distribution was not evaluated in these two countries. Regarding HIV infection, only 6 countries/regions were used in these comparisons because HIV surveillance was not conducted in France or throughout Spain and Italy where information on sex, age, and route of infection was unavailable.

The definition of an AIDS case was the presence of indicator diseases such as *Pneumocystis carinii* pneumonia, pulmonary tuberculosis, or oesophageal candidiasis, as well as a positive HIV test. Although in 1993, the case definition was expanded in the USA to include HIV-infected persons with CD4+ T-lymphocyte counts less than 200 per μl or a CD4+ percentage less than 14, the other criteria were essentially the same between all countries/regions and Japan.

Route of infection was divided into six categories : heterosexual contact (male), heterosexual contact (female), men who have sex with men (MSM), including bisexual contact, injecting drug use (IDU), other routes, and risk not reported or identified. The category of "other routes" comprises 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 with a reported history of IDU). Infection through hemophilia/coagulation disorder was excluded from the investigation. "Risk not reported or identified" includes those with no reported history of HIV exposure, including people whose exposure history is incomplete because of death, refusal of interview, or inability to follow-up. It should be noted that, in all countries except Japan, this category also includes those cases in which the route of infection is under investigation.

Comparisons of the increasing trends at the onset of the epidemic in each country were conducted using data on AIDS cases reported in the Epidemiological Facts Sheets[21] organized by the UNAIDS/WHO (United Nations Programme on AIDS/World Health Organization) Working Group on Global HIV/AIDS and STI Surveillance. Since the onset of the epidemic, the annual trends in the number of people reported with AIDS are shown for 10 countries, including Japan, while the trends according to the route of infection are shown for 5 countries where information on exposure categories was available.

Results

Table 1 and Table 2 show the annual trends in the reported number of people with AIDS and HIV, respectively, in each country. Figure 1 shows a semi-logarithm plot of the reported cases per 1,000,000 individuals. The reported number of AIDS cases peaked in the USA and Canada in 1993, in the EU, Australia, UK, Germany, Spain, and France in 1994, and in Italy in 1995, and decreased thereafter. In contrast, the reported number in Japan continued to exponentially increase even after 1993.

Table 3 shows the cumulative number of AIDS and HIV cases according to sex and age up until 2001. In Japan, the proportion of people reported with AIDS and HIV aged 40 years or older was 64.4% and 35.0%, respectively. In other industrialized countries, these percentages were, at the most, 41.9% and 25.7%, respectively.

Table 4 shows the total number of cumulative AIDS and HIV cases according to the route of infection up until 2001. In Japan, the proportion of males infected through heterosexual contact was extremely high (42.4%) compared to other industrialized countries. The ratio of males and females who contracted HIV as a result of heterosexual contact was extremely imbalanced in Japan (8.5 : 1). The proportion of AIDS cases whose risk was not reported was extremely high (20.9%) in Japan.

Figure 2 shows the increasing trend in reported AIDS cases at the onset of the epidemic in each country. The trend in Japan was extremely slow compared to other industrialized countries. Figure 3 shows the trends according to the route of infection in the countries in which this data was available. The increasing trend was again slow in Japan. There were apparent differences in the reported cases infected through MSM (including bisexual contact) and IDU.

Discussion

Analysis of surveillance data

This study was based on the reported number of people with HIV and AIDS obtained from annual reports of HIV/AIDS surveillance and Epidemiological Fact Sheets from each country. The problems that must be considered in the analysis of the surveillance data are the completeness of coverage, reporting delays, and duplicate reports.

The coverage rate of AIDS cases will be high because AIDS cases have specific symptoms and tend to make more use of medical facilities. In Japan, the reported rate of AIDS diagnosis in the HIV/AIDS surveillance was more than 90%[22]. This rate was about 85% in the USA[1], 95% in

Canada[3], 90% in Australia[4], 80% in the UK[16] and 85% in Germany[17]. On the other hand, HIV infection data should be interpreted more cautiously. HIV surveillance reports might not be representative of all individuals infected with HIV, because most HIV-infected individuals have no specific symptoms for a long time after HIV transmission, and not all infected individuals have been tested, hence identified. Particular care should be taken when interpreting the annual trends in reported HIV cases (Table 2 and Figure 1 (b)).

