meaningful and generative for both the listener and the speaker (or interviewee and interviewer, or patient and practitioner). Furthermore, Tanaka has pointed out in her discussion of literature that writing about illness can also be a form of social engagement and activism (2012); thus narrative can also be meaningful and generative to society. Thus, relating illness experiences can take a number of forms and serve a number of purposes from both lay and academic perspectives.

Narratives about illness episodes or recovery from illness are termed illness narratives in a number of disciplines such as sociology, anthropology, and literature (Frank 1991; Frank 1995; Mattingly and Garro 2000; Jurecic 2012). Illness narratives are not to be confused with the use of the names of illnesses as metaphors, as detailed by Sontag (Sontag 1990). While Sontag describes how illnesses such as tuberculosis, cancer, and AIDS have been used by the public to describe individual personalities (tuberculosis) or social decay (cancer, AIDS) (Sontag 1990), illness narratives are personal accounts of what it is like to live with and often overcome adversity caused by illness.

There are now currently many types of illness narratives, ranging from those told in clinical encounters, to family and friends, and at public events. They can be written or spoken or performed (Mattingly 2008). In written form, they can be considered literature
in their own right (Tanaka 2012; Jurecic 2012). Jurecic draws attention to the fact that speaking or writing about illness publically is a relatively new trend, one that was fostered by the HIV/AIDS epidemic in the United States (2012). She notes that written HIV/AIDS narratives in English exceed the quantity of writing about flu, tuberculosis, polio, cancer, and other illnesses combined, and that these narratives have proliferated due to increased distances between patients and practitioners in the medical profession, improvements in modern health care and understanding of HIV etiology in which a treatment or cure appears feasible, women’s lib, gay lib, and the “inability of master narratives to give meaning to suffering in the modern era… [as well as] the technological advances that promote self-publication and the global distribution of information” (Jurecic 2012:10). In other words, the social, technological, and medical climate in the United States has allowed for illness narratives, particularly HIV/AIDS illness narratives, to become very public there. Additionally, although Jurecic is focused on written narratives, HIV/AIDS narratives in spoken form and as expressed through art were also produced in profusion in the U.S.

Spoken illness narratives in the United States may have roots in self-help groups that formed to fill the gaps between patient and family care of individuals with specialized conditions, such as disability or addiction, that began with Alcoholics Anonymous (AA) in the 1930s and the proliferation of similar groups in the 1950s (Borkman 1990). AA is rooted in Protestantism and therefore incorporated characteristics of religious witnessing, including public (or semi-public) statements about personal experiences, confirmation of faith in the group and invitations to others to join, confirmation of solidarity of the group, a learned, patterned form of experience narrative, and re-writing of personal history according to experience with the group (Christensen 2010; Borkman 1990). These characteristics, having been secularized to some degree, are also apparent in non-religious self-help groups.

Similar types of illness narratives exist in Japan and have followed somewhat similar trajectories, although they have been studied much less extensively142. Mention of

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142 This is partially due to the marginalization of most forms of illness narrative in literature, as well as the relative infancy of medical anthropology in Japan – although these trends are thankfully changing.
illnesses such as Hansen’s Disease can be found even in Japan’s earliest texts and descriptions of the tubercular conditions of writers, poets, and activists are common (Tanaka 2012; Weiner 1997). This generally parallels the trajectory in English literature detailed by Sontag before her discussion of metaphor (1990). An example particularly germane to the discussion of illness narratives is the rise in writing about Hansen’s Disease \(^{143}\) experiences in Japan during the 20\(^{th}\) century. Tanaka distinguishes between leprosy literature and Hansen’s Disease literature this way: “The shift in the illness from one that was incurable to one that could be treated meant a change in the literature: whereas leprosy literature was a heavily censored phenomenon that grew out of hospital administrators urging patient to come to terms with their illness and quarantine policies, post-Promin Hansen’s Disease literature is a politically engaged literature insistent on the restoration of human rights” (2012:5). Although HIV/AIDS narratives in Japan have not attained the same status or recognition as Japanese HD literature, the distinction between “before treatment” and “after treatment” conditions for writing (i.e., preparing for disfigurement and a slow death as opposed to learning to live with the stigma of having been infected) fits both illnesses. Tanaka further notes that patronage by several physicians and the novelist Kawabata Yasunari played major roles in the popularization and literary legitimization of the poetry and narratives produced by patients in leprosaria (2012)\(^{144}\), which parallels to some extent the social conditions that allowed for the explosion of HIV/AIDS illness narratives in the U.S (although the time frame is not the same). Finally, Tanaka also argues that HD literature served many purposes: it helped writers express themselves and detail their experiences, allowed them to build social connections, and was also used to end isolationism and claim personhood though public engagement (2012). I argue that the public narratives of yōseisha included here do similar work.

Speaking and writing about illness is relatively new in the U.S., and it is relatively new in Japan, too. For example, in Chapter 4 I discussed how the process of disclosing an

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\(^{143}\) Leprosy is now called Hansen’s Disease (HD) and is named for the man who discovered the bacteria that causes it. Promin was the first antibiotic treatment to successfully treat HD; efficacy was demonstrated in the United States in 1941, but was not available in Japan until 1946.

\(^{144}\) Mandatory isolation policies for Hansen’s Disease patients were only repealed in Japan in 1996, the same year that the lawsuit lodged by Japanese infected with HIV through medical treatment against the government was settled in favor of yōseisha.
illness is complicated, and may not occur directly in Japan. Speaking about living with cancer or even learning disabilities is difficult. Some of Teruyama’s interviewees related how they had told friends or family members about their learning disabilities not because they felt they wanted them to know per se, but because those particular people had harassed them about their personal lives – why they could not keep a job, for example (personal communication). With regard to alcoholism, Christensen describes how AA members in Japan disclose to the group but keep their status as alcoholics and AA members secret in daily life (2010), indicating inability to fully “come out” or speak publically about alcoholism as a social problem. This is where HIV narratives differ – some yōseisha seem to feel that writing and speaking about the realities of living with HIV are ways to increase public understanding and thus decrease stigmatization. Further, despite being non-religious in nature, their narratives also reflect the characteristics of witnessing described above (discussed below).

There are several people who have written about being infected with HIV as patients and, as noted in Chapter 3, Kikuchi Osamu collaborated with Hasegawa Hiroshi to produce a photo essay on living with HIV a few years ago. Although it may be tempting to describe these new trends of speaking and writing about HIV/AIDS as exogenous, it seems more accurate to say that experiencing this illness has compelled people to communicate about it and to make others aware of it. Although it is likely that overall, those who choose to speak or write about HIV/AIDS have been influenced in some way by those who speak or write in other countries or languages, such narratives in Japan are done in ways that are conceptualized and delivered by Japanese people, for Japanese people, and it would be disingenuous to label them as “foreign.” However, this does not mean that Japanese ways of communicating are static. Rather, I argue that this change is evidence of the ways that culture is indeed dynamic and shifts as people’s needs change.

Littlewood has critiqued medical anthropology in general and the use of narratives within medical anthropology and medicine specifically, asserting that medical anthropologists’ focus on patients is only due to the fact that there are no “barbarians” left to serve as others; that reliance on illness narratives over clinical narratives in clinical
settings may result in compromising health care; and that medical anthropologists fail to explain or theorize the narratives they use, leaving the narrative (or the patient) to make the argument (2003). However, these assertions are based on a number of flawed assumptions. First, anthropologists no longer focus on people they personally consider “others” as was common at the start of the discipline. Rather, they tend to focus on people who are marginalized due to power imbalances and are thus considered “others” by society in general – although a number of researchers have attempted to “study up” and discuss elite “others” as well (Farmer 1992; Farmer 2001a; Cassell 1998; Briggs and Mantini-Briggs 2003). As people who rely on specialists, family members, and the general goodwill of society to support and care for them, those suffering from illness fit the bill. Second, Littlewood fails to consider that 1) medical practitioners are beginning to realize that care can be improved if they better understand patient narratives and that, as discussed above, 2) not all illness narratives are constructed in a clinical setting.

Although time constraints and the construction of a clinical narrative on a patient’s chart limit the amount of time and the number of ways that medical practitioners interact with patients, practitioners do recognize that working more closely with patients does improve care (Shirano 2012 personal communication). With regard to the narrative settings, Cain discussed the importance of narrative in AA as early as 1991, while Frank discusses personal settings such as family and friends in his work (Cain 1991; Frank 1995).

Littlewood’s third critique is the most important because it illustrates how difficult it is for a researcher to appropriate someone’s narrative and use it to make a theoretical point – which is true not only for medical anthropologists but anthropologists in general. Frankly, it can feel somewhat disingenuous to use a story to make a point the speaker did not intend. Allowing the narrative to “speak for itself” may be a method of treating interviewees’ words with respect and blending their expertise with the researcher’s. However, it is important to be explicit about what kind of work narratives are expected to do, and some medical anthropologists do this very well (Crandon-Malamud 1993, for example).

This brings me to Mr. Y’s narrative. What type of narrative is it, and what do I expect to do with it and others like it? First, Mr. Y’s narrative is one that clearly recounts
his own struggles with HIV and his ability to overcome difficulties associated with it. It gives meaning to his experiences. This means his story can be treated as an illness narrative from the standpoint of medical anthropology without question. But when it comes to the practice of telling the story, the question arises: who is doing the meaning-making and for what purposes? While being able to construct his story surely helped Mr. Y re-establish his self-confidence after his initial difficulties with HIV, the telling of this story to a group of potential volunteers is not so much for his benefit as it is for theirs. For mine. It is meant to be educational for the audience. It is meant to be a piece of social activism that influences wider Japanese society. And with my appropriation of his story to show the ways that HIV/AIDS social activism operates in Japan, it becomes part of the academic discussion as well and allows for consideration of his narrative alongside illness narratives that preceded him – both in Japan and elsewhere – while also illustrating how current trends in illness narrative are influencing contemporary Japanese society.

So it is back to the narratives that I turn. Each yōseisha is of course very different and tells their story in different ways for different audiences. But as I noted above, there are general patterns. I illustrate patterns of strategic disclosure through Ms. Ishida’s narrative, patterns of setting control through Hunky’s narrative; and narrative structure by returning again to Mr. Y’s narrative below.

**Managing Identity Through Disclosure: AIDS Bunka Forum in Yokohama and Kyoto**

AIDS Bunka Forums are annual public events that anyone can attend. Admission is free. They are widely publicized and students in particular are encouraged to come. The audience is filled with people interested in learning about sexually transmitted infections, alternative forms of sexuality and gender, and groups that support sexual minorities. Yōseisha who agree to speak about their experiences with HIV in such public venues know that there is a possibility that they may be recognized due to the off-chance that an acquaintance who is unaware of their status opts to attend. It is a risk they accept. But other risks, such as being asked questions they are not willing or ready to answer, for example, are carefully managed by the structure of the narrative and the presence of a
supporter. A key strategy is to give the audience just enough details about a yōseisha’s personal life to encourage a connection with them but no more than the yōseisha is willing to provide.

Ms. Ishida\textsuperscript{145} took the stage and Dr. Iwamuro introduced her, giving the audience time to take in both participants visually. Ms. Ishida’s hair was stylishly bobbed. She looked vibrant and beautiful in her flowing blue tunic, black leggings, and sandals: there was nothing to separate her from any other Japanese women in the audience in terms of her fashionable appearance. Her doctor, Dr. Iwamuro, is rather famous for his role in founding the forum and appeared to be a typical middle-aged professional with glasses and graying hair. The only thing that made him stand out was his famous condom-print tie; but this probably went unnoticed by many in the audience.

The two began a conversation about her life and experiences with HIV. Dr. Iwamuro asked Ms. Ishida about how she found out that she was HIV+, the circumstances surrounding her infection, the symptoms she experienced, the difficulties of disclosure, the care she was offered, and her daily life. Through this interaction, the audience learned things about Ms. Ishida that Dr. Iwamuro already knew. She is married and has a child. All pregnant women in Japan are tested for HIV, and that’s how she found out she is living with HIV. She got a tattoo several years ago and experienced flu-like symptoms (fever, swollen glands) afterwards but thought she had just gotten a bug that was going around. She was shocked to find out she was HIV+ during a prenatal exam, commenting that the tattoo parlor\textsuperscript{146} had probably re-used their needles. She told the audience that she had a lot of difficulty telling her family, but her doctor helped her by being there when she told her mother. She couldn’t bring herself to tell her father; her mother told him for her. At the clinic she visits, the staff all know her and are very friendly to her – she said they notice whether or not she’s gained or lost weight and whether she appears happy or not. Before opening the session up for questions, she noted

\textsuperscript{145} This is a pseudonym she herself has chosen.

\textsuperscript{146} Getting a tattoo in Japan is not the common practice it is in other countries. It tends to be associated with the yakuza (the Japanese mafia), and there are several places like hot spring resorts that reject patrons who have tattoos. Facial tattoos used to be common amongst Ainu women. In this particular case, getting HIV through being tattooed is probably less stigmatizing than getting HIV through sex or drug use but still more than stigmatizing than being infected through medical treatment.
she is living an everyday life taking care of her child, but that it is sometimes hard because there is still a lot of discrimination.

Together, Ms. Ishida and Dr. Iwamuro constructed a narrative that guided the audience down her pathway from diagnosis to acceptance, although acceptance is clearly a daily issue. As the narrative came to an end, it shifted to a question-answer session. While Ms. Ishida answered questions about her feelings – such as whether or not she regretted getting her tattoo – Dr. Iwamuro answered medical questions. He also exhibited great skill in unobtrusively steering the audience away from questions that may have been too personal for Ms. Ishida, such as those about her family life or sex life. Rather than answer questions about her personal experiences, for example, Dr. Iwamuro discussed safer sex and ways to prevent transmission between sero-discordant couples and from mother to child. To use Goffman’s theory of presenting the self, they crafted a careful impression that would not embarrass Ms. Ishida or others in front of the audience (1959); however, their collaboration was more protective than Goffman’s theory intends because the goal the organizers had was not for the audience to get to know Ms. Ishida or Dr. Iwamuro. The goal was to get them to know HIV through Ms. Ishida’s and Dr. Iwamuro’s narrative. While the audience learned about what it is like to be tested, to disclose to family members, and to get treatment through her narrative, Ms. Ishida’s personal identifiers were carefully and purposefully omitted.

Thus, Ms. Ishida’s narrative gave the audience a specific image of someone living with HIV: a beautiful, articulate young woman with a son, someone not much different from the audience members, perhaps. This encouraged the audience members to see that HIV can infect and affect anyone – even in Japan. The narrative by two seemingly “normal shakaijin” provided the audience a chance to learn about safer sex, mother-to-child transmission, and personal responsibility for self preservation. For example, when asked about whether she was angry with the tattoo parlor, Ms. Ishida was adamant that she had chosen to go there in order to pay less than she would have if she had gone to a “regular” shop. Although she said she sometimes regretted all the trouble she had

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147 This term literally means “person of society” and is used to refer to someone who is living in and contributing to society by working – but also possibly being married and having children.
experienced for such a trivial thing, she claimed responsibility – and asserted that the audience members needed to do the same thing when making choices. In this way, in addition to providing a “yōseisha face and experience” that they want to see or “consume,” and providing an introduction to living with HIV, Ms. Ishida was able to use her narrative and questions from the audience to challenge the audience to think about their choices and take responsibility for the consequences.

These interactions make it clear it is not just Ms. Ishida and Dr. Iwamuro who shape the narrative: by the end of the session, it was obvious that the audience shaped it, too. To use Kleinman’s terminology, Ms. Ishida, Dr. Iwamuro and the audience all worked together to develop an “explanatory model” of HIV that they could all understand and use to share information (1988) – all without making any specific references to Ms. Ishida’s life or allowing the audience to approach her alone. Public engagement with HIV through people like Ms. Ishida, then, is considered a success. Similar strategies were also apparent at the AIDS Bunka Forum in Kyoto, where three male yōseisha spoke at a similar type of session with a moderator.

There are a few points to summarize. First, speakers like Ms. Ishida are not alone when they speak: peers or support staff join the speakers on stage, and form part of the audience. This arrangement provides emotional support and allows for the redirection of questions that speakers may not be ready or willing to answer. Second, speakers use pseudonyms or professional names that they themselves have selected. This gives them the power to select the personal information they are willing to share in that specific setting. Recall that Mr. Y above asserted that HIV is only five percent of his life, of himself. Amongst his friends, of course he uses his given name; some people in his everyday life know he is a yōseisha, but his HIV status is not the defining element of his identity to him or the people closest to him. However, when he speaks publically as a yōseisha, he is Mr. Y. He highlights that five percent because that is what is asked of him,

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148 There were, however, major differences between the two sessions. First, the Kyoto session was clearly not as scripted as the Yokohama session, and yōseisha were clearly more comfortable speaking for themselves. Second, the moderator was not a medical doctor and his role was solely to ask the predetermined questions. Third, yōseisha at the Kyoto session were eager to speak to audience members individually: in fact, this is how I made a number of contacts. This just goes to show that each session is really managed to a different level depending on the participants.
and he reminds the audience that they are only seeing part of him. For yōseisha, it is safer – both in terms of an individual’s mental health and in terms of avoiding discrimination – to highlight these experiences and add a sprinkling of personal details using their professional identity when speaking to the general public about being HIV+. Third, although there is an element of performance involved in the telling of such narratives (which I address below), this does not extend to making changes in appearance – either to embellish or hide certain individual attributes. Their narratives cast them as yōseisha, and their clothing and comportment cast them as members of the general public. This is important because many people who have no personal experience with yōseisha tend to imagine them as outside the general public and as belonging to special groups. Therefore, one of the take-home reminders of these sessions is that yōseisha are members of the general public. Although these three aspects are most visible in this type of public appearance, they are also important components in the events described below.

As noted above, Garro and Mattingly assert that “what constitutes a proper story, who can tell what kinds of stories in what kinds of circumstances” is culturally patterned (2000). Moreover, Ochs and Capps state that “narrative allows narrators to work through deviations from the unexpected within a conventional structure” (1996:22). Based on narratives like the one constructed by Ms. Ishida and Dr. Iwamuro, it seems that working through HIV at the social level by means of narrative involves building strategic disclosure into basic structures of presentations already known to Japanese people such as “forum,” “symposium,” or “training.”

