Trends in HIV and AIDS based on HIV/AIDS surveillance data in Japan

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Background In recent years a decline in the number of new AIDS cases has been observed in several industrialized countries. It is important to know whether these recent trends observed in North America and Europe are also occurring in Japan.

Methods The number of people reported with HIV and AIDS by nationality, route of infection, and sex was calculated based on the HIV/AIDS surveillance data available in Japan through December 1997. The effect of reporting delay, which was defined as those HIV and AIDS cases reported in the calendar year following diagnosis, on the trends was examined. The coverage rate in reporting HIV cases was estimated as the ratio of the reported AIDS cases with prior report as an HIV-positive to the total number of reported AIDS cases.

Results The cumulative number of reported cases of HIV among Japanese and non-Japanese residents of Japan up to the end of 1997 were 1300 and 1190, respectively. The cumulative number of reported cases of AIDS among Japanese and non-Japanese up to the end of 1997 were 758 and 298, respectively. The number of reported cases of HIV among Japanese was found to be still increasing, with the major contribution from male cases. The increasing trend in the number of reported AIDS cases among Japanese began to slow in 1996 and 1997. The number of reported cases of HIV among non-Japanese residents of Japan peaked in 1992, and has decreased since then, and remained constant after 1994. In contrast, the number of reported AIDS cases among these non-Japanese tended to increase gradually. There was a slight reporting delay for people with HIV and AIDS. The estimated coverage rate in reporting HIV cases tended to decrease in 1996 and 1997 (1/7.2, 1/10.2, respectively). We point out several reasons for this recent decline and suggest the possibility of an ostensible decline in the estimates.

Conclusions We suggest that the number of people with HIV among Japanese has continued to increase, and that the increase in the number of AIDS cases among Japanese is now slowing.

Keywords HIV, AIDS, surveillance, trends in reported numbers, reporting delays, coverage rate

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In recent years, a decline in the number of new AIDS cases has been observed in some industrialized countries such as the US, Western Europe, Australia, and New Zealand,1–6 although it is not clear whether new HIV cases are consistently decreasing in all the areas mentioned.1,3,4 These trends have been attributed primarily to the effect of combination antiretroviral therapy including protease inhibitors.7–9 It is important to know whether these recent trends observed in North America and Europe are also occurring in Japan.

In many countries a surveillance system is used to estimate HIV/AIDS prevalence and incidence, and these have provided some of the most important data available for gauging the course of the epidemic and for identifying subgroups of the population at high risk.1–3,5 In Japan, HIV/AIDS surveillance has been fully operative since 1984 and several studies have been conducted to facilitate the interpretation and understanding of the surveillance data.12–15 Hashimoto et al.12 predicted the future trends in people with HIV and AIDS based on HIV/AIDS surveillance data in Japan through 1992 and discussed the estimation of the coverage rate in reporting people with HIV. In Japan both HIV and AIDS cases have been monitored since 1989. Some HIV cases have never undergone HIV testing and so the rate of HIV infection is possibly underreported. Therefore, it is important to estimate what percentage of people with HIV would be monitored by the HIV/AIDS surveillance (coverage rate of HIV cases). In Japan the prevalence of HIV/AIDS surveillance (coverage rate of HIV cases).12,14 This procedure has been considered to provide the best estimate for the prevalence of HIV in Japan where the number of AIDS cases is too small for precise estimation by back-calculation method. Hashimoto et al.14,15 further examined the trends in the number of reported cases of HIV and AIDS based on HIV/AIDS surveillance data through 1994 and discussed some problems involved in the estimation of the number of people with HIV and AIDS, including the issue of the reporting delay which is the time lag from diagnosis of HIV or AIDS up until when the case is reported to the surveillance system.

In this study, we investigate the recent trends in the number of reported cases of HIV and AIDS based on HIV/AIDS surveillance data available in Japan through December 1997. The effect of reporting delay on the trends is examined and the coverage rate in reporting people with HIV is also estimated.

Materials and Methods

HIV/AIDS surveillance in Japan

The surveillance of AIDS in Japan was started in 1984 and was legalized through the implementation of the ‘Act of AIDS Prevention’ in 1989.10,11 Both AIDS and HIV infections are notifiable conditions and must be reported by the diagnosing physician within 7 days through Prefecture/Municipal City Health Authorities to the AIDS and Specific Disease Control Division, Health Service Bureau, Ministry of Health and Welfare. For surveillance two types of notification forms were established: one (First Report) is used when the physician has identified an HIV-positive case or AIDS case for the first time, and the other (Second Report) is used when the physician has recognized a change in the pathological status of the cases he has followed from HIV positive to AIDS or from AIDS to death.

