Research Narrative

Japan, Medical Anthropology

Beyond Varieties: Mapping Treatment Selection of HIV/AIDS Patients in Rural Japan

Introduction: The proposed research will examine the processes through which and the extent to which HIV patients make treatment choices that are aimed at 1) aiding their physical, social and mental health, and 2) minimizing incidences of stigmatization and blame for having contracted HIV. By combining concepts from Actor-Network Theory (ANT) (Latour 2005) and medical pluralism (Lock and Nichter 2002), it is possible to view venues for treatment as connected by patient choice and to map treatment selection behavior. This strategy is used to demystify HIV patients' treatment selection and utilization of multiple healing methods, as well as to illustrate ways in which the socialized medical system may be, under varying circumstances, particularly beneficial or detrimental to patients with HIV. The focus on the patients' lived experiences and treatment selection processes augments previous scholarship on 1) medical pluralism, in which "varieties" of care available at hospitals, temples and pharmacies have been considered separately (Lock 1984, Yumiyma 1995); 2) HIV in Japan and Asia, in which prevention efforts and epidemiology are the most common foci (Nakaya et al 2005, Takebe et al 2004, Ruxungham et al 2004); and 3) stigmatization and blame, in which patients' day-to-day coping strategies are mentioned but not thoroughly investigated (Cullinane 2007, Miller 2002, Treichler 1999).

Literature Review: This research builds upon central concepts in Medical Anthropology by combining contemporary theories such as Actor-Network Theory (ANT) and medical pluralism to frame illness narratives in such a way that these narratives can inform public health policy. Simultaneous use of multiple treatments from multiple traditions is referred to as medical
pluralism and has been well-documented by medical anthropologists. Although labels such as “biomedical,” “Chinese,” or “homeopathic,” are often applied to treatments, the boundaries between such systems are more conceptual than actual – particularly from the standpoint of the patient. Patients may utilize treatments considered biomedical, religious, and folk in concert – and then give different reasons for choosing each treatment depending on the social context (Crandon-Malamud 1991). Public health programs may be unsuccessful when this plurality is not recognized, or when the goals and/or rationale of the program managers do not match those of the target group (Hahn et al. 1999). In addition, the target group itself may not be clear, as government statistics may not accurately represent the number of HIV/AIDS related deaths, and ordinarily do not indicate the survival strategies employed by such patients; filling these gaps requires innovation on the part of the researcher (Biehl 2007). Recently, medical anthropologists have been encouraged to step beyond documentation and analysis of medical pluralism and apply it in order to improve public health (Lock and Nichter 2002). The use of ANT answers Biehl’s call for innovation and Lock and Nichter’s call for application of theory to public health: it allows for both people and organizations to be considered actors (active participants in a social network), which in turn highlights the pluralistic behaviors of patients and the relationships between such patients and health care and social support entities (Latour 2005). Application of ANT can illustrate to what degree use or disuse of resources is a function of knowledge (that a resource exists), belief (that what exists is useful or helpful), access (that patients have the physical and financial ability to make use of existing resources) and the level of stigmatization perceived to be attached to a resource (the level to which patients view a resource as making them vulnerable to stigmatization or blame). It also allows for the recognition of how
organizations, through their goals, mission statements and financial support and staff training, shape such knowledge, belief, access, and perception of stigma.

This research relates to current themes in Japanese Area Studies by including religious forms of illness prevention and treatment in the discussion of health and wellness, and discussing how concepts of gender and sexuality indirectly affect the increasing HIV infection rate. Generally speaking, religion and healing have a shared history. Japanese undertake pilgrimages, purchase amulets or talismans at temples, pray to specific deities for recovery from illness, and visit temples or shrines for purification (goma) and/or ritual empowerment (kaji) as a general form of healing (Winfield 2005). It is noteworthy that Kanamara Shrine in Kawasaki was among the first public entities in Japan to acknowledge HIV as a public health problem (Reader and Tanabe 1998). Religious affiliation can also influence treatment availability and choice in non-religious settings such as hospitals (Mizuno and Slingsby 2007). This research expands upon previous scholarship in Japanese studies by considering visits to religious venues and religious healing acts alongside visits to hospitals and other conventional medical venues and therapies. It also considers how decisions regarding disclosure and end-of-life care for HIV patients may differ from those made by the elderly or patients with chronic, non-infectious diseases, which are described in previous scholarship (Long 2005).

This project also builds on previous scholarship on gender and sexuality in Japan. Whereas Japanese men are to some degree permitted/expected to engage in sexual play, it is unacceptable for women to do so (Allison 1994, Miller 2002, Cullinane 2007). Women have thus been blamed for the spread HIV in Japan despite the fact that they comprise a small percent of cases (Miller 2002). Moreover, the narratives of women who offered to tell their stories have been altered against their wishes to fit existing systems of blame: narratives became commodities
designed for consumer entertainment rather than educational information (Cullinane 2007). Falsification of the lived experiences of HIV patients can skew the public understanding of HIV and mask the reality that the vast majority of those infected with HIV are Japanese men – particularly those who have sex with other men (Komatsu and Sawada 2007; Hidaka et al 2006).