**Controlled Settings: Space and Time at PLANET Candle Parade in Kyoto**

“There are many people in Japan living with HIV. I am one of them. Stigma and discrimination are not going away. We cannot forget that eizu is a social disease...” began Hunky149, a Kyoto resident who lives with HIV. Moments before, he had walked up the stone steps of City Hall at dusk, and taken the microphone from one of the sponsors. As he talked about continuing to fight against prejudice and stigma, his voice waivered just enough for me to notice. But his message about the importance of talking openly about

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149 This is a nickname, one he uses when he speaks in public and works with yōseisha.
HIV was as clear as the thick, white letters inked on his blue t-shirt that read, “I am HIV positive.”

When he finished, it was almost dark. We organized into a line behind a large, white banner that featured a red ribbon and the name of the event written in large, black letters. Hunky took one corner and gestured for me to take a section next to him. We all walked from City Hall to Gion, and the procession was a relatively quiet one. People talked in low voices with loved ones or walked alone – all carrying flickering candles in paper cups that sometimes dribbled hot wax down their hands. Someone played a flute as we walked, and the organizer’s voice rang out over the loudspeaker: “We are from PLANET, an organization that remembers people lost to eizu and promotes awareness of HIV. Won’t you walk with us?” This was punctuated by stops in front of shops displaying red ribbons on their facades; in the days before, several of us had visited the shop owners along the parade route and asked if they would put up a red ribbon in their window to show their support. Every time we passed such a shop, Ms. Odagiri would thank them over the loudspeaker and there was an exchange of bows – often through the shop’s windows. When we reached the park, people were invited to give their impressions of the walk. No one spoke as a yōseisha, but several people remarked about the power of being part of the walk itself.

Unlike Ms. Ishida’s narrative above, Hunky did not talk about the circumstances of his infection or his everyday life. He did not tell the audience about his progression from diagnosis to acceptance, or tell them they had to be responsible for their actions. He did not have to do any of these things because the audience – despite being open to the general public – was a much more specific one than the crowd at the Bunka Forum. Although anyone can attend PLANET’s candle parades, participants tend to be those who have personal experience with HIV/AIDS, such as loss of a loved one, or through professional experience (i.e. medical practitioners or educators). Speaking to a sympathetic, even empathetic, audience who had their own experiences with HIV, Hunky focused on the importance of talking about HIV openly as a tool to fight discrimination rather than talking about his experiences as a yōseisha.
Hunky’s speech does not fit the narrative model we see in Mr. Y’s or Ms. Ishida’s performances. But to some degree, his actions at the parade do fit the general pattern of introduction to HIV, experiences surrounding diagnosis, positive and negative experiences living with HIV, and finding support. From the beginning of the event, Hunky announced his HIV status, both verbally and through his clothing. During the parade, he carried the banner; but he also passed it off to others and mingled with the crowd. At the end of the walk, he joined the rest of us in the park – dark but for our candles – and listened to people give their impressions of the walk. He joined the organizers for dinner, popping his ARVs in his mouth, and washing them down with beer and battered fish between bits of conversation. How he participated in the parade is a narrative in and of itself.

Mattingly has argued that “narratives may be acted rather than told,” stating that such “living narratives” suggest the possibility of healing (2008:74). Further, she notes that such performed narratives are similar to healing rituals in that 1) heightened attention to the moment gives the event legitimacy, 2) a number of sensory cues express/create meaning, 3) aesthetic, sensuous and extralinguistic interactions are highlighted, 4) the experience is socially shared, 5) the people involved reflect on the past, present and future, situating themselves in a particular history, as a method of healing, and 6) participants can be transformed (Mattingly 2008:76). Each of these criteria is met by the event: all participants exhibited a heightened attention to HIV/AIDS, whether individual focus was on personal loss or grief, efforts to raise social consciousness, or a combination of the two. Some people dressed up in kimonos, some dressed “smart” as though out on a date, many wore red ribbons. Everyone carried candles. People walked together, grouped together, listened to the flute and Ms. Odagiri’s voice as we moved steadily up the street and towards Gion. This was the 20th parade, and posters showed pictures of some of the first marchers who were now deceased.

So what was Hunky’s part in this? It seemed to me that he moved through the same general yōseisha narrative structure outlined above. Wearing his shirt and standing before a crowd full of his peers, Hunky needed little introduction – nor did the event, which was full of many repeat walkers. But we were all drawn to his voice. It is a
confident voice, even though it wavers, and on that day you could hear parts of his personality: shy but strong. As he made his way amongst his friends, he outlined his peer network and illustrated his position as a confident, kind, and caring friend. When some of the medical practitioners chided him for washing his pills down with beer, he shrugged it off. “It’s fine, it’s fine,” he remarked, and offered me some sashimi with his eyes smiling. The party went on.

One key way that the parade marchers differed from the Bunka Forum audiences was the degree to which they had control over the narrative that was performed. Although the audience members were drawn into the narratives at the Bunka Forums through the question and answer sessions, they were relatively passive participants during the narrative construction between those onstage at the beginning of each session. This was not the case in the Candle Parade. As noted above, Hunky walked, talked, ate, and drank his way through the Candle Parade and the events afterwards. Because he was asked to speak and helped organize the event, his actions stood out. But in reality, all the participants walked their narratives – some without saying a word. It is possible that the power that people said they felt during the procession was this sense of walking narratives together, in an atmosphere where the goals and the rules were shared by everyone.

Although the parade seems open and porous from the outside, there were several factors that functioned to control the setting. The goals of the PLANET Candle Parade are to remember those who were lost to AIDS, raise awareness about HIV/AIDS, and to fight to end discrimination of those living with HIV/AIDS. Those with shared experiences – membership in the same peer support group, those who suffered the loss of a common friend or loss of a child, for example – tended to walk together. Moreover, the pace of the walk, the darkness, the holding of candles, and the solemn mood discouraged interactions between strangers. In Hunky’s case, this meant that although his shirt constantly announced his status as a *yōseisha*, he could vacillate from his “public *yōseisha*” role as a speaker and banner-carrier to other versions of himself as he moved around and talked to friends and acquaintances. In this way, not just Hunky’s privacy, but that of the other participants as well, was protected by the structure of the event – the
darkness, the candles, the pace, the intimate groups. When people take part in this very public event, they are still able to maintain a sense of quiet privacy, all the while being supported by the presence of fellow participants. This makes it very different from what happens at Bunka Forums (above) and in booklets or at trainings (below), but it highlights the degree to which setting shapes narrative and narrative interactions.

Packaging the Messages: The Narrative Structure of Mr. Y’s Story and the “Living Together” Booklet

Finally, we return to Mr. Y’s narrative once more: as I noted in the introduction, I use pieces of his story to illustrate how it is framed and what the components are so that I can compare it to written accounts. His narrative was governed by the same factors discussed above – strategic disclosure and controlled settings. With regard to disclosure, Mr. Y is a pseudonym; and although he used fantastic imagery while detailing interactions with medical staff and friends, like Ms. Ishida, he omitted personal identifiers such as his age, where he is from and where he lives, family and relationship status, etc. Like other speakers, Mr. Y gives HIV a face, but tells the audience: “These are my experiences and I can’t speak for all yōseisha,” thus encouraging the audience to understand the general through his personal experiences, while at the same time asserting diversity and ownership of his narrative.

The setting was also carefully controlled. He was escorted in and out of the room in such a way that prevented one-on-one interaction with the audience; he used his time and space well, taking questions right up until the end of the time slot. Control of the setting extended to the audience itself: it was a relatively small group of people with the specific goal to be trained to work at various NGOs, NPOs, and CBOs related to sexual health at a volunteer training session organized by Place Tokyo. The talk was not open to the public and was not free.

This control extended to the timing of when we heard Mr. Y’s narrative: he spoke on the last day of training, ensuring that what trainees had learned in previous sessions

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150 Hunky, who participated in the PLANET Candle Parade and the AIDS Bunka Forum in Kyoto, also says this; so did the other AIDS Bunka Forum Kyoto speakers.
151 This was also the case with Ms. Ishida.
152 This presentation was included in the training, which cost approximately $60.
solidified and that we had a chance to see and hear about the realities of living with HIV personally. In this way, his narrative was narrower in focus than the Bunka Forum talks, which were aimed at a “general audience,” and more education-oriented than the PLANET Candle Parade. In other words, attendees were primed to hear Mr. Y’s narrative through the educational framework provided by Place Tokyo, to know how to respect his privacy, and to know how to ask the “right” questions: we were trained to participate, to hear his narrative in a way that the general public is not.

However, note that neither the semi-private setting nor the training the audience had undergone led to a higher level of openness regarding Mr. Y’s personal life. Knowledge of HIV and close proximity to Mr. Y did not entitle the audience to any personal information, and we were only allowed to see his “public yōseisha” face. What these differences in setting and training did facilitate was the way audience responses and questions were mediated: questions and responses were guided by training rather than the moderators at the Bunka Forums or the social and physical aspects of the Candle parade. The audience self-monitored.

Whereas disclosure is easy to see in Ms. Ishida’s narrative and the importance of setting is visible in Hunky’s, what is strikingly clear in Mr. Y’s narrative is the basic narrative structure that most public HIV narratives follow. What his narrative highlights most strongly is the way the content of the narrative and the structure for telling it work in tandem with the goals of the organizer of the training, Place Tokyo, discussed above. So what is the structure of his story, and how does it make for an effective narrative? Below, I return to Mr. Y’s narrative and compare it to a booklet prepared by Place Tokyo – the same organization that provided the volunteer training. I use these to illustrate how narratives of HIV – both written and spoken – follow a general pattern: introductions, pre-diagnosis/diagnosis, acceptance/disclosure, finding peer support, becoming peer support, and concluding remarks about the positives and negatives about life with HIV. This structure provides an organizational framework for yōseisha to talk about their

153 The extent of the parade’s educational focus is the distribution of information packets and condoms to participants and passers-by.
experiences, for Place Tokyo to teach about them, and for the audience to understand or hear them.

1. **Introducing the Speaker, Introducing HIV**

   In attending an HIV/AIDS talk or workshop, or reading a publication on the subject, of course one expects to engage with sensitive topics. However, some introduction is still required.

   I can hear Mr. Y’s voice in my head even now over a year after hearing him speak:

   “Not just the words, but the images of HIV are important. You know? In 1996, the image was you suffer, get thin, and die all alone. I thought I should get tested. I knew it was important. But because it was important, I avoided it, ran away from it. I wonder if you can understand that?” asked Mr. Y.

   Beginning his narrative with this contradiction, that people avoid getting tested for HIV because of the importance of the result and the seeming finality a positive result would represent, Mr. Y captured my interest from the start. His physical presence and his words about AIDS imagery provided another contradiction: as outlined in previous chapters, the image of getting thin and dying alone is still prevalent among the general public. But Mr. Y standing before us in 2011, gave credence to what we had learned in the previous workshops about it being possible to live positively with HIV. He is embodied evidence that this stereotype is misleading, if not flat-out wrong for many people living with HIV\textsuperscript{154}. Perhaps most importantly, these contradictions are connected. Mr. Y’s difficulty in getting tested had been connected to the images of AIDS, and of what he would do if he found out he was going to be a dying AIDS patient.

   However, Place Tokyo introduces HIV in their booklet “Living Together: Our Stories” with a poem:

   “Any given day, someone faces it.

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\textsuperscript{154} Of course, it is wrong provided that one is able to access the resources that are available to yūseisha in Japan.
Any given day, someone is informed they have it.
Any given day, someone makes the decision to live with it.

_HIV—_

_A small, small virus in an electron microscope_

_This big shadow thrown into everyday life_

It’s been 20 years\textsuperscript{155} since HIV/AIDS appeared in the world.

>This book contains notes by people living with and affected by HIV/AIDS.

**LIVING TOGETHER.**

_If you can find yourself in the sentences of this book,_

_We’ll be grateful.\textsuperscript{156}”_

The hook is a bit different than Mr. Y’s, but they both begin with a contradiction about HIV/AIDS: the poem paints HIV as an everyday thing, which is contradictory to most people’s image of it. Whether reading the booklet or listening to Mr. Y, the audience is faced with HIV as a virus and HIV/AIDS as a social issue. People live with it, both physically and socially. In the booklet, the authors imply that everyone should be able to find something of value within the pages which, in addition to experiences by yōseisha, also include information about safer sex, STIs, and counseling. Ms. Ikegami and Mr. Ikushima\textsuperscript{157} appeal to readers’ intellect in their factual columns while yōseisha appeal to readers’ emotions by relating their experiences. The hope is that, one way or another, the booklet will have an impact: “If you can find yourself in the sentences of this book, we’ll be grateful.” Mr. Y’s attitude towards the audience, which he carefully

\textsuperscript{155}The booklet was originally published in 2005, so 20 years was accurate at the time it was written.

\textsuperscript{156}Translation by the author. All stories described here are from this booklet. (Ikegami and Ikushima 2005).

\textsuperscript{157}Ms. Ikegami is the founder of Place Tokyo. Mr. Ikushima is a medical social worker who works at Place Tokyo.
engaged though eye contact, as well as his proximity and movement at the front of the classroom, was much the same as when he asked the audience to just listen instead of taking notes.

2. Pre-diagnosis

Although there is some variation in how HIV is introduced in the Place Tokyo booklet and Mr. Y’s narrative due to differences in written and spoken forms (discussed fully at the end of this section), the flow of the talk and the booklet are fairly similar afterwards. For example, when moving on to talk about life just prior to diagnosis, many yōseisha describe feelings of fear or dread if they have started to sense something is not quite right with their physical health.

“I thought I should get tested. I knew it was important. But because it was important, I avoided it, ran away from it... Exactly because it was important, I couldn’t do it.” (Mr. Y.)

This fear of being diagnosed, of getting thin, of suffering, and of dying alone has been voiced by many people who recognized that they may be at risk for contracting HIV or that they have symptoms that correspond to AIDS. For some, like Mr. Y, this translated into fear of being tested and “running away.” For others, it translated into fear that drove them to be tested:

“Thinking back six years ago, I had panicked and thought that maybe I had The Dreaded Disease so I decided to take a test to confirm I was negative.” (Hajime Yamanaka, 4).

While this may seem to be a “helpful fear,” sometimes testing negative can give people a false sense of security about their vulnerability. The same person goes on to comment,

“I should have had comparatively safer sex after that. But I felt safe thinking that HIV was something that just concerned other people... This time the result was positive.”

Testing negative, it appears, served to confirm another common misconception – that HIV was far away and someone else’s problem. Fear of the test and comfort in a
negative result became barriers to treatment, prevention, and care that could only be breached when symptoms manifested to the point they could not be ignored. Thus, in both written and verbal accounts, the time leading up to diagnosis is described as fearful or as a time when they believed “HIV was something that just concerned other people.” This misconception is part of what leads to trauma at diagnosis, which is usually next in the narrative.

3. Diagnosis

The similarity in narrative voice in the talk and the booklet continues in the discussion about diagnosis which, in addition to fear, usually includes feelings of shock, anger, shame and ultimately depression. Consider Mr. Y’s worries about his health and the HIV test:

“My stomach began to hurt, and I knew something was wrong. I had bloody diarrhea. You know – that stuff that they say looks like strawberry jam. I went to the hospital. They told me of all the g.i. tests I’d have to take and release forms I’d have to sign. HIV was on the list, and I thought, ‘Man! Here it is.’” (Mr. Y)

The required HIV test was positive. He underwent surgery for his gastroenterological complications and went into hospice to recover. He had a lot of problems sleeping – but not from the surgery. From anxiety. Mr. Y verbalized his sources of stress and his physical condition; in comparison, a booklet contributor discussed how diagnosis changed their perceptions of the self and others:

“When I was told I was positive, my heart was filled with fear and humiliation. And I felt this sense of confusion that I couldn’t grasp.

Even though nothing had changed about me, while I was in that state, everything I saw was colored by suspicion or even loathing.

When directly faced with various hard facts at the hospital, I felt denied and as though I was guilty of a terrible sin.
The image of this illness that has been presented up until now is that it’s something not worthy of consideration or encouragement. Even I, myself, someone with HIV, had this strong, discriminatory view.” (K, 8)

In addition to the pain and discomfort of the symptoms and the fear of diagnosis described by Mr. Y, many people feel the fear and humiliation expressed by K. The fear stems from the popular image of eizu as equivalent to death. The humiliation stems from the feeling that this illness is only supposed to happen to other people and is not something that someone with a “normal” lifestyle gets. When diagnosed, a person becomes part of a group they considered to be made up of “others.” The shock leads that person to question their selfhood and self-worth: “I felt denied and as though I was guilty of a terrible sin.”

4. Struggles with acceptance and disclosure
The shock of a positive diagnosis, and the questioning of one’s selfhood, self-worth, and normalcy, is often difficult to handle. Not only do yōseisha struggle to accept their HIV status, they struggle with disclosing to lovers, friends, family members, employers, and others. Contemplating the sheer number of people in their lives and whether or not those people would accept or reject them if told can be overwhelming and traumatic. This was apparent in both verbal and written accounts.

“I was OK during the day, but really down at night. I called in the nurse once one night. Told her my back hurt. But really, what did I want? I wasn’t sure. Everything was complicated – friends, family. That nurse rubbed my back, listened to me try to decide, to tell or not to tell? ‘You know, you don’t have to solve everything right now. Just one thing at a time.’ So I did that. One thing at a time. It got easier to sleep.” (Mr. Y)

Whereas Mr. Y expressed his anxiety about how to disclose his status and who he should tell, some yōseisha struggle with how they could possibly go on living at all:

“At first, I thought of nothing but suicide. I’m going to die anyway, so it might as well be now… there’s not going to be a cure in my lifetime… but the people around me wouldn’t accept that and the days went by…
For me, the courage to live with HIV came when the attending physician said, ‘I can help you.’” (KN, 6)

For both Mr. Y and KN, medical professionals were the first group of people to offer support and encourage them to think of things one step at a time. Many yōseisha comment that acceptance and disclosure are daily struggles; a “one thing at a time” mentality may promote a sense of order that helps them make decisions about whom to trust with their status, how to interact with others, and how to re-conceptualize HIV as something that is personal.

“Small nose, unruly hair, round face.

Everyone should be able to give away the things they hate about themselves.

But actually, I’m a person who loves myself best.

And Little Mr. HIV is part of me. I can’t help but love him.

Little Mr. HIV, you’re smart – smarter than we humans. But your purpose is also to live, living in my body. When you kill me, you’ll die, too, without having fulfilled your goal. So for the time being, let’s live a good life together.” (MIKA, 7)

MIKA’s love for herself and “Little Mr. HIV” who lives within her may seem extreme. But as we will see below, stating that one liked themselves better post-diagnosis is not rare. Neither is personification of the illness. Acceptance of the illness, whatever the method, is a process of realizing that HIV does not have to be one’s defining characteristic. Having a key person to rely on helps with this process.