Both reports are examined and approved every 2 months by the AIDS Surveillance Committee, Ministry of Health and Welfare. Cases infected through blood-derived coagulation factor products are not reported, as defined by the ‘Act of AIDS Prevention’.

An AIDS notification must indicate the distinction between HIV positivity and AIDS, nationality, route of infection, sex, age at diagnosis, suspected place of infection (in Japan/abroad), place of residence, and the date of first HIV or AIDS diagnosis and reporting. The format of the Second Report is the same as the First Report except for any additional items needed to describe the change occurring in the case and its date. Neither report includes such information as name, address, and date of birth that could lead to personal identification.

Trends in the number of reported cases of HIV and AIDS

The number of people reported with HIV and AIDS by nationality, route of infection, and sex was calculated based on HIV/AIDS surveillance data in Japan through December 1997. The route of infection was divided into four categories: heterosexual (male/female), men who have sex with men (MSM) including bisexual contact (male), other routes, and risk not reported or identified (male/female). The third category includes injecting drug use, mother-to-child infection, blood transfusion, tissue or organ transplantation from HIV-infected donors, and cases that have more than one probable route of infection (e.g. MSM case with reported history of injecting drug use). The risk not reported or identified involves people with no reported history of exposure to HIV, including people whose exposure history is incomplete because of death, refusal of interview, or loss to follow-up.

Reported numbers of cases from 1993 through 1997 were examined every 2 months in order to investigate the recent trends in detail. All analyses were done based on the calendar year of diagnosis.

Reporting delays

A reporting delay is the time lag from diagnosis of HIV or AIDS until the case is reported to the surveillance system. This is one of the important indexes representing the quality of the HIV/AIDS surveillance data.16,17 For subsequent analyses, delayed reporting was defined as those HIV and AIDS cases reported in the calendar year following diagnosis. The proportion of reporting within the same calendar year of diagnosis was calculated by the year of diagnosis in order to examine the effects of reporting delays on the trends.

Estimation of the coverage rate

Most HIV cases are asymptomatic for a rather long time until the onset of AIDS and they recognize their infection for the first time when they undergo HIV testing. Few cases diagnosed as HIV positive have not been reported to the AIDS surveillance system in Japan.12 The rate of HIV infection is, however, possibly underreported, because some HIV cases have never undergone HIV testing.12,14 Therefore, it is important to estimate what percentage of people with HIV would be monitored by the HIV/AIDS surveillance (coverage rate of HIV cases).12,14
The coverage rate of HIV cases was defined as the ratio of the reported AIDS cases with prior report as an HIV positive to the total number of reported AIDS cases.\textsuperscript{12} Cases whose report of HIV infection and Second Report were obtained at the same time (date of reporting), were excluded from the numerator of this estimation. This proportion has been of vital importance in the estimation and projection of HIV prevalence in Japan,\textsuperscript{12,14,15} since the prevalence of people with HIV has been estimated by multiplying the number of reported HIV cases by the reciprocal of this proportion on the assumption that AIDS cases were completely reported without duplication and that the incidence rate of AIDS is the same between the HIV positives with and without notification.

### Results

#### Analysis of trends in the number of reported cases of HIV and AIDS

Table 1 shows the annual trends in the number of people reported with HIV and AIDS by nationality, route of infection, sex. and the cumulative reported numbers of HIV among Japanese and non-Japanese residents of Japan up to the end of 1997 were 1300 and 1190, respectively. The cumulative reported numbers of AIDS among Japanese and non-Japanese residents of Japan up to the end of 1997 were 758 and 298, respectively. In HIV cases, Japanese males outnumbered Japanese females (heterosexual, MSM, and risk not reported cases), whereas non-Japanese females in Japan outnumbered their male counterparts (heterosexual and risk not reported cases). In HIV cases, the reported numbers among Japanese exceeded those of non-Japanese living in Japan after 1994. The AIDS cases among Japanese males outnumbered those of females (heterosexual, MSM, and risk not reported cases), while non-Japanese with AIDS were about one-third those found among Japanese.

Figure 1 shows the bimonthly recent trends in the reported numbers of cases from 1993 through 1997. The reported numbers of HIV cases among Japanese continued to increase, and in particular, the numbers in 1996 and 1997 seemed to increase rapidly. In contrast, the increase in the reported numbers of AIDS cases among Japanese began to slow in 1996 and 1997.

### Table 1: Annual trends in the number of people reported with HIV and AIDS by nationality, route of infection, and sex

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\textsuperscript{a} Men who have sex with men including bisexual contact.