Reporting delays refer to the time between diagnosis of HIV infection or AIDS and the reporting of those events to the surveillance system. Reporting delays might vary according to exposure, geography, age, and sex, and might constitute several years for some AIDS cases. In Japan, about 95% of Japanese HIV cases and 85% of Japanese AIDS cases were reported to the surveillance system within 1 year of diagnosis[11]. In the USA, the proportions were about 93% and 88%, respectively[1], while overall in the EU about 90% of the diagnosed AIDS cases were reported within 1 year[2]. Considering the effects of these reporting delays, recent trends in the number of reported AIDS cases should be assessed by analyzing the data according to the year of diagnosis rather than the year when reported. In this study, the analyses were performed based on the year of diagnosis, except in a few countries in which the year when reported was used. However, the effect of using the year when reported on the recent

Table 1 Annual trends in the number of people reported with AIDS by country and sex.

Country	Sex	Calendar year of diagnosis																	Total
		85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	
Japan[a]	Male	5	3	6	9	15	18	24	36	53	91	108	156	170	158	212	239	221	1,524
	Female	0	0	3	2	2	3	0	1	5	9	11	15	12	10	12	21	24	130
Total		5	3	9	11	17	21	24	37	58	100	119	171	182	168	224	260	245	1,654
USA		23,205[b]	19,404	29,105	36,126	43,499	49,546	60,573	79,657	79,879	73,086	69,984	61,124	49,379	41,829	38,811	36,087	24,855	816,149
EU[c]		—	—	—	—	—	—	—	21,380	23,256	26,605	25,980	22,769	16,036	12,853	11,788	11,075	9,890	255,621[d]
Canada	Male				7,273[f]				1,604	1,634	1,595	1,451	939	597	517	376	349	184	16,519
	Female				471[f]				120	125	149	141	137	107	95	76	45	35	1,501
Total[e]		646[b]	628	950	1,162	1,377	1,430	1,551	1,724	1,759	1,745	1,593	1,076	705	612	453	394	221	18,026
Australia	Male					4,065[g]				799	905	771	636	350	296	166	214	127	8,329
	Female					152[g]				46	49	38	33	31	19	20	22	17	427
Total						4,217[g]				845	954	809	669	381	315	186	236	144	8,756
UK	Male	391[b]	461	659	870	1,016	1,147	1,250	1,404	1,549	1,628	1,485	1,162	852	585	548	546	417	15,970
	Female	17[b]	13	22	38	66	97	138	173	237	225	281	268	216	190	185	234	200	2,600
Total		408[b]	474	681	908	1,082	1,244	1,388	1,577	1,786	1,853	1,766	1,430	1,068	775	733	780	617	18,570
Germany	Male	453[b]	525	964	1,163	1,448	1,386	1,578	1,656	1,711	1,796	1,610	1,320	807	689	576	502	339	18,523
	Female	23[b]	46	69	104	128	157	183	230	262	256	260	250	203	145	145	101	104	2,666
Total		476[b]	571	1,033	1,267	1,576	1,543	1,761	1,886	1,973	2,052	1,870	1,570	1,010	834	721	603	443	21,189
Italy		244[b]	458	1,030	1,775	2,482	3,134	3,827	4,261	4,814	5,524	5,662	5,051	3,370	2,418	2,111	1,876	1,296	49,333
Spain	Male	222[b]	403	897	1,868	2,635	3,221	3,720	4,101	4,423	5,904	5,655	5,201	3,758	2,746	2,299	1,966	1,590	50,680[h]
	Female	24[b]	92	192	401	522	693	839	958	1,047	1,450	1,424	1,368	982	752	595	578	390	12,322[h]
Total		246[b]	495	1,089	2,269	3,157	3,914	4,559	5,059	5,470	7,354	7,079	6,569	4,740	3,498	2,894	2,544	1,980	63,002[h]
France	Male				17,174[f]				4,305	4,418	4,601	4,202	3,185	1,774	1,488	1,360	1,218	1,009	44,734
	Female				3,136[f]				887	1,103	1,161	1,089	824	493	430	430	456	361	10,370
Total					20,310[f]				5,192	5,521	5,762	5,291	4,009	2,267	1,918	1,790	1,674	1,370	55,104

[a] Calendar year is year of report. [b] Cumulative reported numbers until the end of 1985. [c] Reported numbers in each year was adjusted for reporting delay.