Homosexuality is stereotyped and marginalized in Japan (McLelland 2000), which leads to gaps in sex education and information about disease transmission. For example, the use of condoms decreases when pregnancy is not a concern for either both or the dominant partner – for example, in male-male sex, sex with a prostitute, or casual sex (Kihara 2003). The focus on women, the perception of condoms as birth control rather than disease prevention, and marginalization of homosexuality affect HIV infection rates. While Ministry of Health, Labor and Welfare (MHLW) officials have expressed interest in making changes to educational programs to curb the spread of HIV, actions have not yet been taken to address these factors (Miller 2002). This research provides confidential avenues for HIV patients to give suggestions about what improvements can be made for healthcare, STD prevention, and sex education; it also seeks to remedy the bias towards studying HIV+ women over HIV+ men.

This project also incorporates and elaborates upon current issues in Public Health such as access to health care and responsibilities of socialized health care systems for those who are chronically ill with a "preventable" disease. While boundaries between health systems are mostly conceptual for patients, drawing the line between the responsibility of the individual and the responsibility of a socialized medical system is done through the creation of insurance plans and benefits. As a result, benefits may or may not meet patient needs. Typically, marginalized populations that could benefit the most from particular forms of healthcare lack access to such care due to poverty, lack of transportation, lack of education, and/or lack of social support; this is
particularly true for many people living with HIV, regardless of location (Farmer 1992, Biehl 2007). Despite such barriers to prevention and treatment, cultural practices are often labeled “risk factors,” which results in generalized stigmatization and blame of the people who embody the practices in question (Schoepf 2001, Goffman 1968). This allows a large portion of a given population to feel safe from risk of infection of diseases such as HIV and to place blame squarely upon those who are infected. However, data gleaned through participant-observation, surveys, individual and group interviews, and focus groups with patients, practitioners, policy makers and laymen can highlight discrepancies regarding individual and social responsibility between these groups. Such data can also illustrate how HIV patients select treatments and avoid stigmatization, facilitating the improvement of HIV education and access to resources.

**Research Area:** Japan is an important focal point for studying HIV in general because, unlike other developed nations with socialized health care, the infection rate and costs for care continue to climb (Kihara et al 2003). It has been suggested that the actual number of HIV cases in Japan may be ten times higher than the number of confirmed cases published by the MHLW (Cullinane 2007). More resources will be required to treat the increasing number of patients, who suffer from secondary infections more frequently than non-infected persons. Thus, it is important to understand as clearly as possible what patients need to combat illness and stigma and to what degree the current system provides for these needs.

Nagano Prefecture is an ideal site for HIV research due to its past history in HIV scandals and its rural surroundings. The “second panic” in Japan in 1986 took place in Nagano: rumors about a promiscuous, foreign, HIV+ hostess resulted in the inundation of clinics and hospitals by men requesting HIV tests (Miller 2002). Archival research on the “second panic,” sex education, modern and contemporary concepts of illness and health, and general knowledge of infectious
disease and HIV in Japan will provide a historical context for how treatment options for HIV patients have changed since the first outbreaks in Japan. Moreover, data from a rural setting can be compared to previous research results from urban areas (Miller 2002, Cullinane 2007).

**Methods and Analysis:** What treatments do Japanese HIV patients select, and how do these selections aid their physical and mental health, and minimize incidences of stigmatization and blame for having contracted HIV? This question will be answered by a combination of participant-observation, surveys, individual and group interviews, and focus groups; each stage of research is centered on a sub-question.

Stage 1: Participant-Observation

What resources exist for HIV patients, who uses them, and how does this compare to the plans and statistics on risk groups published by the MHLW?

I will volunteer at an HIV clinic and counseling center in Yokohama City once a week for the duration of the research. This will allow me to observe what healthcare and social support resources are available to patients as well as whether or not the population seeking treatment differs from the population considered to be most at risk by MHLW. Participant-observation will inform questions for surveys, interviews and focus groups. Many patients from rural areas are thought to travel to urban areas for testing and treatment; such observation will help determine to what degree this is true. It allows for regular communication with my affiliate faculty from Tokyo University.

Stage 2: Surveys
Preliminary data indicate that local knowledge about HIV prevalence, methods of transmission, concepts of risk groups, and acceptable forms of treatment differs from official statements, statistics and education materials provided by the MHLW and the Ministry of Education, Science and Technology (MEXT). What are these differences and in what ways do they impact individual and public health?