“I’ve really had a lot of things happen, but now I’m pretty happy. Although it took several years to just accept HIV as a simple fact, maybe that’s okay. Because of that experience, I’m here.

But maybe that was really hard for my family. I told my mother everything, that I have HIV and that I’m gay. I couldn’t bear those two secrets alone. There was only once where my amazing mother, whose love was always unconditional, let her voice waver.
'I gave up on grandchildren, so don’t worry about that. I don’t know anything about being gay or homosexual. About that, whatever is fine. I just want you to be healthy. So I want you to promise me one thing. Don’t be unfilial and die before me! I can’t forgive that.’

Because I believe I was born to be happy, and that was all my mother asked, I thought, I’ll take the time to try to start my life again.” (Dandelion, 11)

Accepting one’s HIV status, accepting oneself, and finding supportive people are important issues throughout a yōseisha’s life. Dandelion’s mother’s unconditional acceptance of her son’s sexuality and HIV status ensured that he had a confidant and motivated him to see an HIV diagnosis as a chance to have a new start. Although the processes of acceptance and disclosure are sometimes not presented as linear, they can be explained as such by noting they are “daily issues” or “constant challenges.” After all, one does not disclose everything to everyone all at one time – whether one is a yōseisha or not. These things happen organically depending on each particular relationship.

Sometimes these moments of acceptance do not stem from someone who has been a constant in the person’s life. The words of acquaintances can be equally valuable in shifting a person’s conceptualization of their serostatus.

“When I looked down, I couldn’t see his face and he couldn’t really see mine. I found myself looking down into my cup, hands shaking, tears falling down... and I told him in English, ‘I am AIDS.’ I couldn’t stop the tears or the shaking, couldn’t let go of the cup.

He reached over and put his hands around mine. ‘You’re going to spoil your coffee,’ he said quietly.

He took me back to his place, hugged me. He hugged me! I couldn’t believe it. We talked some more. When I went to leave, he said, ‘Hey, what you said earlier. You made a grammatical mistake in English. You don’t say ‘I am AIDS.’ You just have HIV.’

‘I just have HIV.’” (Mr. Y)
Many narratives highlight the points where yōseisha realized that being HIV+ was not equivalent to dying of AIDS, or that they were not alone, as moments of relief and growth. Being accepted by an acquaintance or finding another yōseisha are especially important.

5. Finding peer support

Both writers and speakers describe the importance of finding support, such as in Mr. Y’s description of meeting his first fellow yōseisha:

“One day, I saw this guy in this the hall, going about his business. I was watching him. And he knew that. He looked over me and said, ‘Hey Mr. Y, I take the blue pills, too.’ Blue pills. Those were my first drugs to fight HIV. You know, I knew the numbers, I’d heard how many people had HIV. But somehow I felt so alone until I heard him say that. Knowing someone is much different than just knowing the numbers. That’s the first time I felt I wasn’t alone.”

However, the Place Tokyo booklet does something that an individual talk cannot: it breaks from the purely yōseisha narrative at different points by including entries from family members, former lovers and friends. One woman describes the importance of finding empathetic people to talk with about living with HIV:

“I feel like I can understand how it would be a relief for people who are positive to find someone to talk to, too. I’m not positive, so I don’t think I can understand all the difficulties [of having HIV]. I don’t force myself to try to understand. But I want to be with him forever. I understand the reality that that will be difficult regarding various things. Marriage and pregnancy and birth… at every point, there is a risk of infection… even if it’s something I want, I understand that he might have difficulties, too.

So for now, just being together is good. It makes me feel better when I talk about the feelings positive people wouldn’t understand (like family, friends, or partner) with people who surround positive people. The people I’ve met through this illness, I can talk to them with an open and honest mind, and all of them are very important people to me.” (Miu, 14).
Miu draws attention to the fact that it is not just yōseisha who need to find people who have similar experiences: their friends and family also need to find this sort of support. We see that this support needs to be constant as she describes the added difficulties in going through life’s “landmarks” – marriage, pregnancy, birth – because they can pose both physiological stress (possible transmission) and psychological stress (awareness of the risk of transmission, in addition to the added responsibilities). Moreover, she outwardly states what most yōseisha do not when speaking publically: that non-yōseisha cannot fully understand yōseisha perspectives and it is important to recognize that. Yōseisha need their friends and family members, but they need other yōseisha, too. Furthermore, people who support yōseisha need their own networks of support as well.

6. Finding/becoming part of a support network

A step that many yōseisha make once they have found other yōseisha is to become part of a network, or re-integrate into one they were previously estranged from – and this is often included in the narrative.

“It’s hard for me to say I need help. But I started to go to PLACE Tokyo for counseling. I was there for two hours once. And suddenly I thought, ‘I have this much to talk about?!’ And then one day my peer group partner came in, and said, ‘Man, this working overtime is going to kill me!’ ‘What? You’re not going to die of AIDS?’ Another lesson.” (Mr. Y)

Mr. Y’s narrative highlights his interactions with yōseisha in hospice and in counseling, making little mention of his family. This is compared to a booklet contributor, who does essentially the opposite:

“It seems that the number of people infected with HIV in my generation is increasing. But everyone is there for you, so it’s okay. I think you get more than you lose... that’s what I think now. The number one thing I got back after I got sick? My bond with my parents. That’s my most important treasure.

For a long time, I was bored and lonely, played around and stayed over, and then just walked out. This happened because I lived that way for seven years. You could say
that I brought this on myself. But when I said that, my father hugged me and said, ‘Dummy. You’re a dummy, but you’re my precious kid!’ I was so happy. I thought, ‘why didn’t I lean on the people closest to me before?’ If I had done that, maybe it would have been different.

To say that I have absolutely no regrets would be a lie. But I got this. And that’s just fine. In a roundabout way, I got what I’d wanted since I was a child” (H, 10).

Despite their differences, these two accounts refer to the importance of two key social institutions in Japan. The first is the hierarchy of social relationships that includes learning from senpai (those who went before you), teaching kōhai (those who came after you), and sharing experiences with dōryo or dōkyūsei (co-workers, classmates or compatriots). The second is the family, particularly parent-child relationships. This is significant given that interviewees often stated that being social and interacting with others is a component of health (as discussed in Chapter 1).

7. Concluding remarks about living with HIV

Written and spoken accounts almost always end with a positive spin about life. Mr Y states,

“You know, people live and die every day, with or without HIV.

When I first found out I was living with HIV, it was like, ninety-five percent of the pie. But then over time, I considered it less and less a defining part of my identity. I’m not JUST living with HIV. Now it’s, like, five percent of that pie. It’s not that I think so much of living with HIV. It’s thinking that I’m living with something difficult. And most people do.” (Mr. Y)

When people are first diagnosed with HIV, they often feel overwhelmed and that the illness defines them. But this often shifts, and HIV status defines them in a similar manner to gender, sexuality, ethnicity – although it is still stigmatized and can be difficult to talk about. Some people, like KN, state that being HIV+ gave them a chance to take charge of their lives and so gain self confidence:

158 The Japanese is, sore de iin janai ka (それでいいんじゃんか), a rhetorical question.
“Living with HIV, I’ve rebuilt my self confidence and started over. In the last two years plus, I’ve thought, ‘I can’t do it anymore!’ many times. But recently, something about me is different… I’ve been able to like the self that chose to live with HIV a bit more than before. So now when I think ‘I can’t do it!’ or when I’m faced with something over and over, I’ve become able to think, ‘I can get definitely get through this.’ So, I like myself, the me that thinks like that, better.

I don’t know how many years I’ll live. I don’t know what ordeals are waiting for me. I’ve only rebuilt myself part-way. But maybe that is ‘living.’

That’s what I think now. ‘HIV is a big chance to re-think my life, myself.’

So, ‘no matter how hard it is, I can overcome it...’” (KN,6)

Whereas Mr. Y has come to think of HIV as a part of him, as something difficult to live with that is not all that different from the troubles of others, KN feels that s/he has been able to understand her/himself better than before and now considers re-thinking oneself in the face of adversity to be part of life.

**Summary of Written and Oral Place Tokyo Illness Narratives**

From these narratives, the audience gets a clear, linear trajectory of what it is like to worry about getting an HIV test, to get a positive diagnosis, to struggle with negative feelings and issues about who to tell, to find support, to become a supporter, and to learn how to live with HIV positively. Overall this linear structure for expressing illness experiences – whether used for written or spoken narrative – simplifies the story for both the speaker and the audience, even though the everyday reality is much more complex.

First, yōseisha can order their experiences, giving them the sense of coherence that Frank suggests is central to healing through narrative construction (Frank 1995; Frank 1991). Thus, individual yōseisha fit personal experiences to the general structure, but assure the audience that they cannot speak for all yōseisha, simultaneously drawing from a base of shared experience among yōseisha and asserting individuality. This is similar to how participants in AA learned how to share stories in group (Cain 1991). Second, the linear structure provides the audience with a systematic way that facilitates
the hearing of the narratives, which both Frank (1991) and Jurecic (2012) describe as a major difficulty in relating experiences of illness and pain. Miscommunication can occur when the speaker and the audience understand the shared experiences differently (Kleinman 1988; Jurecic 2012). The structure of the narrative as well as the contextualization of the narrative at a particular event helps to reduce the chances of this. Third, the narrative structure is not rigid, so individuals can choose to follow a basic “yōseisha trajectory” but also choose what experiences they want to focus on. This means that the framework is there for support, but it does not interfere with expressions of individuality or the plurality of experiences with HIV that exist. In other words, the structure allows for the careful balance of general experience and personal experience that will hopefully allow audiences to “find themselves in the pages” of the booklet and in the personalities of the speakers, as well as consider the ways that people’s lives have been altered by HIV.

However, there are some differences between the written and spoken narratives that require acknowledgement. First, the issue of tailoring the message to the audience differs in that a speaker must anticipate what the audience is likely to expect and continually adapt to them as they ask questions, while a written message is tailored once and then published. For example, the Place Tokyo booklet narratives are written in journal format in very casual language so that the messages will appeal to young readers and not appear textbook-ish. Additionally, the reader has complete control over what information they choose to read and in what order. If someone was interested in support networks, for example, they could go straight to that section in the written text.

Second, just what is disclosed in written versus spoken narratives can be very different. Because speakers interact directly with an audience, there is a greater possibility that they will be recognized. But even if they are not recognized, they may still face people who judge them or ask uncomfortable questions. This is essentially avoided when narratives are written. In other words, the written form may allow the yōseisha more anonymity and protection because they do not personally face the audience. In fact, this may allow them to be more frank about their feelings and the
various experiences that they have faced because, if they use a pen name or write anonymously, there is little chance of discrimination based on what they wrote.

Third, written and spoken narratives allow for different types of emotional engagement with the audience members, particularly when only one oral narrative is offered. For example, hearing Mr. Y’s story as the story demanded audience attention and focus; his impressive presence allowed the members to connect with Mr. Y as his voice filled the room, his paces drew the audience’s eyes, and his eyes seemed to gaze deeply into the minds of the participants while he described his fear in coming out and the warmth he felt from his friend from the gym. Also, in general, spoken public narratives are rarely recorded and disseminated, making them unique to each event, regardless of whether or not the same people speak at different events, or even at the same event year after year – the audience is different, and the speaker has different experiences that they may incorporate. (Those done specifically for television or movies are at yet another level of performance and are more like written narratives in that they become fixed.) In addition, the audience becomes part of the narrative as members pose questions. This strongly contrasts with reading the Living Together booklet. The reading of the booklet, unless done in a group setting, is a rather individual experience. And although reading a narrative may elicit an emotional response from the reader, the narrator does not have to interact with or respond to the readers; the audience is not an active participant in the construction of the narrative. Furthermore, the texts of written narratives are fixed once they are published and therefore not as dynamic as spoken narratives, although the way a narrative is read is different from reader to reader and ways of reading the narrative can shift over time. However, two rather important points of the Living Together booklet are that it contains a number of experiences written by a variety of people, and that it can be read time and time again. It can even be shared.

One final benefit of hearing a spoken narrative is that a yōseisha like Mr. Y can provide the audience with a personal link between the audience and the support organizations that sponsored the event. In Mr. Y’s case, for example, he described turning to PLACE Tokyo for help and being able to work through the difficulties of living with HIV, and then discussed this process with volunteers-in-training. He is the
epitome of success story. In terms of an event like the AIDS Bunka Forums in Kyoto and Yokohama, audience members could connect speakers with support organizations present at the Forum. Even if they were not mentioned explicitly, the groups were very visible at these meetings. Of course, the Living Together booklet includes contact information for the organization (and those of many others), but as Mr. Y suggested in his narrative, there is just something different about meeting someone and knowing concretely that the statistics really do include the people around you.

By analyzing both written and oral HIV narratives, it becomes clear that we need research on the relationship between verbalizing and writing illness narratives. Relatively recently, people have come to realize that what while something might be difficult to verbalize, they could write about it (Jurecic 2012). And writing about it might make it easier to talk about it. Moreover, when there is a critical mass of people writing and speaking about a topic, a way or a form develops – making it easier for others to follow by example. Although my analysis supports this general theory, more research is needed to see to what degree this happens – particularly since these sources are from the United States and may not be wholly generalizable outside North America. In addition, more research is also needed to consider whether narratives such as the ones I describe above, which focus on a relatively positive “return to life” theme, should be termed “illness narratives” or if “wellness narratives” or “healing narratives” may be more appropriate. While they clearly fit the current standards for illness narratives, it might be time to consider the focus on wellness as a new type of narrative.

**Summarizing what is not part of the narrative**

It is important to note what often goes unsaid or is not the focus of public HIV narratives. Information about transmission, or how each person became infected with HIV, as well as how yōseisha have or have not modified their “dangerous” behaviors to prevent the spread are two examples. Regarding transmission, it is much more likely for a yōseisha to directly disclose the mode of transmission when they were infected through medical treatment (yakugai) – or, in Ms. Ishida’s case, with a needle that was not sterilized according to professional standards. The reasoning for this is that the blame for becoming infected lies clearly with the medical institutions in the case of yakugai patients.
And although Ms. Ishida takes responsibility for opting to get a tattoo and selecting the parlor, it is still possible to consider the parlor partially responsible for improper sterilization of the tattoo needles. This admission also prevents the audience from making the assumption that she is/was a sex worker or someone who engaged in some other form of “deviant” sex, since those who contract HIV through sex or drug use are considered to have transgressed social norms in some way. Thus, discussing modes of transmission involves the same dichotomy of “innocents” and “deviants” who live with HIV/AIDS that exists in places such as the United States, and opting to disclose or not disclose how one was infected functions to shield the yōseisha from blame regardless of how one was infected.

Additionally, as illustrated above, the endpoint of many of these narratives is an assertion that one has decided to “live positively,” to move forward. The message is one of personal growth and acceptance. It is not one that assures the public of what he/she is doing to prevent the spread in terms of physically stopping the transmission of HIV through sexual behaviors or drug use habits. Rather, yōseisha tend to emphasize their efforts to help other yōseisha, or to simply alleviate transmission by telling their stories in the hopes that they increase awareness that HIV is indeed a problem in Japan. Rather than, “I always wear a condom to protect others,” the message is that the audience members should use condoms to protect themselves (as Mr. E said in an individual interview highlighted in Chapter 4). Ms. Ishida pushed the audience to think in this way when she told the audience her actions led to her infection and stated that everyone needs to be responsible for their own actions. The same message is found in Mr. Ikushima’s and Ms. Ikegami’s columns interspersed among narratives in the Living Together booklet.

**Kata and Precarity**

Although Ochs and Capps note that timing, setting, and linguistic tools are used to tell a proper story in a specific situation (1996), and Garro and Mattingly state that storytelling is culturally constructed (2000), it is important to note that illness narratives are a relatively new narrative form. In Japan, developing spoken and written narratives about living with or overcoming illness has developed within discourses about tuberculosis, Hansen’s Disease, Minamata Disease, cancer, and now HIV/AIDS.
However, such discourses, particularly in the case of cancer, are often focused on death and what is not said (2004). The issue of how to formulate narratives, particularly public ones, about life after diagnosis is definitely “under construction.” So when we experience public illness narratives about HIV/AIDS, we are witnessing cultural change. These forms have not always existed – social organizations and 《yōseisha》 had to make them and are still in the process of making them.

So what impact do these narratives have on the contemporary Japanese socio-cultural milieu? I argue that they present a very important role in precarity management at both micro and macro levels. For example, managing public HIV narratives – the controlled disclosure, the controlled settings, and the general framework – all serve to make it less precarious, less dangerous for 《yōseisha》 to engage the public in an attempt to education them about HIV/AIDS. But this is the micro level. The macro level is the increased visibility of 《yōseisha》 and the fact that increased attention to their narratives pushes HIV into the public arena in a way that makes the illness less scary to the public than reports about tainted blood, women as vectors of disease, and foreign or MSM carriers who threaten the safety of Japanese people. Increasing awareness and acceptance decreases the probability that people will discriminate, and that 《yōseisha》 will be victims of discrimination. Thus, developing a form – or kata – makes it possible for people to talk about HIV in public, something that has been very difficult, and in turn alleviates felt precarity in both 《yōseisha》 and the general public. Although there is a lot of work that remains to be done to make talking about HIV/AIDS a more neutral activity, these are the first steps in breaking the cycle of discrimination and fear, my analogues to Butler’s violence and retribution (2004).

Performing Illness Narratives

Throughout this chapter, I have hinted that the narratives shared at events such as the ones detailed above are performed. The use of “perform” and “performances” is a conscious choice, but explaining why these terms are appropriate is important. With regard to performance, Mattingly asserts that narratives can be performed, not just spoken (2008). Moreover, she describes these performed narratives as “living narratives” because they are acted out in the present (Mattingly 2008). A point she does not make, however,
is that performed narratives are not just performed once. Even in the examples she gives with a particular patient and practitioner, both she and an observer suggest the two are acting out roles through the use of gestures and verbal exchange. This in turn suggests they have done these actions before, even if in some other context. Thus, I suggest that performed narratives are not just behavioral sequences to be read as communication. They can, like the narratives discussed in this chapter, be performed and spoken – and also practiced. Therefore, all narratives are “living narratives” – whether they are performed on stage, in a doctor’s offices, or in a booklet because they are active, communicative, and dependent on an audience. But not all “living narratives” are made public. Rather, some remain private, articulated in close circles of friends, family members, and practitioners.

