Deliberate Discrimination
- Women’s Human Rights and HIV/AIDS

What form did discrimination relating to HIV take in Japan? How are women living with HIV treated in Japan? Whose problems are HIV/AIDS issues? How should we deal with issues concerning HIV/AIDS? We shall examine the social structure and HIV/AIDS issues that undermine human rights.

An Interview with Mary Gotoh, the chair of NPO JAPAN HIV CENTER (HIV to Jinken Jouhou Center)

Introduction
The issues of “women and HIV/AIDS” are related to many things globally. Nowadays, over half of the people living with HIV are women, and the number of women living with HIV is increasing both in Japan and in the world. The background of the problem incorporates many kinds of social problems such as the sex industry, infection through gang rapes in places of conflict and refugee camps, IDU (injecting-drug users), sex workers, trafficking including children, street children, the secondary infection of children through their mothers, HIV/AIDS orphans and so on. Moreover, although treatment for HIV exists, in fact, only a few southern countries can use the treatments, since northern countries protect their rights of intellectual property. The HIV issue is concerned with North - South problems and the issue of poverty. This background means it is very difficult for women living with HIV to access medicine and treatment. These issues also exist in Japan because HIV/AIDS happens not only in foreign countries, but also in Japan.

Deliberate Discrimination against HIV/AIDS and Women
In Japan, the topic of HIV/AIDS started with “women.” Firstly, Japanese mass media drew attention to female immigrant workers from other Asian countries. This created the image that “foreigners are HIV/AIDS patients”1. Secondly, the mass media picked up on a Japanese woman, who was considered to be a sex worker in Kobe city, and the image that “women working in the sex industry are HIV/AIDS patients” also came to prevail in Japan2. In the case of the Japanese woman, there was a so-called

‘HIV/AIDS panic’ outburst; that is, the man who was close to the woman and the male participants at her funeral were hounded by the media because they were considered to be men who ‘had some relationship’ with the woman. Thirdly, the mass media reported that a woman living with HIV in Kochi prefecture became pregnant and a controversy about the likelihood of secondary infection from the woman to her child occurred afterwards. This woman’s past was also searched, and the fact that her ex-boyfriend was a hemophiliac was reported. The mass media emphasized that “the woman, who should give birth to a healthy baby, was infected via sexual intercourse with her ex-boyfriend, and then became pregnant and will possibly pass it on to her baby.” Like the above example, criticism of women’s sexual behaviors and enforcement of the value of women as being “the sex of giving birth” were widely promoted by the mass media.

Whenever HIV/AIDS issues are highlighted by the mass media, men’s viewpoints about women appeared, such as the “women’s fidelity” and “good wife and wise mother” myths; that is, women should defend chastity, have a mission to get married to their first boyfriend and give birth to a healthy baby, and should not engage with the sex industry (however, the men who go to such places show no sign of wrongfulness at all).

A certain media outlet wrote that: ‘A Japanese HIV female patient is on the verge of death, Kaposi’s sarcoma, the feared last stage of AIDS’ as the caption of the picture. However, the picture that the media used was a man living with HIV. In addition, the woman the media picked up on did not get Kaposi’s sarcoma. In fact, there are very few cases of a Japanese person infected with Kaposi’s sarcoma. It seems that the mass media invents a fiction to make people scared of HIV/AIDS on purpose. Concerning the public image of HIV/AIDS, many people have the idea that “AIDS is the disease that is contracted from sex workers easily”, but we should remember that it is possible for anyone who has sexual relations without a condom to contract HIV, whether they are a sex worker or not.

According to a report of the Ministry of Health and Welfare, the first HIV infected person in Japan was a homosexual male, but later we found out that the report was manipulated information. Before the report was announced, some people had already known the fact that several HIV infected hemophiliacs existed in Japan and some of them had already died. However, the mass media chose to report the research of the Ministry of Health and Welfare. As a result, the image that “HIV is a disease that only homosexual guys get” prevailed, and most men believed that HIV had nothing to do with themselves. However, when they found that women living with HIV exist, HIV became a threat to heterosexual men. Therefore, the
image that “women are the cause of HIV infection, men are the victims” was made. At the same time, the perception that HIV infection through the treatments of hemophilia is “good HIV” (because they are victims via HIV-infected blood products) and that HIV infection through sexual relationships is “bad HIV” was also created.