\textsuperscript{b} People with no reported history of exposure to HIV, including those whose exposure history is incomplete because of death, refusal of interview, or lost to follow-up.
although reporting delays affect this decline as will be examined later. The reported numbers of HIV cases among non-Japanese in Japan tended to remain constant after 1994, whereas the AIDS cases reported among them tended to increase gradually.

**Reporting delays**

Table 2 shows the reporting delays for people with HIV and AIDS by calendar year of diagnosis. The proportion of reporting within the same calendar year of diagnosis for people with HIV was around 95% both among Japanese and non-Japanese. It was around 80–90% among Japanese AIDS cases, against 90% or more among non-Japanese AIDS cases.

Table 2 also shows the reporting delays for AIDS cases among Japanese based on the information in the Report form. The reporting rate within the same calendar year of diagnosis for the Second Report was only around 50%, while that for the First Report was more than 90% after 1992.

**Estimated coverage rate**

Table 3 shows the annual change in estimates of the coverage rate in reporting HIV cases. The coverage rate in reporting HIV cases among Japanese was estimated to be almost the same in 1994 and in 1995 (1/5.4, 1/5.7), although it had fluctuated before 1994. In 1996 and 1997 it decreased rapidly (1/7.2, 1/10.2). The total coverage rate in reporting cases among non-Japanese was estimated at 1/13.7.

**Discussion**

We investigated the recent trends in the number of people reported with HIV and AIDS based on the HIV/AIDS surveillance data available in Japan through December 1997. The number of reported HIV cases among Japanese was found to be still increasing, with the major contribution from male cases (heterosexual, MSM, and risk not reported cases). In particular, the numbers in 1996 and 1997 seemed to increase rapidly, although this increase was not so sharp as the rise observed among non-Japanese HIV cases in 1992. It is important to continue to monitor carefully this increasing trend and the beginning of a downward trend in Japan.

In contrast, the increasing trend in the number of reported AIDS cases among Japanese began to slow in 1996 and 1997. Although this trend could be attributed to the effect of treatment for HIV cases, there were some reporting delays.

The number of reported HIV cases among non-Japanese, in particular females (heterosexual and risk not reported cases), peaked in 1992, decreased for the following 3 years, and has been constant after 1994. In contrast, the reported numbers of AIDS cases among non-Japanese has tended to increase gradually. This difference in trends between HIV and AIDS cases among non-Japanese is controversial. It might be that even if the number of people with HIV was constant, the number of incident AIDS cases would increase in proportion to the increase in cases that were diagnosed as HIV a long time ago.

We defined delayed reporting as those HIV and AIDS cases reported in the calendar year following diagnosis. This definition of reporting delays may seem problematic. For example, a person diagnosed in January of a given year and reported in December of that same year would not be considered a delay. However, a person diagnosed in December of a given year and reported in the following month would represent a reporting delay. A more traditional approach would be to look at the proportion of cases reported within some time (e.g. 6 months) of diagnosis, or to treat time from diagnosis to report as a continuous variable and report median, quartiles, etc. Although we were aware of this problem, the definition of reporting delays we used is in accordance with the HIV/AIDS surveillance report in Japan.
The proportion of people with HIV whose reporting year was within the same calendar year of diagnosis was around 95% both among Japanese and non-Japanese. It was 90% or more for AIDS cases among the latter. There appeared to be only a slight reporting delay for these cases.14 In contrast, a substantial reporting delay was noted for Japanese AIDS cases. This was due to the delays in the Second Report, which registers the change in the pathological status of people with HIV or AIDS already recorded in the First Report (Table 2). Judging from these substantial delays in the Second Report, we could see that physicians do not feel particularly obliged to report AIDS incident cases that have already been reported as HIV cases. Another possibility exists for these delays in the Second Report. In case of death from AIDS, physicians will certainly report the pathological change of the case. The Second Report on pathological change from HIV to AIDS may be considerably delayed if reported together with the death report (the Second Report on pathological change from AIDS to death). If this occurs, there would be a substantial reporting delay in the Second Report on pathological change from HIV to AIDS.
Fourth, there are differences in the latent period of people with HIV and AIDS cases in the First Report. Third, there is repeated reporting among Japanese tended to rapidly decline in 1996 and 1997. The final problem in reporting HIV is that patients changes rate patients changes rate patients changes rate patients changes rate not be recorded in the Second Report. The estimated coverage rate seems to represent the previous coverage rate because of the long latent period from the infection to the onset of AIDS. Second, new AIDS cases that have already been reported as HIV positive in the First Report might not be recorded in the Second Report if they visited different medical institutions after the report of HIV infection. Third, many non-Japanese HIV cases return home after the diagnosis of HIV in Japan and subsequently develop AIDS in their own countries. Thus, many new non-Japanese AIDS cases that have already been reported as HIV positive in the First Report might not be recorded in the Second Report if they visited different medical institutions after the report of HIV infection.