First, it is important to discuss exactly what leads me to refer to Mr. Y, Ms. Ishida, and Hunky as “performers.” They are not typical or “average” yōseisha. Rather, they represent just a small percentage of yōseisha who have the ability to stand in front of an audience and talk about their lives as HIV+ people. At the events described above, all of them had been aware of their positive HIV status for two years or more. They had all received some form of guidance and support in public speaking. They are active, to varying degrees, in organizations that support people living with HIV/AIDS. They actively participate in spreading information about HIV by speaking in public, running peer group meetings, participating in HIV/AIDS events, and helping to prepare education materials. They are different from yōseisha who do not do these things. After all, recall Mr. Y’s assertion: “Not everyone can do peer support in the first place.” In fact, not everyone living with HIV is physically, mentally, socially, or financially able to make HIV activism a part of their lives.

Furthermore, the desire to be active in HIV movements does not equate to being a performer. There are countless people who work in research, prevention, and counseling who never take center stage. Rather, these speakers’ personalities, experiences, access to resources, and imbedded-ness in social networks combine in such a way that they are able to tell their stories as “public yōseisha.” Quite simply, they are good at being on
stage; they might not have started out this way, but they had the drive and the support necessary to do what they do.

Second, there is an element of preparation that is essential to public speaking. As discussed above in detail, there is a specific time, place, and target audience for each narrative. None of these people read from a prepared script or had memorized what to say. But they did think about what they were going to say (and not say) before they came. The parameters of the events required it, although it is easier to see in some cases than others. In Ms. Ishida’s case, for example, it was evident that the two speakers had agreed upon what would be asked and how they would respond to audience questions beforehand. To put it simply, these public narratives about living with HIV are planned and carried out by people with all the resources they need to do so. These performances were not something that someone did spontaneously, without prior thought, in a public place like a park or the train station. They were performed at specific venues, with the assistance of specific agents, and with specific goals.

There is one set of clarifications to make, considering the fact that “performance” is often associated with actors, characters, and works of fiction. In discussing Mr. Y, Ms. Ishida and Hunky as performers, I am not referring to them as actors. They do not perform shows or portray characters. The performances they give are not fiction. What they do when they are onstage is highlight the presence of HIV in their lives for the benefit of the audience – and to some degree, for themselves and their fellow yōseisha. To use Mr. Y’s comment, “HIV is only five percent of that pie.” Thus, rather than actors on the stage who follow a script written by someone else, who portray a character by allowing that character to blend and bleed into themselves, public yōseisha formulate their own scripts and perform specific parts of themselves. Much like educators in front of a classroom, performativity and the topic are part of them. Mr. Y’s narrative, and how much impact it has on individuals, is a testament to the power inherent in his experiences, his skill in weaving them together in a coherent fashion, his passion as a performer, and the adept inclusion of his session at the close of the training program.

Finally, it is important to point out that the connection between performance and precarity that Butler articulates in her work (Butler 2009) is very applicable here. One
reason yōseisha feel it is necessary to share their narratives in public is because they still feel that Japan is not open with regard to HIV and that they still face discrimination. They share because they sense their existence is precarious and that things must change. In addition, sharing these narratives in public is, in and of itself, precarious because it could open them up to further discrimination. Precarity necessitates performance, and performance is precarious (Butler 2009).

**Conclusions**

In this chapter, I have illustrated the various factors yōseisha and event sponsors must balance when public HIV narratives are part of the schedule, in addition to the methods they employ to do so. Examination of the AIDS Bunka Forums shows that public forums are a chance for the yōseisha, their supporters, and the audience to collectively construct HIV narratives. The audience learns about biological and social aspects of HIV/AIDS by seeing a “real yōseisha” who may not be so different from themselves. Medical practitioners have a chance to educate the public about the practical medical realities of HIV/AIDS, something that is difficult to do in schools. And yōseisha have the opportunity to show the audience, through their bodies and their narratives, that they are not so different from the audience members and that it is possible to live a healthy life with HIV.

Investigating the actions of participants at the PLANET Candle Parade as what Mattingly describes as a “performed narrative” (2008), it becomes apparent that narratives are not limited to what people say, but what they do and in what contexts. Clothing, position in relation to others, movement of the participants, and light (or absence of it) among other factors related to atmosphere can shape how narratives play out. Further, narratives can also be shaped by having a more cohesive, sympathetic/empathetic audience. The balance of a successful narrative is not just mediated by organizational parameters, but by the atmosphere and possibilities for interaction at events.

Additionally, analyzing the written and spoken narratives harnessed by Place Tokyo, although written and spoken narratives do have some differences, demonstrates that fitting the personal to a general structure assists speakers and organizations in
showing audiences both the overall issues surrounding living with HIV while at the same time highlighting that every yōseisha has different experiences. Mr. Y makes this final point explicit in his own narrative:

“[People who join the peer network] have to choose what they want to say about their lives. The definition of a peer is someone that has the same standpoint. But we are all different. We might have some things in common. But you have to remember your own standpoint, and learn how to find your own balance.”

I also discussed the commonalities between the speakers in terms of their ability to formulate coherent narratives from their experiences, adapt them according to the structure and atmosphere of events, and perform those narratives as a version of themselves in front of an audience. The ability to do so sets them apart from other yōseisha who do not have the abilities or the desire to participate in HIV activism in this way – or at all.

And finally, I illustrated that all of these factors combine to create a kata, a way of performing public HIV narratives. This kata is essential in protecting the privacy of yōseisha who share narratives while at the same time giving the public a way to understand and identify with HIV/AIDS and people who live with HIV/AIDS. The direct engagement with HIV/AIDS made possible through kata, which itself is direct in set ways, mitigates felt precarity in both yōseisha by encouraging the public to acknowledge their presence in Japanese society, and the general public by providing clear information about HIV/AIDS. Moreover, these narratives indicate that yōseisha are going beyond the direct engagement with HIV/AIDS at the personal level that getting proper care requires (discussed in the previous chapter). Being able to truly live healthily with HIV/AIDS requires feeling safe in society, and this can only happen when HIV-people are able to consider yōseisha as similar to them. Thus, the push of private illness experience into the public represents a shift in spoken illness narrative form in Japan – one that may help counter the rising rates of HIV there.

In this chapter, it is apparent that sharing public HIV narratives is about more than just talking about HIV. It is about sharing how yōseisha learned to live with HIV and
make the most out of their lives. This often includes the realization that having HIV does not mean that one is sick: people can have HIV and still be healthy. In Chapter 1, I described how one of the obstacles in recognizing this is that the words “HIV” and “healthy” do not often collocate. In the final chapter, I return to this issue, but also illustrate how additional obstacles include perceptions about how yōseishas’ sexuality, ability to perform gender roles, and ability to be “good citizens” supposedly differ from the “norm.” But this time, I focus on what yōseisha say about these obstacles and whether or not they consider themselves healthy.
Chapter 6: Living Precariously with HIV/AIDS: Sexuality, Gender Roles, Health and Citizenship

One of the first things Mr. E told me just prior to our first interview is that he does not like to talk in groups and that he much prefers one-on-one conversations. He asked what I wanted to know. I showed him my list of questions, but also said that I was interested in whatever he was willing to tell me about his experiences living with HIV. He said he had agreed to a two hour interview once, but the end product only included a few minutes of what he had said – and not even the important parts! So I asked him if he would mind sharing, again, what he had wanted to tell the public. The following is an excerpt from a conversation that lasted several hours; other excerpts were highlighted in Chapter 4.

“The thing that puts me off the most about talking about HIV in hospitals in Japan is that the first thing they ask you is how you got it. So you have to tell them about your sexuality. There are a lot of gay people who are out on TV and stuff, but actually, they are kind of special people. And in everyday life, everyday people don’t really talk about their sexuality or their HIV status. Not at work, not at night [with partners]. Everyday people’s knowledge about HIV is from like twenty years ago. Maybe the discrimination isn’t so strong, but they still see it as a scary illness. So people can’t be open about it...

It took about a year to build up enough knowledge to be able to tell people in my life about my HIV status in a helpful way. In the beginning it was really hard because I didn’t know much myself, and there were lots of times where there were misunderstandings. And I had to continue working so I had to control my health...

I told the people in my section that I was HIV+ three months after my diagnosis. That caused a big panic. It’s because I myself didn’t have much knowledge or information about HIV. It became something to laugh about later, but they were shocked, and some people asked me repeatedly, ‘Are you going to die? When?’ Even after three years, people would ask me if I was really OK. That’s how it was... and that is how it still...
is for the general public [if you have HIV, you die]... I started taking medicine two or three years later. Of course I was still living then, and all the people around me had thought I’d just die. But I didn’t die after three years. Or five years. So they thought I was lying! I was healthy and working fine, so some of them were sure it was a lie... So if you get cancer or something, you are often told, ‘you’re going to die in six months’ or three months, or whatever. So you have to tell your office [so I thought HIV was the same]. At the time, I thought I had a deadly disease, that I’d die, so I had to tell them. But, of course, I didn’t. Now I think back and I probably didn’t have to tell them anything at all. But, I didn’t know. Now we have medicine, so there isn’t that worry...

I worked there for twenty years. Actually it was a pretty good environment. The worst thing was that, at the time, there were a lot of people who were fired when their companies found out they had HIV. But in my case, even though it caused a huge panic in my office at first, I was able to explain about HIV to my co-workers as I learned myself... and because I did that, it prevented the panic from continuing... So over time, they were able to understand. After a while, they stopped thinking about my HIV status... they stopped worrying about it... so now I tell people who have just found out to wait a little while before telling the people around them. They need to have a clear understanding [of the disease and its effects] before they tell other people. I mean, some people you can probably tell early on. But it depends on the person [you want to tell]. I tell them they should wait from six months to a year, until they have enough knowledge and information and have become able to talk about their status clearly, before telling most people. If you have to take leave to get medicine or care, it’s OK to lie to your company, tell them it’s another illness, until you’re ready...

Having HIV is only one part of you. Being gay is only one part of you. Your work is a part of you. There is no need, then, to focus on things like that completely... and it isn’t necessary to tell everyone... Someone at the hospital said, ‘You don’t tell people at work you have athlete’s foot, do you??’ I was so surprised – this was twenty years ago when everyone was panicked and HIV meant you were going to die. But he was comparing it to athlete’s foot!... Anyway, I realized it’s not important to tell everyone, and ‘hiding’ my status isn’t necessarily a bad thing. As he said, it’s only a part of me.
The worst thing is when people say things like, ‘I don’t have sex like that, so I don’t have it.’ What I say to them then is, “Do you know what your partner does or has done? Every one of them, every act? You probably don’t know EVERYTHING, so you should get tested. The number of contacts that people have is increasing. So it’s faulty logic to say ‘I don’t do X so I’m safe.’ The only way to know you don’t have it is to get tested. People think that if they live a ‘normal life’ they can’t get HIV. But that isn’t true. It’s just that they think they haven’t seen anyone around them, or any of their friends, living with HIV. So then they think it has nothing to do with them. But do they know everything that their partner does or has done? Tomorrow, that might be them. I often tell people things like that.

And in response to the common claim that HIV is so far away, I have to say: I am standing right next to you, me, an HIV patient. It’s not written on my forehead, but I’m right here.” (Fieldnotes from interviews with Mr. E, 61 year old retired accountant. August 7 and October 23, 2011.)

In his narrative above, Mr. E describes the difficulties of teasing apart HIV and sexuality, dissociating HIV from AIDS and death both personally and when explaining the illnesses to others, and disclosing personal information. He often uses the workplace as an example. Mr. E also attempts to explode two very common misconceptions about HIV: 1) I don’t do X so I’m safe, and 2) HIV is far away. These are themes that have been broached in previous chapters. However, whereas the focus thus far has been on words, images, exhibitions, health networks, and narrative performances in previous chapters, in this final chapter, I focus on how HIV+ individuals struggle to assert themselves as healthy, normal Japanese in the face of discrimination and lack of awareness though a discussion that illustrates the connections between HIV, sexuality, gender, and health.

First, I review the pertinent literature regarding the link between gender and sexuality as well as its significance to citizenship in general, as well as in Japan specifically. I also note that part of being a “good citizen” is being able to contribute to society, and that it is often considered problematic if one is deemed sick, unmarried, or childless. Next, I draw from Whelehan and Budd (2009) and Miller (2002) to discuss
connections between HIV and sex and sexuality to illustrate that although the association between HIV and sexuality is not unique to Japan, it is a point of contention for *yōseisha* who feel the association opens them up to discrimination related not only to their HIV status but also to their sexuality and/or sexual behaviors. Following this, I draw from Saethre and Stadler (in press) and Miller (2002) to illustrate the connections between HIV, sex, and gender roles, asserting that HIV becomes a way of discussing perceived sex and gender-related social problems in Japan as well as in other places, using gel trials in South Africa as an example. Next, I draw from Whelehan and Budd (2009) and Inoue and colleagues (2004) in order to illustrate the fact that although there is consensus amongst medical professionals that improvements in treatment and quality of life can extend the lives of *yōseisha*, it is still difficult for the Japanese public to grasp that HIV+ people can be healthy; however, *yōseisha* who live healthy, productive lives make it clear that equating HIV with being incapable of being a “good citizen” is a misconception. In doing so, I illuminate how claims to “living a normal, healthy life” by *yōseisha* cause mainstream Japanese people to experience felt precarity as their views of what constitutes a “normal life” in terms of gender, sexuality, and HIV status is challenged, as well as how mainstream claims of “normal, healthy living” result in felt precarity by *yōseisha* by using the work of Befu (2001) and Butler (2004). Put another way, in keeping with discussions of directness in previous chapters, I assert that living as openly HIV+ disrupts stereotypes about being Japanese. While such disruption is desirable for *yōseisha* because of the possibility that it will lead to a more open society that understands both HIV and living with HIV more clearly, therefore making their lives less precarious, it feels precarious to mainstream Japanese who take comfort in idealized notions of Japaneseness.

**Gender, Sexuality, and Citizenship in general and in Japan**

In general, sexuality and gender are inextricably linked in the minds of the lay public and in scholarship because sexuality is a constituent of gender (Gilchrist and Sullivan 2006; Boellstorff 2007). They are also both linked to citizenship because laws, which are generally hetero-normative, recognize people who perform specific genders and sexualities (Moon 2008; Butler 2009). Changes in laws over time can indicate changing concepts of what it means to be a good citizen. For instance, Moon argues that the normalization of same-sex marriage in certain states in the United States suggests that
it is becoming more common to consider same-sex couples to be “good citizens” if their relationships are tied to love and monogamy (2008). While the concept of what a “good relationship” is for “good citizens” has remained relatively conservative, opinions about who can be in such a relationship appears to be broadening. However, as Asencio has shown, in some cases stigmatization or even physical violence in response to perceived or actual sexual transgressions is considered a method of maintaining gender roles (1999).

Performing the “proper” gender, gender roles, or sexuality is only one aspect of being considered a “good citizen,” however. Another point germane to this discussions is that since the 1950s in the U.S., being a productive member of society has also often been considered to be essential to being a “good citizen,” being perceived as unhealthy or unwilling or unable to recover from the “sick role” calls into question one’s citizenship by questioning their productive worth (Parsons 1951).

These links between gender, sexuality, and health and citizenship generally hold true in the Japanese context as well; this can be seen by briefly tracing the historical connections between gender, sexuality, and health in Japan. Although it is common for Japanese people to downplay the current and past existence of non-normative gender roles and forms of sexuality in Japan, there is a long history of sexual diversity and resistance to male-centered hetero-normativity. For example, drawing from a number of texts and works of art, Leupp has demonstrated the presence of male-male sex amongst monks and samurai, as well as in the context of male-only teahouses and kabuki theaters during the Tokugawa period; he also notes that bisexuality was not uncommon (1995).

Pflugfelder asserts that this male-male sexuality was considered something akin to an art form in that it was considered to have a form (kata) and required mastery (1999), and it appears that at the time, male-male sexual interactions did not disturb one’s masculinity. Pflugfelder also states that these relationships were in part due to the fact that associations with women were viewed as an obstacle to enlightenment by monks, as polluting according to Shinto doctrine, and as a sign of weakness amongst samurai (Pflugfelder 1999). Furthermore, these male-male acts were allowed as long as they did not lead to political conflict. Sex acts became more highly regulated with the creation of the Meiji state in 1868, when male-male sex was considered part of a feudal past; although policing and prosecution rates were very low (Pflugfelder 1999), it was
becoming less acceptable for “good” Japanese men to openly engage in male-male sex. Furthermore, the rise of evolutionary biology in the early 1900s led public health officials to consider sex as part of individual, family, and ultimate national health (Pflugfelder 1999). This placed sexuality, gender, and the health of citizens’ bodies squarely under the purview of governing bodies.

With regard to women’s sexuality and gender roles, Robertson describes how men attempted to shape feminine roles using the all-female theater Takarazuka, started in 1913, as an example. The founder referred to the actresses as *musumeyaku* rather than *onnayaku*159 to emphasize their supposed “filial piety, virginity, and pedigree” and separate them from “women of disrepute” who otherwise performed in theater (Robertson 1991:168). Further, it was his goal for the women who performed male roles to learn to “understand and appreciate the masculine psyche” so that when they got married – being a wife was supposed to be their ultimate career – they would exemplify the slogan “good wife, wise mother” because their roles had taught them what men expect (Robertson 1991). In this way, sexually modest women were cast as good wives and mothers who supported men as fathers and leaders. Although Kobayshi, the founder, planned to make Takarazuka a form of “healthful family entertainment” in which whole families could come and witness the proper performance of state-supported gender and sexual roles, actresses often engaged in both same and opposite sex affairs, cut their hair, and refused to marry (Robertson 1991:171). In these ways, Takarazuka women protested the prescriptions of sex and gender written by men for women, although members of the public sometimes commented that the portrayal of male characters by women “naturally” made the women lesbian. Similar sentiments were voiced by Asencio’s interviewees, who asserted that doing “women’s work” around the house made men gay (Robertson 1991; Asencio 1999). In any case, women who actively rejected the idealized roles were often labeled “bad women” or “bad girls” (Miller and Bardsley 2005). Frühstück has noted that during the 1920s and through the end of WWII, public health officials couched sexual health in terms of sexual health for soldiers so that they could fight, and women were blamed for illness. In addition, abortion, family planning and contraception were

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159 Literally, this is “daughter role” rather than “female role” and was used because women had been banned from theater. Thus, the only women who acted were, by definition, “bad women.”
banned as “immoral” (2003). While condoms were used to prevent STIs in soldiers\(^\text{160}\), they were disallowed for married women because the state did not want to slow the birth rate (Frühstück 2003). Feminists such as Yosano Akiko and Hiratsuka Raichō openly debated such policies (Rodd 1991). To summarize, during wartime, “good women” gave birth to babies for the future of the nation (and were not permitted to use protection), whereas “good men” used condoms to prevent STIs so that they could preserve their health and fight for the nation.