Excepting the Matsumoto, Kobe and Kochi “scandals,” the cases of men’s HIV infection were not seen as “scandals.” The discrimination against people living with HIV were conducted via several kinds of discrimination against women; for example, discrimination against sex workers, migrant workers (foreigners), sexual minorities, and sex-transmitted infections. Why were such types of discrimination against women enabled through the coverage of HIV/AIDS? The reason is that there are few women in the mass media and only news that is convenient for men is produced and broadcasted. It is social sexual harassment.

We have been insisting that HIV/AIDS issues are women’s human rights issues. But the male-centered mass media seldom picks up on our opinion for an article. The mass media creates the people’s fear via the headlines of articles, such as “the first woman HIV patient,” “the first Japanese woman HIV infection,” “the first HIV infected pregnant woman,” “the evil infection,” “the fatal disease”, “the husband of an HIV infected-pregnant woman,” “the HIV family,” “HIV children,” and so on. The mass media produced discrimination against women and HIV/AIDS through incorrect information. On the basis of such a background relating to HIV/AIDS, the AIDS Prevention Law was established. The law was focused on tracking down HIV-infected people and monitoring them. This kind of law can only reinforce the prejudice and stigma that people living with HIV are “the problem that is spreading HIV.”

I can’t forget a newspaper article that I read in London in 2001. There was a picture with the article, a woman with a smile wearing a nurse cap and red ribbon. The content of the article said: this woman living with HIV will work at a hospital as a nurse and both the hospital and society welcome her. In contrast to this, in Japan although the family members of the person who disclosed his HIV infection for the first time in Japan were not infected with HIV, they were laid off by their employers several times. When I read the article in London, I felt the huge difference between the social attitudes towards people living with HIV/AIDS in Japan and in the UK. That is, in Japan people have to suffer from layoffs just because they have a family member living with HIV/AIDS, while people living with HIV/AIDS themselves can work in UK because people know that people living with HIV/AIDS can work with no problem as
usual as others. The differences between two countries reflect the influence of the mass media very greatly. All institutions concerned with HIV/AIDS issues, including the mass media, should educate themselves with correct knowledge about HIV/AIDS.

**Lingering Social Discrimination against People Living with HIV/AIDS**

Our organization, JAPAN HIV CENTER, conducted a survey of local health centers from the late 1980s to 1990. In those days, not very many women went to health centers for HIV antibody checks, so women were treated differently than men as rare things. The health-center staff sometimes asked too many private questions and stared at them on the assumption that such women who came the health centers for HIV/AIDS tests must be sex workers.

During the same period, the AIDS Prevention Law was enacted in 1989. The law stipulated that when doctors diagnosed HIV infection, they had to report the diagnosis to prefectural governors, and in case that the HIV infected person did not follow the instructions of doctors or was likely to infect many people, doctors had to report to prefectural governors the name of the infected person, their sex, address and the reason for HIV infection. Under this law, prefectural governors have the right to access an individual’s information about HIV/AIDS status and forcibly hospitalize people with HIV/AIDS. Furthermore, the law could permit the authorities to monitor the private life of people living with HIV/AIDS, such as sexual partners.

Later, thanks to a campaign against the law, the New Law on Infectious Diseases (the Law Concerning the Prevention of Infectious Diseases and Patients with Infectious Diseases) was enacted in 1998. This law recognized “the patients” for the first time. Several laws for “prevention” of infectious diseases enacted before 1998 were to protect HIV-negative people. These laws excluded the patients, ignored their human rights, and were solely based on the perspective of an able-bodied person.