[d] Cumulative total since the beginning of reporting (not adjusted for reporting delay). [e] Includes 6 persons whose sex is unknown.

[f] Cumulative reported numbers until the end of 1991. [g] Cumulative reported numbers until the end of 1992.

[h] Includes 86 persons (male 71, female 15) whose year of diagnosis is unknown.

Table 2 Annual trends in the number of people reported with HIV by country and sex.

Country	Sex	Calendar year of diagnosis																	Total
		85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	00	01	
Japan[a]	Male	0	0	34	15	35	27	52	108	102	134	147	189	234	261	379	336	475	2,528
	Female	0	0	11	4	18	10	17	16	22	32	19	41	34	36	45	32	50	387
Total		0	0	45	19	53	37	69	124	124	166	166	230	268	297	424	368	525	2,915
USA[b]								—	—	—	—	—	—	—	19,393	21,419	22,144	35,575	174,026[c]
EU[d]		—	—	—	—	—	—	—	—	9,617	9,931	11,665	17,705	24,748	24,397	36,578	82,316	112,210	403,359[c]
Canada	Male						27,771[f]						1,988	1,785	1,746	1,653	1,557	1,601	38,101
	Female						3,342[f]						541	457	499	543	494	535	6,411
Total[e]							36,075[f]						2,785	2,541	2,328	2,239	2,119	2,172	50,259
Australia	Male				13,060[g]					997	921	854	838	729	661	649	664	680	20,053
	Female				893[g]					81	94	76	77	86	99	76	82	97	1,661
Total					13,953[g]					1,078	1,015	930	915	815	760	725	746	777	21,725[h]
UK[i]	Male	7,085[k]		2,199	1,719	1,866	2,169	2,269	2,201	2,084	2,039	2,070	2,100	2,063	2,052	2,113	2,420	2,685	39,134
	Female	513[k]		302	231	270	369	446	539	529	532	568	584	658	746	926	1,352	1,733	10,298
Total[j]		7,613[k]		2,509	1,952	2,140	2,543	2,715	2,741	2,614	2,571	2,640	2,684	2,723	2,799	3,042	3,772	4,419	49,477
Germany[l]										2,417	2,334	2,277	1,907	2,096	1,959	1,769	1,712	1,482	17,953

[a] Calendar year is year of report.

[b] Before 1991, surveillance of HIV infection was not standardized. The numbers of reported areas is 33, 34, 36, and 39 in calendar year order.

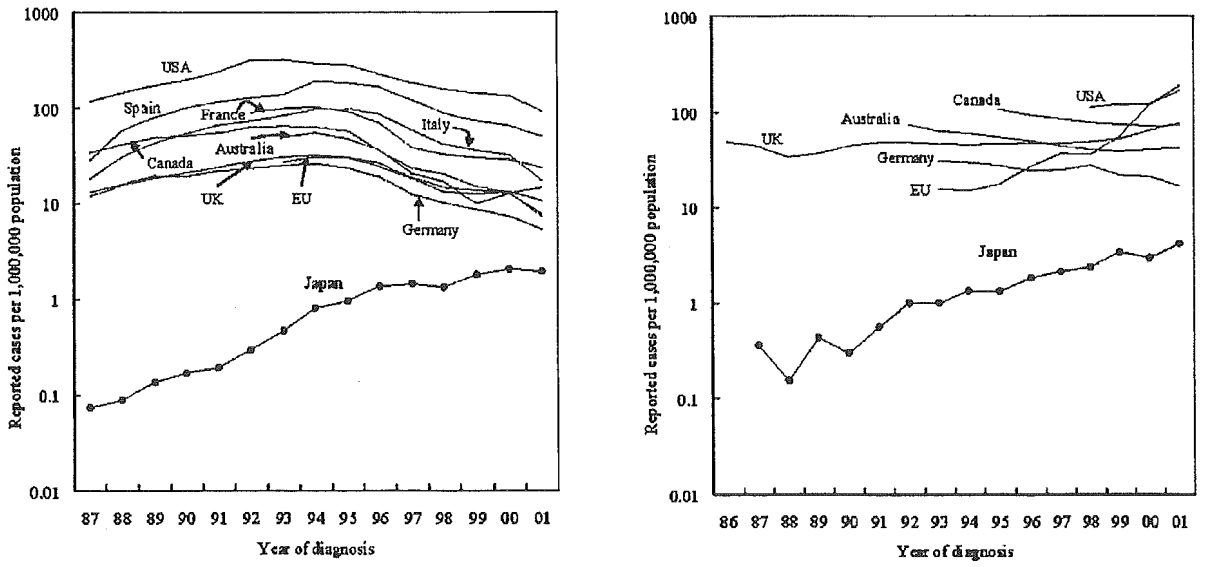
[c] Cumulative total since the beginning of reporting which includes persons whose year of report is unknown.

