Delays and Continuation of Hospital Visits Among HIV-Infected Persons and AIDS Cases in Japan

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This study attempts to clarify the distribution patterns of delay between HIV transmission and the first hospital visit among HIV-infected persons and AIDS cases in Japan except those infected through blood products. Such hospital visit patterns were analyzed, and the rates of reporting for HIV/AIDS surveillance among diagnosed HIV-infected persons and AIDS cases in hospitals were shown. From 1991 to 1997, a survey and subsequent follow-up were conducted among HIV-infected persons and AIDS cases diagnosed at 74 hospitals in Tokyo. The numbers of HIV-infected persons and AIDS cases were 590 and 208, respectively. The percentage of patients whose estimated date of HIV transmission was obtained ranged 23-41% among Japanese and non-Japanese HIV-infected persons and AIDS cases. Among these patients, 28% to 86% showed a 3-year delay between HIV transmission and their first hospital visit. The rate of HIV-infected persons who continued to visit hospitals within 1 year after their first visit was 77% for Japanese and 45% for non-Japanese; among those after 1 year or more following their first hospital visit the rate was more than 80% among Japanese and over 70% among non-Japanese. The rate of reporting to HIV/AIDS surveillance among diagnosed HIV-infected persons and AIDS cases was 90% or more after 1994 in Japan. The delay between HIV transmission and the first hospital visit was suggested to be very long. Not a few patients stopped visiting hospitals after only a short time. Most diagnosed HIV-infected persons and AIDS cases were reported to the surveillance system of Japan. *J Epidemiol*, 2000 ; 10 : 65-70

HIV, AIDS, delay of hospital visits, continuation of hospital visits, surveillance

HIV/AIDS has a profound impact on the health of peoples worldwide. WHO reported that the cumulative number of AIDS cases was more than 1.8 million by the end of 1997, and that the number of HIV-infected persons was estimated to be more than 30 million^{1,2}. In Japan, according to the report on HIV/AIDS surveillance by the Ministry of Health and Welfare

of Japan^{3,4}, the numbers of HIV-infected persons and AIDS cases, excluding those infected through blood coagulation factor products, were reported to be 2490 and 1056, respectively, by the end of 1997.

Most HIV-infected persons have no specific symptoms for a long time after HIV transmission. The delay between HIV

Received March 10, 1999; accepted May 26, 1999.

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transmission and diagnosis of HIV infection may be very long^{2,5,6)}. Reducing this delay is important for the treatment of HIV-infected persons and for preventing the further transmission of HIV^{7,8)}. However, to study the delay between HIV transmission and diagnosis of HIV infection is very difficult because of uncertainty regarding the date of HIV transmission⁹⁾. After the diagnosis of HIV infection, for HIV-infected persons and AIDS cases, continuation of hospital visits is necessary for their treatment. The continuation status of hospital visits among these patients has not been sufficiently investigated^{8,10)}.

The most important information source for HIV and AIDS trends is HIV/AIDS surveillance. Among the most critical problems of HIV/AIDS surveillance is the low coverage rate^{3,11-13)}. At the very least, the surveillance must have high reporting rates among the diagnosed HIV-infected persons and AIDS cases¹³⁾. The rate reported to AIDS surveillance in the US was 92%¹⁴⁾, and the reporting rate of diagnosed HIV-infection in one State was more than 75%¹⁵⁾. These rates have not been established in Japan yet¹⁶⁾.

This study attempts to clarify the distribution patterns of delay between HIV transmission and the first hospital visit among HIV-infected persons and AIDS cases in Japan except those infected through blood products. Such hospital visit patterns were analyzed, and the rates of reporting for HIV/AIDS surveillance among diagnosed HIV-infected persons and AIDS cases in hospitals were shown.

MATERIALS AND METHODS

The survey and subsequent follow-up for the indicated HIV-infected persons and AIDS cases diagnosed at 74 selected hospitals in Tokyo were conducted during 1991-1997. The patients diagnosed in 1991 and before were registered in the year 1991, and the patients diagnosed from 1992 to 1997 were registered annually. Information on the patients obtained by physicians from the registration included hospital name, patient number (coded by each hospital), the date and diagnostic status (HIV or AIDS) of the first visit to the hospital, refer-

als by other hospitals, nationality, sex, date of birth, source of exposure to HIV infection, estimated date of HIV infection based on patient recall, and reporting to the HIV/AIDS surveillance of the Ministry of Health and Welfare, Japan. In the subsequent follow-up, information on patients included current status (alive or dead), record of visiting the hospital and reasons for discontinuing visits (move to another hospital, departure from Japan or unknown reasons). Among patients who moved to other hospitals that were also included in this survey, their hospital visits were assumed to continue.