According to our survey, 52% of people living with HIV in Japan have not informed their family about their infection. The reasons are multifold: some people said that they are afraid that their family might feel a sense of discrimination against people living with HIV/AIDS; others said that not only themselves but also their family members might be discriminated against by society if they disclosed their infection. It seems that many people hold the perception that HIV/AIDS is a disease for sexually promiscuous people. When people come across someone living with HIV/AIDS, they tend to blame the sexual behavior of the infected person. Some parents, who have found out that their children have HIV from their partners, even went to the partners’ house to accuse them. Some people living with HIV/AIDS became homeless because their family could not accept the fact. We have a shelter for such cases.

In the case of men living with HIV/AIDS, they tend not to end up in divorce. On the other hand, some women living with HIV/AIDS are forced to get divorced. A women living with HIV/AIDS contacted us because her in-laws criticized her severely. Therefore, it takes more courage for women than men to inform their partners concerning HIV infection. Some husbands of wives with HIV/AIDS are afraid that they might get infected or misunderstand that they cannot have a baby anymore. Moreover, some of them cannot accept the fact that an ex-partner gave HIV to their wives. This is consistent with the message that Kochi incident showed above. Recently, there was a
case where a child was refused entry by his/her kindergarten because his/her mother was infected with HIV. The media placed emphasis on “mother.” If it were “father,” it would not be scandalous news.

At the Medical Scene

There is also a difficult environment on the medical scene for women living with HIV/AIDS. The ultimate inequality for women comes from the fact that diagnosis and treatment methods for women with opportunistic infections (i.e., infection by germs that would not affect a healthy person, but it is easy for a person with a low immune system to get infected with the germ) had not been established for a long time because there were very few women with HIV. There is a HIV diagnostic criteria. However, the criteria did not include a female-specific disease such as uterine cervical cancer until 1994. The dosage of HIV medicines used to be determined based on a man as a standard. Therefore, quite a few women were hospitalized because of side effects.

In addition, there are still only a few hospitals accepting women with HIV/AIDS for giving birth or having an abortion. Some hospitals refuse to see these women. We have had to go far away to find a hospital that accepts women with HIV/AIDS. There was a hospital where women were refused after they had HIV tests without the woman’s prior consent. When I gave a lecture about discrimination against women with HIV/AIDS at a training session for doctors and nurses, I asked them whether their hospitals accept pregnant women who are infected with HIV. Nobody answered my question by raising their hands.

Nowadays, it is not difficult for women with HIV to have a baby, and there is almost no risk of secondary infection from mother to baby. HIV is not hereditary and it is possible to remove the HIV virus in the plasma by anti-HIV medicines. Also, it is possible to prevent a baby contracting HIV infection in several ways, as follows: giving anti-virus medicines to the mother before delivery, choosing a C-section, cleaning the mucous immediately after the delivery, avoiding breast feeding, giving anti-virus medicine to a newborn, and so on. Using these measures, there has been no case of secondary infection from mother to baby in Japan in cases where the HIV positive status of the mother was known before the birth.

I think that it is not appropriate to differentiate “with HIV/AIDS” from “without HIV/AIDS.” We cannot distinguish scientifically between an infected person and a non-infected person. Although people who take an HIV antibody test can find out whether or not they are infected, it takes two...
or three months to find HIV antibodies after infection. Therefore, even if a person were diagnosed as HIV negative, it would just prove that they hadn’t been infected in the last 2 or 3 months. It could not certify that they were not currently infected. It is said that less than 1% of the Japanese people have had HIV antibody test so far. Even those who have taken the test are not aware of their status for the preceding two or three months. The only certain results are those who tested positive. Most people do not know whether they are HIV positive or negative. They also do not know about their partners. As a result, there might be a possibility that HIV is expanding widely and we just do not know it.