More recently, Japanese women have fought the ideals thrust upon them by men – as well as the men themselves – by searching for employment and companionship overseas (Kelsky 2001). Believing Japanese men to be weak, immature, and unchivalrous and Japanese working environments to be sexist, some Japanese women have pursued western men that they viewed to be gentlemanly and kind in comparison, and work environments they perceived to be more equitable (Kelsky 2001). However, Kelsky notes that many of these women grew disappointed when reality did not match their expectations (noting in particular that many western men who pursued Japanese women wanted them to be demure and domestic), and ultimately returned to Japan to play roles similar to those they originally wanted to escape (2001). Other ways of rejecting female gender roles include dress and make-up that downplay “traditional” femininity, assertion of their right to sex for pleasure rather than conception, and refusal to marry or have children (Cullinane 2007). However, these behaviors are often considered to be deviant and detrimental to the country by conservative Japanese men and even some women (Cullinane 2007). Additionally, men are often viewed to be inherently sexual and in need of release (Allison 1994; Miller 2002), thus allowing for participation in the sex trade without stigmatization, while the sexuality of women is often couched in terms of motherhood and family planning. Women who seem to gain from sexual encounters, either emotionally or financially, are considered transgressive and dangerous, while men are simply considered normal (Miller 2002). Attitudes about the normalcy of men’s sexuality and the pathology of women’s sexuality have bled into pharmaceutical issues.

\(^{160}\) Compare this to the current image of condoms, which is for birth control and not necessarily STI protection. There has been a 180 degree change.
In fact, the government approved Viagra years before allowing the birth control pill under the flimsy rationale of trying to prevent the birth rate from decreasing further.

To summarize, concepts of citizenship from gender, sexuality, and health are inextricably linked. When someone appears to have transgressed in some way, their citizenship is called into question. Moreover, the performance of normative gender, sexuality, and health-based roles reaffirms the “correctness” of these roles. Thus, it is common for there to be conflict between people who feel they fulfill the norms and those people they view as transgressing them and resentment towards “proper performers” from people who feel that the status quo needs to change. This dis-ease people feel vis-à-vis others is precarity. To fully understand this precarity in relation to HIV/AIDS, it is helpful to tease these factors apart. I begin with associations between sexuality and HIV.

**Sexuality and HIV**

Globally, HIV is linked to sex: eighty percent of cases are contracted sexually (Whelahan and Budd 2009). Because of this, HIV is often associated with sexuality, and particularly with behavior that is considered by mainstream populations to be deviant. This is also true in Japan, where the vast majority of cases are sexually transmitted (API-Net 2013). Further, because the majority of sexually transmitted cases are in men who have sex with men, HIV is conceptually linked to sexuality. Although HIV/AIDS has been linked to women in the past, particularly those who slept with foreigners or participated in sex work and were thus termed “bad women” (Miller 2002), it is slowly becoming associated with male-male sexual behavior in Japan. This linkage occurs in many ways, but here I focus on the forging and reinforcing of this linkage in medical settings, as Mr. E discussed in the opening anecdote.

Because medical professionals are charged with recording information regarding transmission, they ask patients directly how they became infected and behavior is often treated as a proxy for or indicator of sexuality. As Mr. E described, asking patients “How did you get it?” forces patients to disclose their sexuality via their habits. Although uncomfortable for everyone, patients who are sexual minorities are particularly vulnerable to judgment and discrimination because of their already marginalized position in society (McLelland 2000). Recall that Mr. E asserted that sexuality is not overtly
discussed even among partners in many cases. In comparison, consider that discussing sexuality in the context of an HIV diagnosis requires speaking to an unknown person, in a stark and formal setting, in which one’s HIV status and sexuality become part of a written medical record. Disclosure in a medical setting is everything that private disclosure (which may be acknowledged only through a sex act) is not: verbalized, objectified, recorded, and permanent. Such a disclosure may force a “coming out” experience that is incredibly traumatic to the patient but considered routine or matter-of-fact to the clinician, which further complicates the experience.

This link between HIV to sex and sexuality in medical settings is made repeatedly by clinicians and patients alike, but in different ways and with different results. As discussed in Chapter 4, patients who visit a new hospital or specialist outside the hospital’s group are required to re-test and re-disclose when preparing new patient forms, something Mr. E himself has had to do many times. In addition, he volunteers in a hospital, working alongside medical social workers, to counsel HIV+ MSM about how to practice safe sex. The fluidity with which he discusses HIV, sex, sexuality, and coming out is most likely a result of articulating HIV, sex and sexuality multiple times, with multiple others, and in multiple situations. The ease with which Mr. E moves from talking about HIV diagnosis, to disclosure about sexuality, and back to discrimination and disclosure about HIV also illustrates the degree to which he has internalized these linkages. Moreover, his analysis is productive: he is able to illustrate the difficulty of both HIV and sexuality disclosures, as well as provide a critique of the way medical professionals attempt to monitor and record epidemiological trends. If the linkage is viewed in a destructive way, the link between HIV and sexuality can cause a yōseisha to blame him/herself for the HIV diagnosis (as described below).

In comparison to patients who reinforce the link through multiple disclosures and internalize it as part of themselves, clinicians reinforce and internalize the HIV-sexuality linkage as part of their medical training when treating patient after patient. Such experiences can result in improved treatment and understanding of yōseisha, but it can also lead practitioners to link HIV with MSM, homosexuality, or being gay. In other words, internalizing the HIV-sexuality link can morph into an HIV-gay linkage, which is
the basis for the stereotype that “HIV is a gay disease.” When medical practitioners subscribe to this stereotype, often unconsciously, the chance that a patient – and not just a patient who belongs to a sexual minority – will experience judgment increases. Even though not everyone who tests positive contracts the virus sexually, and not everyone who contracts HIV sexually gets it through same-sex sexual intercourse, virtually everyone who tests positive for HIV is vulnerable to assumptions about their sex lives regardless of their sexual identity or orientation. For male patients, the common assumption is that they are gay:

“When an internal medicine doctor first diagnosed me, he introduced me to a specialist in the same hospital. That specialist was an authority on HIV and had been to San Francisco and everything. He actually said, ‘Oh, you must be gay. You must like men,’ even though I didn’t say anything about that... He’s actually a really good doctor and now I know he didn’t mean it to be discriminatory like that, but I had a really bad first impression of him because of how he talked about these delicate issues.” (Field notes from an interview with Taiyo, a 35-year-old male nurse. October 9, 2011.)

Taiyo did not (and does not) identify himself as gay or as having male partners, but that did not stop this doctor, an HIV specialist, from making assumptions about Taiyo’s sexuality. The doctor knew he had HIV, assumed he was gay, and even went so far as to verbalize his assumption rather than asking about Taiyo’s behaviors.\footnote{The reverse can also happen: sometimes people assume that if someone participates in homosexual acts or works as a sex worker they have STIs.}

Considering that Taiyo had known his status for approximately two years at the time of the interview, he probably had this experience sometime in 2009. Despite biomedical advances in treatment and care, it appears that stereotyping and judging patients still occurs – even among specialists who are at the cutting edge of HIV medical research and treatment. And if HIV and sexuality are linked in the minds of medical professionals who see yōseisha on a regular basis, it is perhaps understandable that it is also linked in the minds of the general public as well as in a fair number of yōseisha themselves – even if they do not have the same experiences working in a hospital as Mr. E:
“What I was most distressed about when I found out my status was, ‘Why am I gay? Did I get HIV because I’m gay?’ It took time to accept my own sexuality. And I’m married, right? I got married when I was 32. I was having sex with women, too, at the time. Actually, I thought I was bisexual. But after I got married, I realized that I’m gay… accepting that took a long time. And telling my wife I was HIV positive took me a year and a half. That year and a half was necessary for me to accept that I was gay. So when I told my wife, I felt I had to tell her that I’m gay and HIV positive at the same time. When I told her, she said, ‘Well, we can keep on doing as we’ve been doing, right?’ So – I’m married, but I’m gay. I’m positive, but my wife isn’t. After I told her, I felt so much better. I’m not sure how she felt, but I was relieved.” (Field notes from an interview with Hunky, a 55-year-old civil servant. July 29, 2011).

Like Mr. E, Hunky also connects HIV to sexuality. However, Hunky is more direct and more personal about his assessment. While Mr. E describes the general difficulties of disclosing both same-sex lifestyles and HIV statuses to partners, Hunky ponders the relationship between his sexuality and his infection. It took eighteen months to accept his HIV status and come to terms with his sexuality – issues that he could not separate then, and did not separate while speaking to me during the interview. This connection is further evidenced by how he chose to disclose both to his wife at the same time, and how the link between the two seems to be at least partially responsible for his reluctance to disclose either status to members of his family:

“It’s harder to tell my parents that I’m gay than telling them I have HIV...

Sometimes people compare living with HIV in rural and urban areas, but I compare living with HIV in Tokyo and Osaka. In Tokyo, people come from everywhere, and you can be ‘free.’ But for me, my family all lives in Osaka and coming out for either thing is hard. Being gay is hard, harder than having HIV. When I was 18, it was like, where are the gay adults? There was no role model for us, for 30, 40 year old men with no families. I felt like I was going to die. Even the thought of making a baby was scary, because I was worried – what if my child is gay? I don’t want them to have such a hard life. Now people are learning more about being gay, but still my brother and father think being gay is unimaginable.” (Hunky, 55, July 29, 2011).
Comparing the experiences of Mr. E, Taiyo and Hunky, we can delineate four issues that come to the fore when someone is first diagnosed with HIV: 1) patients are confronted about their sexuality and sexual behaviors in ways that they perhaps have not been confronted before, 2) yōseisha struggle to reconcile their sexual identities with HIV diagnosis, 3) they struggle to find a way to disclose these private issues with others and often find that discussing the two cannot be dissociated, and 4) separating HIV from sexuality is just as difficult amongst people who are not HIV positive\textsuperscript{162}. These issues can cause considerable stress, particularly when such disclosures have a negative influence on family life. For example, disclosure resulted in the end of Taiyo’s marriage. Hunky’s marriage remained intact after disclosure, but he has not told his immediate family. Mr. E lives several hundred miles from his extended family, so disclosure appears to not be an issue.

What do these issues tell us? It seems that one fundamental problem is at the core of all four issues: a positive HIV diagnosis leads people to realize that there is a disconnect between what they as individuals feel about being normal and what mainstream society views as normal. Even if individuals in question had been relatively comfortable with their sexual behaviors prior to diagnosis, being HIV+ called those behaviors into question, and even pushed them to attach a label – gay, bisexual, et cetera – in the clinical setting. On an individual level, Hunky questioned his actions as he struggled to make sense of his diagnosis: “Did I get HIV because I’m gay?” On a social level, he questioned how his actions would be perceived by others and, based on his assessments, opted to tell his wife but not his family. Hunky eventually accepted that his sexuality and his HIV status are parts of him; however, he also realized that disclosure would endanger some of his relationships. This could be due to how his sexual behaviors may be perceived; or, to return to Butler’s discussion of performativity, it may be because he might be considered to have “failed” to perform particular gender roles. I discuss this more fully below.

\textsuperscript{162} Here, I solely discuss sex and sexuality; however, in cases where HIV was transmitted in other ways, such as medical care, use of non-sterile injection equipment, etc, patients are still confronted about behaviors that are often perceived as moral/immoral choices. It is common to search for blame and to reason that the infection must be someone’s fault.
Summarizing the Sexuality Link

From the anecdotes above, we can see that yōseisha and medical practitioners tend to see HIV as connected to sexuality; as noted above, this is association is not particularly unique to these two groups or to Japan. However, the anecdotes also help illustrate that the ways in which practitioners and yōseisha make these connections are different because they are based on different lived experiences or the performance of different roles. Men who identify as MSM or gay and who test positive link the two at least in part because of their sexual experiences and their experiences in medical establishments. Most medical staff link the two because sexual transmission comprises the majority of cases, because of their personal experiences in treating MSM or gay patients, and because of epidemiological trends highlighted in journals and conferences. Members of either group can perceive these linkages in productive, nuanced ways or in potentially destructive, stereotypical ways. This variation is to be expected because, as Desjarlais has suggested, the processes of experience are not universal: people are not the same in their abilities to narrate, interpret actions, or be reflexive, and the hows of experience itself are historically and culturally mediated (1997).

Further, variation in the ways that these links are perceived can result in a number of outcomes. For example, it can be used to stereotype or judge yōseisha, or even oneself; it can also be used to create HIV prevention materials and open discussions about living “in the closet” and “coming out” – both in terms of sexuality and HIV. In other words, how this link is exploited determines whether or not the link opens up people to be stigmatized, blamed, and judged for their HIV status.

Finally, the ways that linkages are perceived by yōseisha and medical practitioners is not static. In the case of yōseisha, the way they link sexuality and HIV shifts as they become more and more comfortable with themselves and their diagnosis – regardless of their sexual orientation. In all three cases highlighted above, for example, the men were able to talk about their sexuality openly and earnestly, although they were all confronted with questions about their sexuality when they were diagnosed. Medical practitioners (both individually and in groups) also shift their understandings about the linkages between HIV and sexuality as they gain experience and technologies improve,
and this often results in positive improvements to patient care. For example, Dr. Goto described the “three generations of doctors” who have treated yōseisha this way: the first generation gave palliative care, the second generation administered palliative care and ARVs, and the third generation has been administering HAART and caring for chronic patients (Field notes, November 2011). In addition, although the anecdote utilized above illustrates how a specialist stereotyped a patient, other doctors have discussed their attempts to focus on daily life experience rather than sexual experience when treating HIV+ patients (Shirano and Goto, field notes November 2011).

**Gender, Social Roles and HIV**

Further analysis of the excerpts above suggests that the link between sexuality and HIV is actually too simple, and that it includes a third element – gender. Sexuality is what people talk about, the word they use, but in many cases, talking about sexuality also seems to include elements of what would often be called gender or gendered roles because interviewees talk about what happened with their family lives. This is due to the fact that performing gender, in this case, includes sexual behavior. Therefore, the inability to separate gender from sexuality is very common not only in the lay public around the world, but also in scholarship (Boellstorff 2007; Gilchrist and Sullivan 2006). In this way, gender and sexuality may be conflated or the relationship between them may be obfuscated, and this happened often in my interviews. But the two factors are discernible upon close inspection.

First, note that when Hunky commented that “Being gay is hard, harder than having HIV,” it is in the context of telling his family about his sexual preferences and the issue of not having had gay role models. This suggests that managing his identity as a gay man, not intercourse or sex acts with another man, is what he finds difficult. Later in the interview he stated that “I take medicine just twice a day and other than those times, I usually don’t think much about HIV. It’s just one part of me” (2011). This indicates that perhaps managing his gay identity is more difficult than managing HIV is, because HIV is something for which he can take medication, and otherwise does not affect his daily life. So why would being gay, rather than having HIV, be most problematic in terms of identity and disclosure?
Recall that Hunky states that being gay is “unimaginable” to some of his family members, and that he does not include his friends when he discusses the difficulties of being gay. This indicates that being gay in the family arena is what is problematic. Specifically, being openly gay in the presence of his parents and sibling is unacceptable for him. Interestingly, when he disclosed to his wife, they opted to stay married – even though their marriage is not likely to include sexual activity or, by extension, children. Disclosure and acceptance by the spouse, but fear of disclosure to parents and siblings in this case suggests that sex and reproduction are not always the primary concerns when discussing sexuality (or HIV, as we will see below): there are also fears about whether the ability to play the expected, gendered social roles will be disturbed if one deviates from “acceptable” sexual patterns. Although he has no children, being married probably offers Hunky some measure of protection from the criticism and scrutiny he might face from his family if he were single, and although Hunky and his wife are satisfied with their marriage, disclosure to other family members about his sexuality may endanger their happiness as individuals and as a couple – particularly if family members responded negatively to his sexual preferences or questioned his ability to fulfill his roles as husband and married son.

Given these difficulties, part of what makes being gay difficult for Hunky is his proximity to his family, who live in the next city, and the overall social make-up of the cities themselves: “Sometimes people compare living with HIV in rural and urban areas, but I compare living with HIV in Tokyo and Osaka. In Tokyo, people come from everywhere, and you can be ‘free.’ But for me, my family all lives in Osaka and coming out for either thing is hard” (2011). Even if he is openly gay with regards to his wife and friends, there is the danger that rumors of his sexuality will reach his family due to the small-town feel of cities in Kansai.

The significance of proximity to family is further illustrated by considering Mr. E’s case. Unlike Hunky, Mr. E lives in Yokohama, far away from his rural-dwelling parents in southern Japan. Moreover, he has several siblings, many of whom are older than he is. Large family size, his position as a younger child, and the geographical distance between Mr. E and his parents may be enough to make him “free” as Hunky
describes gay yōseisha in Kantō. Particularly if older siblings have gotten married and had children, there may be less pressure for Mr. E to marry and have children, which in turn may leave questions about his sexuality unnecessary to broach. The variation of these two cases alone suggests that perceptions about sexuality and the importance of adhering to gender roles differs greatly from family to family and are influenced not only by individual belief systems, but also living conditions, family size, position in the family and geographic distance from other family members.

For men and women who opt to live openly or selectively disclose as anything but heterosexual, the door to criticism for not being a “normal163” Japanese man or woman is open wide164 because perceptions about one’s sexual identity influence perceptions about the same person’s ability to fulfill expected familial and social roles. While performing various forms of sexuality may be perceived as tantamount to a refusal or inability to perform socially ascribed gender roles such as filial child (who marries, reproduces, and cares for aging parents) or a productive husband or wife (who together earn a living and care for the house, as well as produce children) on a personal level, on a social level it can be perceived as failing to be a good citizen. This is especially true in Japan, where getting married, working full-time (inside or outside the home), and having children are markers of adulthood and signify that someone is a full participant in and contributor to society (Dasgupta 2005). In fact, failing to get married and have children is sometimes considered to be selfish and unpatriotic: critics have been known to use the mass media to berate wakamono, or young people, particularly women, for the rising average age for marriage and the falling birthrate because, they assert, these trends will lead to the disintegration of Japan as a nation (Coulmas 2007).