The number of patients registered was shown in Table 1. HIV-infected persons included 429 Japanese and 161 non-Japanese. AIDS cases included 147 Japanese and 61 non-Japanese. Transmission routes of HIV among Japanese and non-Japanese HIV-infected persons and AIDS cases were comprised of homosexual/bisexual contacts 31-60%, heterosexual contacts 26-54%, and other and unknown routes 10-26%.

For patients whose estimated date of HIV transmission was obtained, distribution patterns of the delay between HIV transmission and the first hospital visit were calculated. These distribution patterns were also calculated for patients not referred by other hospitals because such patients would have thus visited these other hospitals before making their first visit to ours. The continuation rates of visiting hospitals each year after the first hospital visit, and the reasons for discontinuing the visits were analyzed. The rates of reporting to HIV/AIDS surveillance were calculated. These analyses were conducted for Japanese and non-Japanese nationalities because there would be differences in medical care use between these 2 groups.

RESULTS

Delay between HIV transmission and the first hospital visit

The analysis of patients whose estimated date of HIV transmission was obtained was shown in Table 2. HIV-infected persons were 41% Japanese and 29% non-Japanese, while AIDS cases were 24% Japanese and 23% non-Japanese. There were

Table 1. Number of subjects.

Transmission routes of HIV		Japanese	Non-Japanese
HIV-infected persons	Homosexual/bisexual contacts	211 (49.2)	50 (31.1)
	Heterosexual contacts	176 (41.0)	87 (54.0)
	Other and unknown routes	42 (9.8)	24 (14.9)
	Total	429 (100)	161 (100)
AIDS cases	Homosexual/bisexual contacts	88 (59.9)	19 (31.1)
	Heterosexual contacts	38 (25.9)	26 (42.6)
	Other and unknown routes	21 (14.3)	16 (26.2)
	Total	147 (100)	61 (100)

small differences in the rates between patients with and without referral by other hospitals.

Distribution patterns of the delay between HIV transmission and the first hospital visit were shown in Figure 1. Among Japanese HIV-infected persons, such delay patterns were 36% in less than 1 year, 25% in 1-2 years, 9% in 2-3 years, and 28% in more than 3 years. Patients with delays of more than 3 years were 69% in Japanese AIDS cases, 37% in non-Japanese HIV-infected persons, and 86% in non-Japanese AIDS cases. There were small differences in the delay between patients with and without referral by other hospitals.

Continuation of hospital visits

The numbers of Japanese HIV-infected persons observed were 429 at the first hospital visit, 263 after 1 year, 187 after 2 years, and 125 after 3 years. The numbers of non-Japanese HIV-infected persons observed were 161 at the first visit, 56 after 1 year, 34 after 2 years, and 18 after 3 years.

The continuation status of visiting hospitals among HIV-infected persons each year after the first visit was shown in Figure 2. Among Japanese HIV-infected persons, 77% continued to visit hospitals within 1 year after their first visit. Other developments included death 2%, move to other hospitals 7%, departure from Japan 1%, and unknown reasons for discontinuing visits 14%. After 1 year or more following the first hospital visit, more than 80% of the patients continued to visit the hospitals. The mortality rate of patients increased with the years after the first visit. Inversely, there was an annual decrease in the percentage of patients whose reasons for discontinuing the visits were unknown.

Among non-Japanese HIV-infected persons, 45% continued to visit the hospitals within 1 year after their first visit. Other developments included death 1%, move to other hospitals 8%, departure from Japan 23%, and unknown reasons for discon-

tinuing visits 24%. After 1 year or more following the first hospital visit, more than 70% of the patients continued to visit the hospital. The percentage of patients who departed Japan after 1 year or more following the first visit was as high as among those who departed Japan within the first year. The percentage of the patients whose reasons for discontinuing the visits were unknown after 1 year or more following the first visit, was lower than among those who stopped within the first year.

Reporting to HIV/AIDS surveillance

Rates of reporting to HIV/AIDS surveillance among diagnosed HIV-infected persons and AIDS cases were shown in Table 3. The reporting rates among HIV-infected persons were 91% among Japanese and 84% among non-Japanese, and those for AIDS cases were 90% among Japanese and 84% among non-Japanese.

Rates of reporting to HIV/AIDS surveillance each year after the first hospital visit were shown in Figure 3. The reporting rates among both HIV-infected persons and AIDS cases increased for both Japanese and non-Japanese, reaching 90% or more after 1994.

DISCUSSION

Our study subjects were HIV-infected persons and AIDS cases diagnosed at 74 selected hospitals in Tokyo up to the end of 1997. Institutions surveyed included leading hospitals for the treatment of HIV infection and AIDS in Tokyo. The numbers of HIV-infected persons reported to the HIV/AIDS surveillance of Japan by the end of 1997 were 1300 Japanese and 1190 non-Japanese³⁾, while AIDS cases numbered 758 Japanese and 298 non-Japanese. Although the numbers of our subjects in Table 1 did not strictly coincide with these figures, we considered that our subjects included the majority of HIV-

Table 2. Proportions of patients whose estimated dates of HIV transmission were obtained.