[d] Calendar year is year of report. Individual data on all cases are reported since 1997 according to a standard data file.

[e] Includes 5,747 persons whose sex is unknown. [f] Cumulative reported number until the end of 1995. [g] Cumulative reported number until the end of 1992.

[h] Includes 11 persons whose year of diagnosis is unknown. [i] Includes AIDS or death cases without the report of HIV infection.

[j] Includes 45 persons whose sex is unknown. [k] Cumulative reported number until the end of 1986. [l] Reporting is started from 1993.



(a) AIDS cases (b) HIV-infected cases

Figure 1 Annual trend in the reported number of people with (a) AIDS and (b) HIV per 1,000,000 individuals (the vertical axis is a common logarithm scale).

trend in the reported numbers of AIDS cases would be small.

Duplicate positive HIV test reports (repeated testing of the same HIV-positive individual) results in an overestimation of the number of positive reports. In Japan, if new AIDS cases that have already been reported as HIV-positive in the first HIV infection report visit different hospitals, the physicians are likely to mistake such AIDS cases for first report cases and will file the First Report. The removal of duplicates or linking the First and Second reports is difficult because of the anonymous nature of the HIV/AIDS reports in Japan. In contrast, all other countries[1-4, 16-20] with HIV/AIDS surveillance systems include an identification number or code name such as the first two letters of the family name and the given name. Using such information along with the date of birth and sex data allow the detection and elimination of possible duplicate reports. This is therefore one of the defects in the HIV/AIDS surveillance system in Japan. In the future, if certain individual information is included in the surveillance data, it will be possible to exclude duplicate reports.

Differences in the hierarchy of exposure categories between countries

In all countries, HIV-infected and AIDS cases were counted only once in a hierarchy of exposure categories for surveillance purposes. This hierarchy varied slightly between countries. In this study, exposure was divided into six categories, excluding infection through hemophilia/coagulation disorders. In some countries, however, infection through "MSM + IDU" was included in the "IDU" category and infection through hemophilia/coagulation disorders was included in the "others" category. However, it is unlikely that these differences significantly change the comparative results in Table 4.

Table 3 AIDS cases and HIV infection cases by sex or age reported through the end of 2001.