As for the second reason, Table 4 shows the annual change of estimates in the coverage rate by year of surveillance data. The estimates of the coverage rate in reporting HIV cases among Japanese tended to rapidly decline in 1996 and 1997. Several reasons should be considered for this recent decline. First, the coverage rate in reporting HIV is truly decreasing. Second, there are delays in reporting AIDS cases that have already been reported as HIV positive in the First Report and then developed AIDS or died. Third, there is repeated reporting of the same people as HIV and AIDS cases in the First Report. Fourth, there are differences in the latent period of people with HIV between those medically treated or not. It does not seem reasonable to conclude that the true coverage rate in reporting HIV is decreasing considering the three other reasons mentioned above.

As for the second reason, Table 4 shows the annual change of estimates in the coverage rate by year of surveillance data. The estimates of the coverage rate increased with each passing year of surveillance. For example, the coverage rate in 1994 based on the surveillance data through the end of 1996 and 1997, respectively, were both estimated at 1/5.4, while it had been estimated at 1/7.6 based on the surveillance data through the end of 1994. If such a phenomenon is emerging, we can say that the estimated coverage rates in 1996 and 1997, which were shown in Table 3, will increase in the near future.

It seems reasonable to suppose that there is an effect of repeated reporting of the same people in the First Report on the estimates of the coverage rate (the third reason). For example, if new AIDS cases that have already been reported as HIV positive in the first HIV infection report, visit different institutions (physician), the physicians are apt to mistake such AIDS cases for the first AIDS report cases and will notify using the First Report form. These new AIDS cases should be essentially reported as cases of pathological change from HIV to AIDS in the Second Report. Thus, the estimated coverage rate would be underestimated due to the decrease of the numerator (the reported AIDS cases with prior report as an HIV positive) and the increase of the denominator (the total reported AIDS cases). Even if there is duplicate reporting of the same person as an HIV and AIDS case in the First Report, one can not exclude those people simply because of the absence of the information in the surveillance data that could identify individuals. This is one of the defects in the HIV/AIDS surveillance system in Japan. We can estimate the proportion of such duplications if some individual information like date of birth is added to the present surveillance report form in the future.

As for the final reason, highly active antiretroviral therapy has been widely available in Japan since 1996. Thus, the estimated coverage rate, which is based on the ratio of the reported AIDS cases with prior report as an HIV-positive to the total number of reported AIDS cases, may be less than the true rate. This is due to the possible violation for the assumption that the incidence rates of AIDS are the same between the HIV positives with and without notification. For example, suppose there are 5000 HIV cases (1000 treated [reported] people and 4000 untreated [unreported] people). In this situation, the true coverage rate is 1/5. Suppose that the incidence rates of AIDS between treated and untreated people with HIV are identical, and that there are 170 AIDS cases. In this scenario, 34 AIDS cases are reported from the treated HIV cases and 136 AIDS cases are newly reported from the untreated HIV cases (estimated coverage rate is 1/5). On the other hand, if we assume there is a 20% decrease in the incidence rate of AIDS for treated as compared with untreated cases, the estimated coverage rate decreases to 1/6 (= 27.2/[27.2 + 136]). Since the decline of the AIDS incidence rate for the reported HIV cases may be estimated through the effectiveness of the treatment and the proportion of treated people, we can adjust for the underestimation of the true coverage rate, if such information is available.

Table 4 Annual change in the estimated coverage rate in reporting HIV cases by year of surveillance data

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<td>1/5.4</td>
</tr>
<tr>
<td>No. of patients</td>
<td>1997 year-end</td>
<td>97</td>
<td>18</td>
<td>1/5.4</td>
</tr>
</tbody>
</table>

Note: Not available.
Therefore, there may well be an ostensible decline in the estimated coverage rate even if the true coverage rate is unchanged. It is important to obtain more information and to examine this problem in detail.

In this study, we investigated recent trends in the number of people with HIV and AIDS based on the HIV/AIDS surveillance data in Japan through December 1997. It is suggested that the number of Japanese HIV cases including unreported ones has continued to increase, and that the increasing trend in the number of AIDS cases among Japanese has slowed.

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