			Date of HIV transmission		Total
			obtained	not obtained	
All patients	HIV-infected persons	Japanese	176 (41.0)	253 (59.0)	429 (100)
		Non-Japanese	46 (28.6)	115 (71.4)	161 (100)
	AIDS cases	Japanese	36 (23.8)	112 (76.2)	147 (100)
		Non-Japanese	14 (23.0)	47 (77.0)	61 (100)
Patients without referral by other hospitals	HIV-infected persons	Japanese	118 (49.0)	123 (51.0)	241 (100)
		Non-Japanese	38 (33.3)	76 (66.7)	114 (100)
	AIDS cases	Japanese	26 (34.7)	49 (65.3)	75 (100)
		Non-Japanese	11 (25.6)	32 (74.4)	43 (100)

Figure 1. Distribution pattern of the delay between HIV transmission and the first hospital visit.

Figure 2. Continuation status of visiting hospitals among HIV-infected persons by the year after the first visit.

Table 3. Rates of reporting to HIV/AIDS surveillance.

	Nationality	To HIV/AIDS surveillance			Total
		reported	not reported	unknown	
HIV-infected persons	Japanese	392 (91.4)	9 (2.1)	28 (6.5)	429 (100)
	Non-Japanese	135 (83.9)	7 (4.3)	19 (11.8)	161 (100)
AIDS cases	Japanese	132 (89.8)	7 (4.8)	8 (5.4)	147 (100)
	Non-Japanese	51 (83.6)	5 (8.2)	5 (8.2)	61 (100)

Figure 3. Rates of reporting to HIV/AIDS surveillance.

infected persons and AIDS cases diagnosed in Tokyo.

Patients who delayed more than 3 years between HIV transmission and their first hospital visit accounted for 28-86% (calculated from patients whose estimated dates of HIV transmission were obtained), and they were 24-41% of all patients. Our data supported the idea that the delay was so long that promoting voluntary HIV testing and counseling for HIV-infected persons had become more necessary^{2,5,6}.

HIV-infected persons who discontinued hospital visits except for reasons of death, movement to other hospitals or departure from Japan, were 14-24% within 1 year after the first

visit, and decreased each year. A previous study reported that a follow-up loss among HIV-infected persons who presented themselves for care at a hospital in the US was 14% over 1.6 years¹⁰. The reason for this discrepancy in continuation of hospital visits is unknown, although patients who received no follow-up care were included in our study and were excluded in the above-mentioned study. Several studies reported that seeking medical care among HIV-infected persons and AIDS cases was associated with some factors including race, sex and drug use^{10,11}. In our study, the proportion of patients who discontinued hospital visits among non-Japanese HIV-infected persons

was higher than among Japanese cases. These findings suggested that not a few patients soon stopped visiting hospitals, and that it was important to investigate the reasons in detail.

The rate of reporting to the HIV/AIDS surveillance of Japan among diagnosed HIV-infected persons and AIDS cases reached more than 90% after 1994. Although the reporting was not complete, we considered the rates high enough to demonstrate a trend in HIV infection and AIDS^{14,15}. However, the coverage rates among all HIV-infected persons including cases not diagnosed would not be high because the delay between HIV transmission and the first hospital visit was very long^{2,12,13}. It is important to estimate and improve the coverage rates.

A major limitation in our study is the uncertainty of information, including estimated dates of HIV transmission and reasons for stopping hospital visits. Information on the estimated date of HIV transmission was obtained through interviews by physicians. If HIV transmissions originate from experiences such as blood transfusion and travel abroad, HIV-infected persons and AIDS cases might recall their estimated date of HIV transmission. In Japan, HIV transmissions through blood transfusions have been few because 100% of blood bags were screened for HIV after 1986^{3,4}. HIV transmissions in foreign countries among Japanese HIV-infected persons and AIDS cases were reported to be 19% or more³. Although we failed to confirm the distribution patterns of delay between HIV transmission and the first hospital visit, it became clear that the delay was very long. Data on whether patients continued or discontinued their hospital visits were quite reliable, but the reasons for stopping the visits (e.g., departure from Japan or switching hospitals) were not so reliable because information was obtained from physician interviews. Although the distribution patterns of visiting hospitals may be biased, the suggestion that not a few patients soon discontinued their hospital visits may be valid. The information on reporting to HIV/AIDS surveillance was not confirmed by the surveillance data because the information did not include a patient's name and address, so individuals could not be identified³. Although the rates of reporting to surveillance were not completely accurate, the general finding of high reporting rates would not be significantly affected.

ACKNOWLEDGEMENTS

This study was supported by a Grant-in-Aid from the Ministry of Health and Welfare, Japan for Research on HIV/AIDS.

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