I will administer anonymous paper surveys to 100 patients (who self-select at counseling centers), 100 lay persons (who self-select at a community center in Nagano City), and 100 practitioners from various clinics, hospitals, pharmacies, temples and shrines in Nagano Prefecture (selected randomly by the researcher from telephone directories). Surveys and stamped envelopes addressed to the researcher will be made available at information corners for the first two groups and sent to practitioners. Data from these surveys will be analyzed to determine whether or not trends exist based on sex, age, education level, or job type; this data will also illustrate to what extent and in what ways official and lay knowledge regarding HIV converge or diverge. Finally, it will inform the questions formulated for the individual and group interviews.

Stage 3: Individual and Group Interviews

It is generally agreed that people exhibit medically pluralistic behavior in order to balance the physical needs of their individual bodies and their social roles as family members, workers, and citizens – or social bodies (Helman 2000; Inoue 2004). How do health seeking behaviors of HIV patients compare to those of the general population, as well as to the ideals set forth by the MHLW?
I will conduct interviews with 50 patients (who self-select either where I volunteer or from within a support group I will take part in), 50 practitioners, and 50 members of the lay community. Following introductions from Dr. Kojima, practitioners from major health care facilities and religious institutions in Nagano and Matsumoto will be contacted via letter or telephone and asked to participate. Calls for participants will posted in the community center. Data from interviews will be used to shape discussion questions for focus groups, and focus group participants will be recruited from these pools of interviewees.

Stage 4: Focus Groups

How can the national health care program and education policies aimed at sexual health be improved to meet patient needs and prevent further infections?

Three focus groups comprised of ten participants, one for patients, one for practitioners, and one lay community members, will be formed. The main topics of discussion will be media representations of HIV, sex, and gender; issues of stigmatization; sources of social support; and suggestions for improvement on healthcare and education.

Preparation and Preliminary Research: Through my MA research, comprehensive exam preparation, and seven years of experience living in Japan, I have developed both the connections and regional knowledge necessary to undertake this dissertation research. For my Master's research, I completed an overview of the history of the HIV epidemic in general and in Japan specifically. I outlined the emergence of the disease, the genetic variations of HIV prevalent in Japan and epidemiological theories for these patterns. I also described how nationalism, paternalism, and homophobia have led the public to conclude HIV is a disease brought to Japan by foreigners and spread by women – despite the fact that the vast majority of
HIV patients are Japanese men who engage in sex with men. This research is buttressed by my comprehensive exam foci, which included specializations in Japan, theory and methods in anthropology, medical ethics, medical pluralism, and religious responses to health and illness.

In addition to classroom training, I have extensive experience in Japan. I worked with a group of doctors from 2003 until 2006. During this time, I became well-acquainted with the hospital and clinical settings and procedures, and became familiar with necessary precautions for protecting patients’ privacy. Of this group, Dr. Eigo Kojima of Nagano Central Hospital has agreed to to provide support and assistance for the project detailed here.

I am currently studying at Inter-University Center in Yokohama, where I am learning to converse at a professional level and read academic texts. For my final project with IUC, I will work as a volunteer at an HIV clinic to gain experience working with patients. By the time I undertake this research, I will have the language skills and the contacts necessary to complete this project; I will also have established and solidified connections with a community center in Nagano and an HIV support group in Yokohama. These skills and contacts will allow me to contribute to the existing corpus of literature on Japanese society, socialized medical care and public health, and the HIV experience while at the same time providing an avenue for HIV patients to speak about their experiences and voice their opinions about care options anonymously.

**Affiliations and Support:** Affiliations with Nagano Central (Chuo) Hospital and Tokyo University will support dissertation research that has a strong applied component within Japan, and the methodology I will use may be adapted for and applied to other locations so that useful comparisons can be made. Dr. Kojima of Nagano Central Hospital and Dr. Yujin Yaguchi at
Tokyo University have agreed to assist me in my research. I intend to collaborate with local researchers to produce a number of short articles in Japanese that illustrate the results of the research outlined here. After my research is complete, I will present copies of my research to the Japanese Ministry of Health, Labor and Welfare and Tokyo University as well as to all institutions that assist me in my research. I will present my research in person at Tokyo University at various stages. Thus, the results of this project will be available to academics as well as policy makers in Japan and the United States. Additionally, I intend to work within this network as a researcher and an educator, and will include both Japanese and American university students in future research projects. This project serves as the basis for my career commitment to medical anthropology, public health and education.

In addition to the contacts named above, I currently have a five-member committee at the University of Hawaii which includes Dr. Eirik Saethre (chairperson), Dr. Christine Yano, Dr. Geoffrey White, Dr. Andrew Arno, and Dr. Helen Baroni. I have completed my comprehensive examinations under their guidance and have begun developing a full research proposal that will have committee and IRB approval before I depart for the field in October 2010. My dissertation will be written under their guidance.

The proposed project meets the goals of Fulbright Hays by offering an innovative approach to the study of treatment selection in general and HIV specifically, including an applied component that aims to improve public health, providing an avenue for Japanese HIV patients to voice opinions about various healthcare-related topics, and providing an opportunity for research collaboration between Japanese and Americans.