People tend to pay special attention to people with HIV/AIDS. However, as long as nobody knows for sure who is positive and who is negative, everybody is at risk of becoming infected if they have unprotected sex. That is, HIV/AIDS should be everybody’s concern. All of us were born as a result of sex and everyone is somehow connected to some sort of sexual activity. Why do people designate the HIV/AIDS issue as only for the people infected and discriminate against them? Although sexual activity requires a pair, lots of surveys and articles mention that only women are becoming sexually active or emphasize only women’s misbehavior, such as “young girls seeking sugar daddies.” The HIV/AIDS issue is pertinent to all people, who have a sexual partner regardless of whether it is a sugar daddy. However, the image is that only women are responsible for these issues. I believe that this is because discrimination against women is used to scapegoat women for widespread HIV.

A national hospital and our organization work together to conduct voluntary HIV-antibody tests for pregnant women along with counseling before and after the test. If the result is negative, we give them advice on how to stay negative, including safer sex education and encouraging their partners to have a test. When I made a presentation about our project’s successful outcomes, a nurse working at the hospital with specialized HIV/AIDS treatment said “It’s a great program. My hospital doesn’t have such a program.” Currently, these efforts are still only an exceptional case.

**HIV/AIDS is Everyone’s Issue**

Nowadays, the number of people with HIV has reached 40 million globally, that is, one in 150 people in the world are infected with HIV. Every year, 5 million people are infected HIV and 3 million are dying of AIDS. All of us live in the era of HIV/AIDS. We need to tackle not just singled-out HIV/AIDS issues, but also to fight comprehensively against various discrimination; such as discrimination against foreigners, women, and sexual “minorities.” We cannot solve the whole range of discriminations by eliminating just one of the issues above. In addition to confronting these types of discrimination, we need to take every opportunity to encourage people to gain a sense of empathy and to learn the importance of a tolerant society so we can see other people’s feelings and eliminate any form of discrimination.

A half of new HIV infected people in the world are less than 25 years old. The future population depends on this young generation. Recently, we have held a youth education program including how to use female condoms, how to respect women’s human rights and how to discuss issues with them. But criticism and backlash against HIV/AIDS education and sex education is growing both in Japan and in the world. The Bush administration’s policies influence this trend. The leading organizations for HIV/AIDS education face budget cuts from the US unless they promote abstinence-only
education. We are having difficulties both in sex education and HIV/AIDS education.

There are about 10 thousand people living with HIV in Japan. I have worked with about 1,000 people out of them until now. The living environments of the people with HIV are diverse including their family, workplaces, community, etc. It is important for them to have high quality of life. Non-governmental organizations support them to maintain the high quality. I hope that everyone thinks seriously about what we should do in order to coexist with people living with HIV/AIDS in our society, not only from the aspect of medical treatment, but also in society as a whole. I would like to see a society where everyone can consider the others' privacy and feel empathy for others.

In order to make visible our engagement with HIV/AIDS issues, we are promoting AIDS memorial quilts and a red-ribbon campaign. It is indeed important for the mass media as an opinion leader to report correct information. In terms of a social system, national and local governments should have practical policies by making laws and ordinances. The efforts will be multifold. In order to achieve the above, we should sincerely listen to the voices of the people living with HIV/AIDS and learn their realities. I hope that we will create a safe and diverse society where everyone can feel empathy for each other and live together.

( Interviewed and summarized by Shihoko Kato, Asia-Japan Women’s Resource Center )

Notes
1 Matsumoto incident: The media gave much attention to the fact that a Filipino woman was found HIV positive at a test and that she was working in the sex industry in Matsumoto-city, Nagano prefecture in 1986.
2 Kobe incident: The media reported on the first Japanese woman living with AIDS in Kobe-city, Hyogo prefecture in 1987
3 Kochi incident: The media reported that a woman living with HIV was pregnant and was going to give birth in Kochi prefecture in 1987.
4 Red ribbon: A symbol of the mourning of the dead by AIDS, understanding, and support to people living with HIV/AIDS.
5 JAPAN HIV CENTER: The first non-governmental organization in Japan working with HIV/AIDS issues established in 1988. Its mission includes: support of people living with HIV/AIDS regardless of how they were infected, counseling for people affected by HIV/AIDS, education for a society where everyone's life is respected and valued equally. There are eight offices in Japan and it is the only nationwide organization involved in HIV/AIDS issues.

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