These are the issues that are brought to the fore with an HIV diagnosis first for new yōseisha, and then for members of their social networks as they begin to disclose their HIV status. Yōseisha may question their previous behaviors and identity; friends and

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163 The term “normal,” or futsū in Japanese, can be quite hegemonic in Japan. Falling outside the norm is held in negative regard, and is thus avoided at all costs.
164 Furthermore, options would be limited for same-sex couples even if they did want to get married and have children. Same-sex marriage is not legal anywhere in Japan, and adoption is rare even amongst heterosexual couples. In short, there is currently no social support, resources, or infrastructure in place to allow such arrangements.
family members, in shock, want to know how their loved one could possibly have HIV. This brings up questions of sex and sexuality in cases where it was contracted sexually. Sometimes people express an aversion to sexual practices considered to be outside the norm; sometimes people are afraid of the social consequences of a lifestyle that does not fit the gendered norm. These are further complicated when yōseisha and members of their social networks begin to contemplate living with HIV.

It is important to recognize that an HIV diagnosis, regardless of one’s sexuality, also complicates the ways in which people perceive yōseisha as willing or able to perform idealized gender roles. Common misconceptions include the assumptions that yōseisha cannot or should not have sex, that they cannot safely have children, and/or that HIV+ parents would die before their children reached adulthood. Sometimes rather than misconceptions, they are beliefs grounded in religious or legal frameworks (Malhotra, Malhotra and Sharma 2008; Ko and Muecke 2007). This leads people, sometimes yōseisha included, to think that they cannot have normal family relationships.

Biologically speaking, if a yōseisha is diligent about medication and condom use, it is unlikely that HIV would be transmitted to a sex partner. Furthermore, transmission can be prevented with the use of ARVs and special precautions during conception, birth, and infant feeding in the case that a sero-discordant couple wishes to conceive. Nonetheless, yōseisha who wish to conceive may be treated as though their decision is selfish or unfair to their child or society (Ko and Muecke 2007); moreover, an HIV diagnosis is sometimes enough to encourage yōseisha to pursue a single life so as to minimize pain and suffering.

“I have no memory of being told [about my condition] by the doctor. The thing I was most worried about at the time was what to do if my girlfriend had gotten it. When her result was negative, I was so relieved. For a while I thought I wouldn’t live very long so I was consumed by desperation. On top of that, I was scared of what kind of discrimination and prejudice my family would face after I died. I decided I would go through life alone [not get married]. I lost my friends one after another. But after seeing that, this strong desire to live for them grew inside me.” (Field notes from written survey by Mr. O, 52, program director. November 2011.)
Notice that Mr. O, who contracted HIV through treatment for hemophilia, was initially most concerned about his girlfriend, his family, and the friends he had lost. He feared how his family would be treated if his illness became known, and the possibility that he had transmitted HIV to his girlfriend. HIV altered his relationships with his girlfriend and family members specifically, and altered the social course of his life in general. Although he eventually decided to live positively as a way of honoring the friends he had lost, his positive life does not include a spouse or children, nor does he consider himself to be healthy because he has “many difficulties” in his daily life (Field notes Mr. O).

**Summarizing the Gender Link**

Considering the cases of Mr. E, Mr. O, and Hunky discussed above, we can see that when yōseisha discuss sexuality and HIV, they often discuss the difficulty disclosure will cause because of how they will be judged, often by family members. Both sexual orientation and HIV are perceived to change the ways in which yōseisha are willing and able to perform gendered roles as children, spouses, and parents. Problems are anticipated when sex is not focused on reproduction and when someone is perceived to be too ill to be sexually active and reproduce – issues which are compounded when yōseisha are also members of a sexual minority. Regardless of how yōseisha perceive themselves, social pressures to be “normal Japanese” can impinge upon their abilities to assert their identities.

This nexus of gender roles, HIV, and sexuality is not new in general or to Japan, although the focus on male homosexuality in the Japanese context is fairly recent. In terms of heterosexual relationships, Cullinane described how “compensated dating” amongst high school girls and HIV became the media for discussing the “failing Japanese family,” with blame placed squarely on women who sold sex not on the men who bought it (2007). Further, Miller has described how the sex trade has been described as necessary to fulfill the “male needs” that are tied to their masculinity, while Japanese women who participate in it are described as financially “selfish” and foreign women who participate

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165 *Enjo kosai* in Japanese. This practice involves young women being paid in cash or goods for accompanying an older man. It may or may not include sexual contact.
are described as financially “needy” (2002). In both cases, the open expression of male (hetero)sexuality is considered a normal, natural part of performing masculinity while “good women” are not permitted to be openly sexual outside the confines of motherhood – and those who are openly sexual are dangerous to the institution of family as well as to the nation. Saethre and Stadler note a similar trend in South Africa, where HIV preventive gel trials became the medium for discussions about sex and gender: discarding gel is aligned with transaction sex\(^{166}\) carried out by “deceptive females” who value individual gain, while the label “virtuous volunteers” is applied to women who married and provided a dowry and were thus contributing to the family or social group (in press). Thus, HIV or HIV-prevention tools have become avenues for people to discuss “who should have sex and for what reasons,” and this often has to do with family (Saethre and Stadler in press). In such cases, discussions revolve around what is good for the family, the community, or the nation – and around who is disrupting that through “selfish” individual acts.

**Health and HIV**

An HIV diagnosis often leads people, newly-diagnosed yōseisha included, to conclude that the infected person is not healthy and to question one’s ability to have sex, reproduce, and be a “normal” family member – even though medical technology continues to improve (Whelehan and Budd 2009). Although instability and stress can influences the overall health of yōseisha, Inoue and colleagues have asserted that the quality of life of yōseisha is greatly improved when they have a solid social network – particularly when the network includes a sexual partner (2004). In support of this, healthy yōseisha with families demonstrate that it is not only possible but fulfilling to live with HIV, but also that family connections improve health:

> “I was born with hemophilia, which can be a difficult illness to manage. When I received care for it in infancy, the blood products contained HIV and Hepatitis C so I was infected... Health is about your body and mental health. You don’t have to worry about being sick. Even if you have something, knowing you don’t have to worry about

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\(^{166}\) This refers to the financial benefits a woman gets while in a sexual relationship with a man, such as the payment of her living expenses or those of her child(ren).
being sick is part of health. I’ve been going to the hospital for treatment when I feel bad or am in pain for a long time. I think being able to live with your illness without worrying about being sick is part of health. To keep your health, eat well, sleep well, exercise... people with HIV need to manage their health carefully. They also need to make sure they don’t have sexual intercourse without telling their partners about their status, get regular health checks, and take their medicine in addition to things like eating well, sleeping well, and exercising... Laughing is also really important, and good for your immune system. In my own case, I was much happier after I got married and my immunity went up. Your mental health can really affect your physical health, so if you can laugh, be happy, it’s important for your health. I think I’m healthy now.” (Mr. Kawada 35, National Diet Member September 22, 2011)

Mr. Kawada is perhaps the most well-known public figure living with HIV amongst the general public in Japan. As a member of the National Diet, he often pursues health initiatives, and holds public forums on a range of issues. As a self-described healthy, married man who is active in politics, Mr. Kawada can be considered a role model for other people who are living with HIV. But Mr. Kawada also plays important roles in legislation and providing the public an example of a healthy, productive family man who happens to have HIV. As discussed in Chapter 1, “healthy” and “HIV” do not collocate well in the minds of most Japanese people. Yet, Mr. Kawada successfully performs the roles of husband and diet member, and is able to assert that “Even if you have something, knowing you don’t have to worry about being sick is part of health.” In other words, you can have a health issue but still be healthy, and being free from worry about that health issue contributes to feeling and being healthy. Not only is he living proof that HIV does not equate to AIDS, being sick, or dying, he verbally makes it clear that one can still be healthy and have HIV – or any number of other illnesses. In addition to this insight and his general list of health-promoting behaviors (eating and sleeping well, getting exercise, getting health checks, and taking medicine), Mr. Kawada also notes that laughter and happiness can improve your health and cites his own marriage as a case in point: “After I got married, my immunity went up.”
Of course, Mr. Kawada’s happiness and ability to feel free from worry with regard to his HIV status is the result of several factors that include his out-going personality, education, profession, connectedness to his family and friends, and financial security. He has also known his status since he was ten years old; at the time of the interview, that equated to twenty-five years. However, a portion of this happiness and ability to be free from worry may be due to being fully open with his family, friends and constituents about his HIV status. This level of openness is something other yōseisha simply do not enjoy. As someone who was infected through medical treatment, Mr. Kawada is not blamed for his HIV status as people who were infected through sexual contact or unsterile needles often are. That he was infected as an infant makes him a sort of “double-innocent.” Combined with the factors listed above, not being judged for his status has made it possible for him to live as a public figure who happens to have HIV rather than an HIV+ person who became a public figure. Recall from Chapter 5 that many of the yōseisha who speak in public as yōseisha highlight the HIV part of themselves to educate the public. This is very different from Mr. Kawada, who highlights his HIV status only when motivated or called on to do so, and who is accepted by the public as someone with multiple roles and statuses. Many yōseisha feel this level of openness with only a limited number of people – even if they, too, were infected through medical treatment.

“I’m 52 and was born in 1959. When I was a second year junior high school student [age 13, 1972], I went in for a hemophilia exam and had a blood (product) transfusion. I lived a normal life. When I was a first year university student [age 18, 1979], I started bleeding from my knees and had treatment for a year and a half. I was told I’d be in a wheelchair, and I left the university. I did rehabilitation until I could live as before, but in 1989, I started showing symptoms of AIDS. Miraculously, after three months of treatment, I could return to work. In 1995, I got interferon treatment for Hepatitis C. After one year, the virus disappeared but in 1996 I began showing symptoms of AIDS again and stopped working. In 1997 the AIDS Relief Center established the Habataki Project and I have been a director since (fourteen years). I’ve known my HIV status for twenty-five years [since age 27, 1986]...
Having HIV does not affect my ability to work and I’ve never had problems getting treatment. I’ve never been the victim of discrimination. The most distressing thing about having HIV is taking medications that cause strong side effects. The medicines we have now are a treatment, but you have to keep taking it. I would be extremely happy if we could develop medicine that you take for a set time that could completely heal you, and that you would never have to take it again...

Being healthy means being able to use your five senses and go about everyday life. I’ve had this idea of health since 1972, when I was admitted to the hospital and I couldn’t use my right hand for a half a year. Keeping health requires good communication with your doctors. I try to live a kisoku tadashii seikatsu\textsuperscript{167}. I don’t think I’m a particularly healthy person because there are a lot of difficulties in my daily life.” (Mr. O, November 2011).

Like Mr. Kawada, Mr. O has hemophilia and was infected with HIV and Hepatitis C through blood transfusions that occurred in the 1970s. Both men were treated with interferon and ARVs, both had known their HIV statuses for twenty-five years at the time of the interviews, and both have worked to improve the lives of people living with HIV – Mr. Kawada through his work as a Diet member and member of various organizations and Mr. O through his work at Habataki. Despite these similarities, however, their definitions of health, senses of personal health, and personal lives are very different.

The first difference is that they were infected and learned of their infections at different times in their lives even though they had known about their HIV status for the same amount of time. Mr. Kawada was an infant when infected, and his mother told him he was HIV positive at age ten. He lived part of his childhood and into his teenage years with this knowledge, and reports that he learned about HIV through reading books and going to conferences from a relatively early age. Thus, he was able to gradually build his life around the knowledge that he was living with HIV. In comparison, Mr. O learned about his status when he was 27 years old and had a girlfriend. Recall from the excerpt above that he feared his girlfriend had become infected and decided not to marry.

\textsuperscript{167} Literally, “correct rule lifestyle”
Although he had been ill throughout his teens and 20s, he did not grow up with his HIV diagnosis the way that Mr. Kawada did.

Another difference is that the two men are based in very different settings. As a Diet member, Mr. Kawada is based in Tokyo. There are a number of hospitals with HIV specialists that yōseisha can visit, and there are many, many groups that provide resources for yōseisha – although Mr. Kawada says he relies mostly on family and friends for support. In comparison, Mr. O has lived in the same rural area all his life. There is one hospital where he can get care in the immediate area, and he works at the only office that caters specifically to yōseisha. Moreover, the circle of friends who may have helped Mr. O has shrunk: a number of his friends have died and, rather than seek a marriage partner, Mr. O lives with a parent. In other words, Mr. O has a limited network of resources and social support in comparison to Mr. Kawada.

In addition, Mr. Kawada chose to discuss his happiness with me rather than past difficulties, but Mr. O shared the harsh realities of his life with HIV – including the fact that he has recovered from AIDS not once but twice. In addition to that, he was confined to a wheelchair and lost the use of his hand at different times. Based on what the two men shared, it appears that Mr. O’s physical health was compromised a greater amount of time and to a greater degree than Mr. Kawada’s (although Mr. Kawada may have chosen to focus on health because my interview questions focused on health). Perhaps this signifies the different ways HIV manifests biologically in different people as discussed in the Introduction. Perhaps it signifies a difference in care or treatment over time and geography. Perhaps it reflects a variation in mental states between the men. Regardless of which factor or combination of factors is behind their experiences, these differences explain why Mr. O describes health as “being able to use your five senses and go about everyday life” while Mr. Kawada includes “being able to laugh and be happy” as part of his definition of health, and why Mr. Kawada views himself as healthy while Mr. O states that he is not healthy.

Some yōseisha describe part of health as not “happiness” per se, but as self-acceptance:
“I think to be healthy, you have to accept yourself. If you don’t accept yourself, you body and mind can’t be healthy. Before I got HIV, I didn’t really think about it. Before, I thought if I didn’t get sick I was healthy. But after I was infected with HIV, I had different experiences, and I realized that me just being alive was a great thing. I’ve known that I’ve had HIV since 2001. But if I were infected earlier, like five or six years earlier, maybe I wouldn’t be here. Maybe I’d be dead… When I first found out, there still wasn’t a lot of information. I had to learn a lot about HIV and medicine, and at first I thought this is a terrible illness! And I was shocked. But now, I take medicine just twice a day and other than those times, I usually don’t think much about HIV. It’s just one part of me.” (Hunky, 55, July 29, 2011).

As discussed above, it took Hunky eighteen months to accept that he is gay and HIV+. Unlike Mr. O or Mr. Kawada who came to terms with a medical condition, hemophilia, before accepting their HIV statuses, Hunky and others who identify as gay or bisexual come to terms with a part of their personalities. Of course both medical conditions and sexual identities influence identity, but having a genetic condition that cannot be helped is often perceived differently than sexual identity and behavior which may be considered a choice by some people. Again, it is not simply a question of what the individual thinks about having hemophilia, being gay or living with HIV – what others believe the realities are also influences reactions to friends and family members, and this in turn contributes to what individuals think of themselves. Often perceptions are negative, particularly when accurate, fair information is difficult to find. Recalibrating one’s selfhood and definition of health may take time and may even foster changes in personality:

“HIV is a problem in Japan, especially because people don’t have correct knowledge about it. They don’t really learn much about it in elementary or junior high schools. I myself don’t remember when I first learned about HIV/AIDS. It’s kind of embarrassing, but, before I got it, I had no interest in HIV. I didn’t have much awareness about it at all. My image was that it was this terrible illness. Now I know HIV is a strong

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168 It is also important to note that aversions to alternate forms of sexuality are not based in religious belief as they are in the United States and other primarily Christian societies. As we shall see, there is more concern about filling gendered roles. For more information, see McLelland 2001 and 2005.
illness, you can feel it physically... Even though I have HIV, I think I’m healthy. I’m physically and mentally stable, and my life isn’t much different than before. I enjoy it.

Even though I’m not working now, I’ll return to work soon, so I think I’m pretty healthy...

Taking care of your body, being able to work, and having motivation are all important parts of staying healthy. Because I was a nurse, and was thinking about the places where a patient isn’t healthy, I’ve been thinking about health for a while. Before [I found out my status] I used to hate comedy shows, but I had a ‘U-turn’ after my diagnosis. I watched those shows and started making jokes. I gained my immunity back through laughter! In general, staying connected is important for yōseisha. We need to have people to talk to, people to share information with. I was hospitalized for two months, and then six months. Going home was hard because I lived alone. So having someone to talk to is really important.” (Taiyo, 35, October 9, 2011).

Even as a nurse, Taiyo did not have a strong understanding of HIV and he was scared to have a “terrible illness.” He described knowing the strength of HIV while referring to his experience with AIDS. Soon after he was diagnosed, he developed lymphatic cancer and intestinal cancer, which rapidly decreased his immune functions to dangerously low levels. However, after taking chemotherapy and anti-retrovirals, he has become cancer free and is no longer living with AIDS. Like Mr. O, Taiyo made a miraculous recovery. During his talk at the Bunka Forum, he stated that his doctors predicted he would be dead before the Forum. He countered this with a defiant smile at the end of his talk, saying loudly, “But I’m still here!”

Not only is Taiyo “still here,” he has gone back to work. Like Mr. E, Taiyo often contemplates living with HIV and work, although Taiyo describes the connection between work and health more explicitly: “I’ll return to work soon, so I think I’m healthy.” Whereas Mr. E describes how his co-workers saw his ability to work as a sign that he was not sick – to the point that some of them even came to the erroneous conclusion that he had lied about his HIV status – Taiyo considers his ability to work as confirmation of his health.

Further, like Mr. Kawada, Taiyo pinpoints laughter as a component of health. Having HIV engendered a change in his personality, and he found that he began to
appreciate comedy shows and even make jokes, which probably helped him form more social connections and elevated his immune levels. Considering that he feels “having someone to talk to is really important,” it should come as no surprise that Taiyo also makes efforts to be sociable and go on dates. These changes were likely facilitated by social conditions considered to be conducive to supporting yōseisha: he lives in an urban area in Kansai with a number of hospitals and organizations that cater to yōseisha.

Thus, despite an intense encounter with AIDS shortly after an HIV diagnosis, Taiyo considers himself happy and healthy. At the close of the interview, I asked him if there was anything he would like to change about his life. He shook his head and said, smiling, “Nope. Actually, I like myself better now than I did before.”

Summarizing the Health Link

Although many yōseisha, such as Mr. Kawada, have discussed the importance of eating well, sleeping well, getting exercise, taking medication, and practicing safe sex, each yōseisha interviewed described health in a slightly different way that cannot be attributed to a single factor such as age, socio-economic status, amount of time living with HIV, et cetera. Rather, each definition was very personal and provided insight into what each man found to be an essential component of health. In Mr. Kawada’s case, he discussed the importance of laughter and happiness with particular emphasis on the happiness friends and family can provide. Taiyo discussed the significance of being able to go to work. Mr. O mentioned the necessity of being able to use your five senses and go about everyday life.

More than providing a varied list of possible ways to be healthy, these men provided a sense of what was required for each of them to be healthy. Both Mr. Kawada and Taiyo considered themselves to be healthy. But if Mr. Kawada were to lose his spouse or connections with friends, it stands to reason that he would lose a measure of his health. If Taiyo were to be unable to return to work, he might find himself in a similar situation. And Mr. O, who states that he is not healthy, might be able to regain a sense of health if his daily difficulties were remedied. What is significant here is that although there is general agreement about some factors that are essential to health, it is still a very individual experience.
In this section, I have hinted at some yōseisha’s financial and social status or class (what type of work they do, for example), but other than stating that none of my interviewees were living in poverty, it is difficult to assess how financial standing and class status directly contributed to their health status. This is partially because it is common for the majority of the population to consider themselves middle-class, and partially because it is actually more difficult to ask someone about financial and professional standing than it is to talk about HIV. Although it is clear that many yōseisha in Japan appear not to be impoverished, and this is very different from global statistics for HIV/AIDS, more focused research needs to be conducted in this area.

**Linking the hegemony of homogeneity to precarity**

Heterosexuality (with the assumption that sex is for reproduction), the fulfillment of gender roles (particularly with regard to family responsibilities), and health maintenance through “living by the rules” (kisoku tadashii sekatsu) are all considered parts of being a good Japanese citizen, or it is often put, of “being Japanese” – along with other assumptions about daily life. At the basis of this “being Japanese” is the feeling that Japanese people are relatively homogenous, and this belief is commonly illustrated by the common use of the phrases ware ware nihonjin (“we Japanese”) and nihon de wa (“in Japan…”) in daily conversation to describe a cultural phenomenon supposedly common amongst all Japanese people and particular to Japan. And although Sugimoto and Weiner have illustrated the broad range of diversity amongst the Japanese population with regard to differences in age, occupation, education, region, gender, socio-economic status, ethnicity and family history, the simplicity of the concept of “being Japanese” as monolithic continues to be appealing to many Japanese citizens and residents (2003; 1997). However, not even this stereotype of “being Japanese” is as flat and simple as it appears to be. Rather, the stereotype is a composite of stereotypes that are based on idealized aspects of life in Japan. Stereotyped concepts and images of sexuality, gender and health are part of this composite and are pervasive despite research attesting to the diversity in all these areas.

With regard to sexuality, for example, it is not uncommon to hear comments such as, “there are no gays in Japan,” or “there are hardly any people in Japan like that” when
broaching the subject of alternate forms of sexuality or sexual orientation. Such comments are not only untrue (Leupp 1995; Pflugfelder 1999; McLelland 2000; McLelland 2005), but problematic because the terms gay, lesbian, and bisexual conjure stereotyped versions of such people in the minds of the speakers (McLelland 2005) and they ignore or denigrate active forms of resistance to norms (Cullinane 2007). For example, when some measure of sexual diversity is acknowledged, TV personas such as those described by Mr. E above are often named as examples but, as he notes, “these are actually very special people” in that they are emphasizing their sexuality in public for profit and entertainment. In addition, the image of the openly gay and highly sexualized image of “okama from Shinjuku” is often utilized by both gay and mass media (McLelland 2000). But these figures and images only represent a portion of men who identify as gay, and ways to be gay, in Japan. Non-heterosexual interviewees told me repeatedly that “there are many ways to be gay/lesbian/bisexual in Japan;” this is documented in detail by McLelland, who has not only interviewed a number of gay men and in so doing demonstrated their diversity (2000) but has also explored the diversity of sexual behaviors and labels for people who practiced these behaviors from World War II to the present (2005)\textsuperscript{169}. It is also important to note that McLelland’s interviewees frequently stated that being gay was only one part of their identity (2000) in the same way that Hunky and other interviewees in this study do, illustrating the fact that sexuality is often not considered one’s defining characteristic.

Thus, expressing alternative forms of sexuality goes against claims of Japanese homogeneity at macro and micro levels: not only does it go against the assumption that Japanese people are all heterosexual, but the claims to diversity within sexual minorities disputes homogeneity with regards to stereotyped versions of being gay, lesbian, bisexual – and even heterosexual. The bottom line is that there is a variety of ways to have sex – regardless of sexual orientation – and that there is also a variety of reasons to have sex. However, acknowledging such variation causes a sense of fear or felt precarity in the general population, who worry about the affects such diversity will have on Japanese

\textsuperscript{169} See Leupp 1995 and Pflugfelder 1999 for histories of male sexuality from 1600-1868 and 1600-1950, respectively.
society. In contrast, failure to acknowledge this diversity results in a sense of felt precarity amongst people whose sexual orientation varies from the stereotyped norm.

A similar pattern is visible when we consider idealized Japanese gender roles relating to family life. Although the stereotypical Japanese family purportedly consists of a salaryman father, a stay-at-home mother, and children, this is not the reality for many Japanese now, nor has it been the dominant pattern historically. Roberts has detailed the lives of women who work in factories and are often wives and mothers (1994), and, as Berstein states, the role of women as mothers has shifted dramatically over time: “in Tokugawa times they were expected to contribute mainly as farm laborers and household managers, yet in the Meiji era their place was either in the home, raising good disciplined citizens, or in the factories, supplementing household income and providing cheap labor for Japan’s industrial effort. In wartime Japan they were called on to raise large families to contribute to Japan’s imperialist efforts, while in postwar Japan they were enjoined to raise small families to foster Japan’s economic prosperity” (Bernstein 1991:13).

Although Japanese men have been characterized as absentee family members with regard to child rearing and household chores in contemporary Japan (Nakagawa 2011), the concept of the salaryman is relatively new in that it dates to the 1930s and developed alongside the concept of women as housewives in postwar Japan (Miyake 1991). However, Dasgupta illustrates how the concept of salaryman as family provider and epitome of male shakaijin has become hegemonic, downplaying and distorting the diversity of Japanese men’s lives (2005). This is to say nothing of the number of men and women of marriageable age who choose to remain single, the couples who choose not to or cannot conceive, the single parent families from death or divorce, and the children whose guardian is someone other than a parent. In other words, historians and anthropologists have established that these stereotypes are just that – stereotypes. They do not represent the lived experience of many Japanese people.

Further, there is evidence that even though people discuss these stereotypes as idealized goals or as though they represent reality, they do not necessarily want to live them themselves. For example Coulmas, citing a 2004 Asahi Shimbun poll, notes that although seventy-eight percent of respondents said they were concerned with the falling
birth rate, seventy-four percent said that raising a child in Japan is difficult, and forty-five and forty-four percent reported that raising a child was mostly a pleasure and mostly a burden, respectively (2007:6). Furthermore, fifty percent of respondents in a 2003 NHK survey stated getting married did not necessarily mean that having children should follow as a ‘matter of course’ (Coulmas 2007). Nevertheless, young people who worked but did not marry (and often continued to live with their parents) were considered selfish “parasites” because they spent their time and money as they wished instead of building a family – even though the economy made it more and more difficult for singles to move out, get married, and support spouses and children (Coulmas 2007). It appears that although many people express concern with the falling birthrate, the number of people willing and able to personally take measures to arrest it is decreasing as well – but criticism is not aimed at everyone who feels this way. Rather, it is reserved for those in the population who are viewed as making conscious decisions to live for themselves rather than for society.

This data illustrates the fact that not only is there is a gap between the stereotypical Japanese family and what the actual average Japanese family looks like, there is also a gap between the stereotype and what Japanese people want for themselves in terms of marriage and children – at least in anonymous surveys. The word “anonymous” is key here. Voicing such opinions anonymously is unlikely to result in criticism, while embodying such an opinion by choosing to forgo or delay marriage and children or being perceived as unable to have a “normal” family life is much more likely to raise concerns and objections. Perhaps it should not come as a surprise that people who belong to sexual minorities, and are perceived as failing to conform to the stereotypical, gendered roles that would support family building stand out and are thus open to ridicule – even if what stands in their way of having a family is adequate finances, social support, or Japanese laws on marriage, childcare leave and adoption – and not sexual orientation or HIV status per se. However, when legislation to remedy these issues is broached, conservative groups experience felt precarity and protest that such changes would destroy Japanese society; this results in felt precarity by those who lives would be improved by such legislation.
The pattern continues with stereotypes about HIV and ill health. As discussed in Chapter 1, HIV is generally equated to AIDS, terminal illness and a difficult and imminent death. Therefore, it is difficult for most Japanese people to entertain the idea that someone who is HIV+ could be healthy. The prevalent, stereotyped image of the dying AIDS patient makes it nearly impossible even though there are a significant number of Japanese people living positive, healthy HIV+ lives and treatment and care have vastly improved in the past twenty years. Moreover, general knowledge about how HIV is transmitted is low: interviewees and participants at various community events often had to be reassured that they could not get HIV from mosquito bites, casual contact, or kissing. As discussed in the introduction, misunderstandings and a lack of knowledge about HIV/AIDS are a result of poor sexual health education. The combination of misconceptions about yōseisha health and what is necessary to protect oneself from HIV indicates that members of the general public fear both HIV/AIDS and contact with yōseisha. On the other hand, yōseisha who have stable conditions and find that they can live relatively normal lives are frustrated by the lack of education and subsequent fear of HIV and yōseisha in the general public.

What is interesting is that although health definitions in Japan tend to be fairly set with regard to diet, exercise, sleep, and stress relief, people do not have difficulty relating health to personal experience and then drawing from those experiences as a means to articulate their own personal ideas of health (see Chapter 1). This is significant because this trend could be utilized to draw connections between living positively with any number of chronic conditions, and it also sets health aside from many other factors of “Japaneseness” as the parameters are much more malleable and variable at the individual level than concepts of ethnicity, sexuality, and socio-economic standing. I would argue that this is because of health and illness-related experience and the ability to actively draw from such experiences. Virtually everyone has experienced an illness episode of

170 Although sex, bodily fluids, and death are considered polluting according to Shinto cosmology, and could be therefore be considered the source (or at least a reinforcing factor) of fears regarding HIV/AIDS in Japan, fear of contagion is common with regard to infectious diseases in general, and is not limited to HIV or Japan. It therefore makes more sense to consider such rationale as justification for fear of HIV/AIDS or a way of talking about it rather than an actual cause of fear.
some type, and chances to learn about health in general are common – especially when compared with chances to discuss sexuality and gender roles in a critical, reflexive manner.

This brings us back to the concept of Japaneseness itself and why these three issues are considered so central to the stability of “being Japanese.” Recall that “Japaneseness” is based on the idea that the Japanese population is relatively homogenous and unique. Although various writers have chosen to express Japaneseness through a variety of subjects ranging from climate, to psychology, to social structure, the format is the same: a single trait or characteristic is selected to epitomize all Japanese people, and compared to non-Japanese examples to illustrate Japanese uniqueness (Befu 2001). As Befu notes, “Nihonjinron” is like ready-made clothing. Most people do not have the competence or time to write or formulate their own nihonjinron so they buy a book that suits them” (2001:64). But the fact that this concept remains prevalent in Japan is not just about the simplicity of the argument or simple ignorance, although these are certainly factors, it is also indicative of the legitimacy this sense of sameness and uniqueness gives to the general public, people’s reluctance to move outside their personal comfort zones, and their lack of motivation to face social issues as individuals. In other words, the stereotypes advanced in discourses of Japaneseness are popular because they validate what mainstream Japanese collectively hope to be true: that there is an ideal and it has not changed.

Therefore, when increasing numbers of Japanese people are openly not heterosexual, such populations become the target of fear about what kind of “threat” this poses to “normal” sex lives. When increasing numbers of Japanese people of marriageable age remain unmarried or do not have children, anxiety about the birthrate and the future of Japan as a nation manifests in social pressure and blame (Cullinane 2007). When increasing numbers of Japanese test positive for HIV, assumptions about yōseishas’ sexuality, ability to perform gender roles, and perceived virulence and pathogenicity are compounded and result in highly concentrated discrimination. That anyone in these categories – gay or not or HIV+ or not – could lead a normal, healthy

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171 Theories of Japaneseness.
“Japanese” life is difficult to comprehend because each of these realities destabilizes a number of stereotypes upon which “being Japanese” is premised. A gay, unmarried, HIV+, healthy Japanese man destabilizes what it means to be “Japanese” on multiple levels. And this destabilization results in fear and in the felt precarity of those who subscribe to the stereotypes.

Ironically, this destabilization both decreases and increases felt precarity in minorities. By asserting their existence, sharing their experiences and arguing for their rights as Japanese, they are able to gain some measure of peace – even if such actions themselves put them at risk for losing jobs or loved ones, and open them up to discrimination. For example, patients infected through medical care fought the Japanese government and secured health benefits for themselves and future yōseisha. However, as we know from Mr. O’s narrative above, these measures did not stop discrimination, even though they provided the means for yōseisha to seek care and financial assistance.

So what we have in these narratives is an active resistance by yōseisha to the stereotyped version of what it means to be “Japanese” and both active and passive resistance to the destabilizing of the stereotype. Mainstream Japanese might say that the yōseisha in this chapter are not typical Japanese people, with the assumptions being based on their sexuality, (non) adherence to gendered family roles, or HIV status. With these as the basis, perhaps they would be right as far as numerical averages go in terms of the percent of Japanese people who identify as non-heterosexual. In terms of family, they may even be similar to the average. But in any case, as each yōseisha interviewed has said, these things are only a part of them. In all other ways, they are typical Japanese people in how they work, manage their health, go out with friends, et cetera.

But there may be one important difference. Yōseisha know the fallacy of the phrase “ware ware nihonjin” and explicitly state that their experiences are theirs alone. This, perhaps more than their sexual orientation, family or HIV status, may be most disturbing thing to mainstream Japanese people. With these narratives they are not only sharing their stories, explaining their anger at having their stories reconfigured into stereotypes by the mainstream media, and asserting their presence and rights – they are also arguing for the importance of asserting difference and independence, things
considered to be “western” and un-Japanese. “I cannot speak for all yōseisha, my experience is my own” is worlds away from “ware ware nihonjin,” even though as Mr. E says, “I’m right here.”

**Conclusions**

In this chapter, I have illustrated connections between sex, sexuality, gender roles, HIV/AIDS, and citizenship through re-telling the stories of several yōseisha. I have shown that an HIV diagnosis is often associated with sexuality, although the way patients and medical practitioners make these associations differs based on their experiences. I demonstrated that fear of disclosure is not limited to revealing their HIV status, but is also related to “coming out” in the situation that the yōseisha is not heterosexual. In any case, yōseisha are often faced with questions about their abilities and desires to perform expected gender roles, including getting married and having children, as well as their ability to perform work-related responsibilities. This culminates in having to assert their rights, their personhood, and their place in Japanese society as a “good citizen” who is every bit as Japanese as the people around them. This assertion, paired with the prevalent assumption that Japanese society is fairly homogenous leads to a sense of felt precarity amongst everyone else, as they feel their sensibilities about what it means to be Japanese are challenged. As I have argued in previous chapters, dealing with HIV/AIDS and its related issues encourages both direct and indirect responses, with the tendency for indirectness or avoidance being the norm amongst the general Japanese population and directness being the general rule for activists and vocal yōseisha. In this chapter, I highlighted the ways yōseisha challenge the hegemony of homogeneity by asserting their normalcy via health, the ability to work, and the chance to build relationships in spite of their HIV status. And finally, although economic status and class are discussed in passing in various sections, more research is needed in order to fully address just how concepts of HIV/AIDS and epidemiology data correlate to these categories and how they fit (or do not fit) into the global discussion of who has HIV, who supports people living with HIV/AIDS, and why.

Returning to the issue of health and HIV, and how these concepts do and do not collocate in the minds of the general public in this final chapter, I have come full-circle.
Through the discussion above, however, it is clear that it is not just collocating HIV and health that is difficult. For many people, the concepts of HIV, alternative forms of gender and sexuality, and Japaneseness (or being a “good Japanese”) do not fit into the same conceptual spaces. However, many of these concepts have now become atarimae – they “go without saying” for the yōseisha included here because such collocation is their lived experience. They live every day as HIV+ and Japanese while also being a family man, a gay man, a straight man, a man in a relationship, or a man who avoids relationships – and to include Ms. Ishida from Chapter 5, a wife and mother. So on the one hand, yōseisha plead for a Japan that recognizes multiple forms of sexuality, multiple types of families, multiple ways of being Japanese, and/or the acknowledgement of the reality of HIV in Japanese society. On the other hand, there are people who, for whatever reason, remain blind to or indifferent about these issues. Each group feels fear of the other, and each feels the need to hold onto what they consider to be a “kisoku tadashii setkatsu.” Enter precarity. Although Butler’s description refers to an ongoing cycle of violence and retribution, in this case we have an emotionally precarious situation made physically precarious by the presence of a chronic, stigmatizing infectious disease.
Conclusions

“Help me write a story,” Mr. T asked.

I opened this dissertation with this anecdote. So what story have I written?

I began with two goals – to use precarity to understand HIV/AIDS in Japan and to better understand precarity through focusing on HIV/AIDS in Japan. Butler uses precarity to illustrate how destructive cycles are perpetuated in society: for example, endless cycles of violence and retribution continue because of emotions such as grief, fear, or anger aimed at others remains the focus while the suffering of others is ignored (Butler 2004). In other words, in-groups are emotionally driven by what out-groups have done to them and either minimize their own transgressions or dehumanize the other group so that these transgressions can be justified. These cycles can only be broken if “dominant forms of representation are disrupted” so that people can see the source of their reactions (Butler 2004). Changing the content is not enough – changing the way people experience representations also has to change. To put it simply, people have to learn to be critical and reflexive. In her more recent work, Butler describes how precarity is linked to performativity for exactly the reasons outlined above: something does not feel right and something needs to change. Actions are both motivated by precarity and are precarious (Butler 2009). She also asserts that precarity is linked to gender norms and citizenship because those who perform alternative gender roles are often not counted as people deserving of rights by the state (2009).

Japanese responses to HIV/AIDS, framed by these definitions of precarity, can be parsed in the following ways. First, mainstream Japanese people, disturbed by associations between HIV, AIDS, death, pollution, sex and drugs, are uncomfortable engaging with the thought that these issues are part of the lives of “normal” Japanese. Discussing HIV/AIDS, then, is precarious and threatens idealized notions of Japaneseness. The response is to mitigate this form of social precarity by avoiding it or engaging with it in a superficial manner. Glossing HIV/AIDS as eizu, disseminating educational materials and posters that broach the subject in vague terms, and relying on
mass media representations of it provide some examples of this. Avoidance or indirectness can extend to medical settings and professionals: finding HIV test centers or support groups may be difficult, and yōseisha may be faced with non-HIV specialists who are afraid to treat them, though they can only muster an ambiguous response as to whether or not yōseisha can get care at a certain facility. Although indirectness may be considered protective for yōseisha visiting HIV-specific support services, it can be a barrier to locating those services in the first place.

Second, yōseisha and HIV activists are uncomfortable with the flat, monolithic conceptualization of Japaneseness that leads to the stigmatization and discrimination of people living with HIV/AIDS, as well as other minorities in Japanese society. Life for these people is precarious – not only because of what HIV is doing in their bodies, but also because of how they are viewed and treated in Japanese society. The response is to mitigate this form of social precarity by pushing for direct discussions of HIV/AIDS and related topics in Japanese society. The formation of support networks, the use of public HIV narratives, and actively living as “regular, healthy Japanese” in spite of idealized conceptions of Japaneseness are examples of this.

Third, paralleling Butler’s assertion that performance is precarious, these responses to the precarity engendered by HIV/AIDS in Japanese society are, in themselves, precarious. Avoidance of the topic provides ideal social conditions for the virus to spread, while forcing discussions important to minority groups can open individuals and groups up to further stigmatization and discrimination. In these ways, precarity is felt by all Japanese, but in different ways. Further, as indicated with Butler’s example of violence and retribution, responses to precarity beget precarity and the cycle can only be stopped by encouraging people to be reflexive about their responses such that representations (and therefore responses) change.

Activists, educators, and vocal yōseisha have been working to elucidate which types of information about HIV/AIDS are necessary to do this, which information “goes viral,” and how to package information so that it is easy to find and circulate. Others have attempted to broach the topic through exhibits. But even with these very direct engagements, avoidance or indirectness is sometimes unintentionally favored. For
example, museum exhibits about HIV/AIDS in Japan do not focus on current, domestic HIV issues such as the high rates of incidence among Japanese men (specifically MSM), increasing infection rates due to the use of intravenous drugs, or the problems of aging with HIV (chronicity). Instead, the focus remains on foreign others, women or hemophiliacs. While there is no doubt that developing nations need financial aid from Japan for ARVs, and that hemophiliacs infected in the 1980s and 90s still need care, domestic rates of sexually transmitted HIV infections continue to increase. Moreover, messages of women (including Japanese women) as vectors for HIV infection may have functioned, ironically, to protect women: mother-to-child transmission is almost negligible thanks to prenatal testing, and HIV rates among women have been steadily declining in Japan in general.

Despite the difficulty in dealing with HIV/AIDS because of taboos about related issues, there are significant efforts being made by support organizations to change the ways that Japanese engage with HIV/AIDS. Organizations like Place Tokyo and Happy Life Peers are working to de-link some of the problematic associations such as eizu being untreatable and, therefore, a death sentence. This de-linking even occurred in my own interviews when I explained the differences between HIV and AIDS, and described therapies; this made it possible for interviewees to realize the possibility of living a healthy life with HIV. What this indicates is that there is room for these discussions to happen in Japan, and that it is possible to change the ways HIV is conceptualized. To put it another way, the transmission of HIV and the transmission of harmful ideas about HIV can be disrupted in Japan (which should help to alleviate the epidemic) in much the same way that Butler asserts that both content and conceptual frameworks must change for patterns of violence to be disrupted.

The bottom line with regard to framing HIV/AIDS in Japan in terms of precarity is that it allows us to make sense of the characteristics of the Japanese epidemic (for example, the factors that contribute to MSM being a large risk group), as well as Japanese patterns of response. It can also encourage reflexivity on the part of researchers. For example, I am aware that my own interpretations and representations of the data I analyze here – including the stories of yōseisha – are precarious: yōseisha I spoke with
asserted that their stories were their own and that they could not speak for all yōseisha. However, I have tried to paint a picture of what it is like to live as an HIV+ person in these pages. Acknowledging the individuality of these people while also outlining common experiences is a challenge. What this tells us about the utility of precarity as a theoretical framework is that it can be applied to a range of social issues to facilitate understanding of the roots of those problems – including issues of disciplinarity.

With the particulars of Japanese HIV/AIDS responses elucidated, thematic contextualization according to research done in other regions by other researchers is possible. In the Introduction, I noted how common HIV/AIDS-related themes include representation via images and narratives, religious aspects of illness and healing, the (in)visibility of social problems, embodiment, access to resources, citizenship, and the performance of gender, sexual and familial norms. These themes continue to be salient; given the framework above, we can talk about these themes in terms of Japanese trends and compare them to trends elsewhere, noting what is and is not being disrupted: the movement of information about HIV, the movement of the actual virus, both of these things, or neither of these things.

**Representation**

HIV transmission may or may not be disrupted by representations of HIV/AIDS, ranging from terminology visual images in publications, the mass media narratives, and museum exhibits that “go viral.” For example, the elision of HIV and AIDS into *eizu* allows for the virus to be associated with death and pollution. This in turn makes *eizu* something to fear and avoid. However, rather than avoiding the virus through condom use, the response is to ignore it which, of course, disrupts neither the spread of the virus nor the spread of misinformation. However, in Uganda, where the category *siliimu* or “slim” (among other terms such as *omunywengye*, meaning “rough cast”, *mukenenya* and *ziridde* referring to “drying up”, *etawoi* or “wildcat”, *oridi* for “squeezed and squashed,” and *ukimwe*) pre-dated HIV/AIDS, and helped Ugandans view it as a local problem from the very beginning, thus making it easier to address (Thornton 2008:111–112).

Sensationalized information related to HIV/AIDS, particularly in image form, often travels faster (is more “virulent) and has a bigger impact (is more “pathogenic”)

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than educational information about HIV/AIDS – particularly when one is faced with multiple sensational memes about the same topic (is “co-infected), and is also immersed in multiple sensational memes about other issues that foster uptake of all these memes (is part of a “syndemic”). Women in Japan have been consistently portrayed as vectors of HIV despite the rising numbers of MSM who are becoming infected with HIV. The spread of these memes is engendered by long-term trends in ignoring sexual minorities, and by gender inequality in which the status of men (and male heterosexuality) is prized over that of women. Moreover, information that would combat these stereotypes is complicated and thus not amenable to “going viral,” and this makes for gaps in public knowledge about HIV/AIDS. Community-based organizations work to alleviate gaps through specially tailored forms of outreach such as peer education programs like Happy Life Peers in my rural field site and Place Tokyo in Tokyo. But gaps can also be filled with disinformation, such as the HIV/AIDS disinformation campaign designed by KBG operatives from the former USSR that implicated the United States government in the design and spread the virus (Boghardt 2009). This meme was constructed during the final years of the Cold War as a means of destabilizing trust in the U.S. It spread through India in 1983 and eventually worked its way through East Germany, parts of the United States, and several African nations – beginning with Zimbabwe (Boghardt 2009). The effects are still being felt in the form of distrust of US aid and health programs, including polio vaccination campaigns (Boghardt 2009). Memes based on overly-simplified information or outright lies can contribute to epidemics when people are unable to distinguish helpful information from harmful information; as such, they do not help arrest viral transmission – metaphoric or actual.

Representations of HIV/AIDS in museum exhibits can also work to alleviate gaps in the public’s knowledge about HIV/AIDS, thereby breaking the cycle of fear and avoidance; however, there is also the possibility that they may unintentionally perpetuate various stereotypes due to their goals or organizational frames. In the case of “Love’s Body,” “Access to Life,” and “The Brilliance of Life,” for example, the goals of each exhibit and the training of those involved in the organization influenced which representations would be shown. This ranged from predominantly gay men from upper-class, western backgrounds or who had western training; to HIV/AIDS sufferers from
global south nations; to those who were infected through blood products in the 1980s. The overall message is that HIV/AIDS is far away and is someone else’s problem. This issue is not unique to Japan, as exhibits like “Access to Life” are traveling exhibits, and it is not unique to museum exhibits that seek to raise funds for HIV. For example, a U.S.-based 2010 campaign entitled “Digital Death” by the group “Buy Life” capitalized on the fame of various celebrities who use social media to entice fans to make donations for HIV/AIDS. The stars were pictured in coffins, gave “last tweet and testaments,” and played dead on social media until fans had donated enough money to “buy their lives back.” The idea was that by “buying back” the lives of celebrities, donors were actually “buying life” for people – children in particular – as in the global south by providing them with money for meals and school. This was quite a clever campaign in terms of how it utilized fame and social media, and organizers also refrained from using stereotyped images of the people they aimed to help (although some pictures of recipients are featured on their website). The campaign raised the target amount of money and did indeed help others. However, the campaign most likely reaffirmed beliefs that HIV/AIDS is someone else’s problem (not a local one), and that it can be fixed by donation (rather than practicing safer sex) (Buy Life 2010). The degree to which such campaigns disturb transmission is, therefore, ambiguous.

**Religious Aspects**

Although religion did not play a major role in shaping the HIV/AIDS discourse in Japan, which is instructive in its own way, religion certainly has played important roles in responding to HIV/AIDS in other areas around the world. Klaits, for example, illustrates how verbalized prayer and other church activities in Botswana can show love for those infected with HIV and how this social support can influence their health (2010). Although such actions are not necessarily meant to prevent infections, they do increase awareness and compassion; however, Klaits also describes how negative labels such as promiscuity can be used to purposefully damage one’s social standing (2010). In terms of support organizations, Zignon argues in his 2011 work that an HIV diagnosis can be considered “a blessing” by church-affiliated programs in Russia because such diagnoses can provide heroin users with the motivation to fight addiction and attempt to live a “normal life.” However, Hammar paints a much bleaker picture of the roles of religious
groups in Papua New Guinea, arguing that, with regard to HIV prevention programs, “the real focus is not and perhaps never has been as much about preventing sexual transmission of anything so much as about realigning sexual practice to fit certain Christian ideals of monogamous heterosexuality” (2010:1). Disruption of HIV transmission and HIV/AIDS meme transmission is likely to be difficult under these circumstances, as it is when religious conservatives in the United States oppose harm reduction programs such as syringe exchange and condom distribution on the grounds that they tacitly approve of immoral behavior (Wynia 2005).

**Access to Resources**

As in the United States, Japan has been very successful at disrupting transmission through medical treatment. But that does not mean the epidemic has been curbed. Instead, new risk groups have emerged and the epidemic continues to worsen: men who have sex with men now comprise the bulk of new HIV/AIDS patients (Japan Foundation for AIDS Prevention 2013). This is perhaps not so different from the U.S. epidemic, where transmission amongst marginalized peoples including intravenous drug users, prisoners, and the urban poor increased after transmission amongst patients and MSM was disrupted through the treatment of blood products and community-based health campaigns for gay men in San Francisco and New York began (Center for Disease Control 2013; Whelehan and Budd 2009). The difference is that Japan’s rate of incidence continues to increase, while the U.S. rate of incidence remains relatively stable. Overall, both countries have HIV/AIDS epidemics that have proven difficult to control.

Efforts to control HIV/AIDS epidemics include legal and medical systems to provide for and protect people living with the condition. However, sometimes these very systems work against patients and public health. Privacy and anonymity can make resources difficult to find, such as in the case of testing sites in Japan. Moreover, disclosure of a patient’s HIV status in a health facility does not ensure access to care – in either Japan or the U.S. – because patients can still be rejected by practitioners who are uncomfortable treating HIV patients (Jeffe 2000). Additionally, local and federal governments depend on non-governmental organizations to provide services for the public and PLWHA, but they are not always willing or able to provide financial or other
support. These contradictions in social systems can actually fuel the epidemics they were supposed to alleviate.

Furthermore, an HIV diagnosis may be problematic not just because accessing HIV-related resources is a problem, but the diagnosis may cut off general resources as well. For example, Van Hollen describes how an Indian interviewee was rejected by her in-laws even though she was likely infected by her husband (2013). This woman was accepted by her own family, but she feared that her status would influence her siblings’ marriage prospects, thereby cutting them off from lucrative partnerships. Clearly, this indicates that when we consider whether or not transmission has been interrupted, we need to think about this on multiple levels.

**Citizenship vis-à-vis Gender, Sexuality, and Familial Roles**

In Japan, an HIV diagnosis calls into question one’s health, sexuality, and gender roles, as well as one’s ability to be a “good citizen” – or in this case a “good Japanese.” Given that part of being a productive contributor to society in Japan means working, getting married and having children, being HIV+ and gay makes people question whether or not these roles can be adequately fulfilled – particularly since having eizu is associated with illness and death (making it difficult to work or have children) and being gay may lead people to think marriage and children are not options (gay marriage is not legal in Japan, and adoption in general is extremely rare). In any case, many Japanese may believe an HIV+ person, regardless of sex or sexuality, is unable to perform the necessary gender roles to make them fully Japanese – even though Japanese yōseisha are doing just that every day. Additionally, any increase in the visibility of yōseisha may make those who are not living with the virus experience felt precarity, centered on the sense that such people are a threat to Japan and mainstream Japanese society as they know it. Yōseisha, on the other hand, experience felt precarity when mainstream society ignores them and the presence of HIV/AIDS in Japanese society.

These issues are not unique to Japan, but they are of course expressed differently depending on cultural context. Drawing from interviews in the United States, Barnes argues that women living with HIV may actively attempt to become pregnant because they feel that becoming a mother will bring them some measure of respect and sense of
normalcy; it may also give the woman a reason to live (Barnes 2013). Simpson argues that Zambian men view sexuality as a space to create masculinity, and the desire to demonstrate sexual prowess most likely contributes to the spread of HIV and other STIs through the practice of unprotected sex (2009:8). Similarly, in her study of HIV/AIDS and sex work in China, Zheng describes how rising rates of sexually transmitted cases there are in part due to a general silence surrounding sex, gendered ideals of sex and contraception, and assertions of individuality through sexuality in the face of the authoritarian Chinese government (2009). Zheng notes that because sex is often not discussed even between married couples, there are not many chances to talk about issues such as HIV/AIDS. Further, contraception is supposed to be the “woman’s responsibility,” and men tend to show their “bravado” or “valor” through rejection of condoms (2009:8). In addition, interviewees often insisted that government-sponsored condom campaigns infringed on their private lives, so having condom-less sex was considered to be way to assert freedom from an oppressive, controlling government (2009:8).

Moreover, HIV has an influence on global citizenship as governments around the world determine who should be eligible for what aid based on how they behave and whether or not that behavior is deemed appropriate by the people who manage grant funds. For example, PEPFAR funds to Uganda were reduced when local officials refused to promote abstinence-only programs. To put it bluntly, once Ugandans refused to follow funders’ requirements for prescriptions on sexuality in sex education, they were not “good enough” global citizens to receive PEPFAR aid, even though local techniques had led to falling rates of infection (Thornton 2008).

**The (In)visibility of Social Problems**

I argued above that recognition of minority groups in Japan, whether they are ethnic groups, sexual minorities, intravenous drug users, or yōseisha, is difficult for Japanese to face because of what Befu terms the “hegemony of homogeneity” (2001). This results in mainstream Japanese either blaming minorities for HIV or avoiding the reality that HIV is a problem amongst Japanese. Zheng has noted similar problems of silence and denial of HIV in China with regard to sexually transmitted infections (2009);
further, Hyde remarks that the Chinese government chose to focus on HIV and ethnicity because it did not want to acknowledge issues of poverty (2007). In a similar vein, Liu illustrates how HIV infection through heroin use in the Nuosu people in China can be partially attributed to rapid political changes that resulted in an increase in the availability of opiates, an increasing emphasis on autonomy, and the increasing likelihood that young men “come of age” in urban centers (2011:13). In other words, it is common to avoid HIV and associated issues for reasons ranging from fear to pride, and then to blame minorities or cite the most “convenient” reasons for spikes in HIV. Van Hollen further illustrates this issue, asserting that the presence of HIV in populations viewed as morally good and chaste in India illustrates the “cracks between imagined cultural ideals and actual practice” (2013). Sex, drug use, political instability, and other difficult issues may make it difficult to address HIV/AIDS directly unless those who contract the virus become visible in some way – either through public narratives and court cases, such as in Japan, or in terms of loss of life in places where incidence and prevalence are at epidemic levels.

**Facing Precarity?**

*My wife and I have a dream. It’s not a big dream, but this is our dream. We hope to have a nice little café with good coffee and music and have a nice life. You know that Eagles song, ‘Take it easy?’ That is my philosophy.” (Field notes, October 9, 2011).*

Sitting across from me in a café in Osaka, explaining his life and his ambitions, Mr. T seems peaceful. His “take it easy” philosophy is the antithesis of precarity. Where did it come from? To some degree this has always been his philosophy, his way of life. Imprisonment for drug possession in Thailand disrupted that. His HIV diagnosis disrupted that. But getting out of jail, returning to Japan, staying clean, getting married, and having a regular job have brought it back. In the end, he can live with being HIV+, but he can no longer take it easy and take heroin – the heroin is what made his life precarious. Perhaps he would agree with Zignon’s interviewees in Russia who deemed HIV a blessing.

It is important to realize that this philosophy, “take it easy,” is a very different from what has been the Japanese norm. For many Japanese people Mr. T’s age, life is
more likely to be characterized by the motto “work hard, play hard.” But it seems that perhaps Mr. T is ahead of the times. Young Japanese people, who are increasingly unlikely to work as lifetime employees at a single company due to instabilities in the Japanese economy, are thinking more and more about what they want to do with their lives rather than filtering into the societal roles of workers, mothers, fathers, and filial children. As noted in Chapter 6, they are getting married later and having fewer children. What it means to be Japanese is, considering factors like these, shifting. This also means that responses to HIV are shifting.

Although the Japanese have had fewer chances to engage directly with HIV/AIDS specifically and minority issues in general, they are curious. Unlike Zheng’s experiences in China where she was often met with opposition to her research or simply silence (2009), I was met with shy interest, questions, and often enthusiasm. Moreover, the voices of yōseisha and HIV activists – which includes many people in their 20s – are getting louder. It seems that the disruptions Butler says are needed to break harmful cycles, at least with regard to HIV, are in motion. Whether or not the transmission of helpful information about HIV can lead to the aversion of transmission of the virus and thus finally stabilize the Japanese epidemic, however, remains to be seen.
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