HIV/AIDS	Country	Cumulative total	Sex (%)		Age (%)							
			Male	Female	-14	15-19	20-29	30-39	40-49	50-59	60-	Unknown
AIDS	Japan	1,654	92.1	7.9	0.7	0.1	10.1	24.7	31.4	23.6	9.4	0.0
	USA	816,149[a]	82.2	17.8	1.1	0.5	16.4	44.4	26.5	8.1	3.0	0.0
	EU	255,621[b]	80.7	19.3	3.8	0.7	23.6	44.3	17.5	10.1[c]		0.1
	Canada	18,026[d]	91.7	8.3	1.1	0.3	15.9	43.9	27.3	8.4	3.1	0.0
	Australia	8,756	95.1	4.9					—[e]			
	UK	18,570[f]	86.0	14.0	2.7	0.5	19.5	42.6	23.4	8.4	2.9	0.0
	Germany	21,189	87.4	12.6	0.7	0.5	15.5	41.6	25.4	12.9	3.6	0.0
	Italy	49,333	77.9	22.1	1.5	0.2	25.8	50.9	14.0	5.2	2.4	0.0
	Spain	63,002[g]	80.4	19.6	1.6	0.6	30.4	47.8	12.6	4.2	2.5	0.3
	France	55,104	81.2	18.8					—			
HIV	Japan	2,915	86.7	13.3	0.6	1.4	32.9	30.0	18.8	10.8	5.4	0.1
	USA	174,026[h]	70.6	29.4	2.2	3.8	30.2	38.1	18.9	5.2	1.6	0.0
	EU	403,359[i]	75.0	25.0	2.7	11.8	44.5	19.9	6.4	3.0[c]		11.7
	Canada	50,259[j]	85.6	14.4	1.4	1.3	24.6	37.8	18.3	7.4[c]		9.2
	Australia	21,725	92.3	7.7					—[k]			
	UK	49,477[l]	79.2	20.8	2.4	2.3	34.2	38.5	14.9	5.2	1.7	0.8
	Germany	17,953[m]	77.4	22.6	2.1	2.4	29.5	38.0	14.5	8.0	3.1	2.4

[a] Includes 1 person whose sex is unknown and 1 person whose age is unknown.

[b] Includes 7 persons whose sex is unknown and 265 persons whose age is unknown. [c] Proportion of people (%) aged 50 or older.

[d] Includes 6 persons whose sex is unknown and 2 persons whose age is unknown. [e] Median age is 37 for males and 33 for females.

[f] Includes 3 persons whose age is unknown. [g] Includes 174 persons whose age is unknown.

[h] Includes 9 persons whose sex is unknown. [i] Includes 44,116 persons whose sex is unknown and 47,304 persons whose age is unknown.

[j] Includes 5,747 persons whose sex is unknown and 4,631 persons whose age is unknown (two regions does not collect data on sex and age before 1998).

[k] Median age is 32 for males and 29 for females. [l] Includes 45 persons whose sex is unknown and 405 persons whose age is unknown.

[m] Includes 592 persons whose sex is unknown and 435 persons whose age is unknown.

Table 4 AIDS cases and HIV infection cases by route of infection reported through the end of 2001.

HIV/AIDS	Country	Route of infection (%)					
		Heterosexual contact Male	Heterosexual contact Female	MSM[a]/Bisexual contact	IDU[b]	Others	Risk not reported
AIDS	Japan	42.4	5.0	28.6	0.3	2.8	20.9
	USA	4.0	7.1	45.5	24.9	8.5	10.0
	EU[c, d]	10.0	7.7	31.4	38.3	6.5	6.1
	Canada	8.0	5.1	69.6	6.6	7.1	3.6
	Australia	4.0	2.5	80.3	3.2	6.5	3.5
	UK	11.3	11.0	65.0	6.3	5.2	1.2
	Germany[d, e]	4.1	4.7	63.2	15.5	4.7	7.8
	Italy	9.6	8.2	15.7	59.6	4.1	2.8
	Spain[e]	8.7	5.6	13.8	65.5	2.0	4.4
	France[d]	12.3	9.7	42.8	22.5	6.8	5.9
HIV	Japan	30.3	10.9	45.2	0.3	2.7	10.6
	USA	4.9	11.0	30.1	13.6	6.3	34.1
	EU[d]	5.8	6.5	11.2	39.5	2.6	34.4
	Canada[c, f]	2.7	2.3	31.4	8.2	4.9	50.5
	Australia	8.9[g]		65.0	3.8	4.8	17.5
	UK	12.8	17.3	54.7	7.8	3.8	3.6
	Germany[c, e]	12.5	12.9	35.0	10.5	2.4	26.7

[a] Men who have sex with men. [b] Injecting drug use.

[c] Excludes heterosexual contact cases whose sex is unknown.

[d] Infection through hemophilia/coagulation disorder is included in the "Others" category.

[e] Infection through MSM+IDU is included in the "IDU" category.

[f] One province does not collect data on the route of infection.

[g] No classification between males and females.

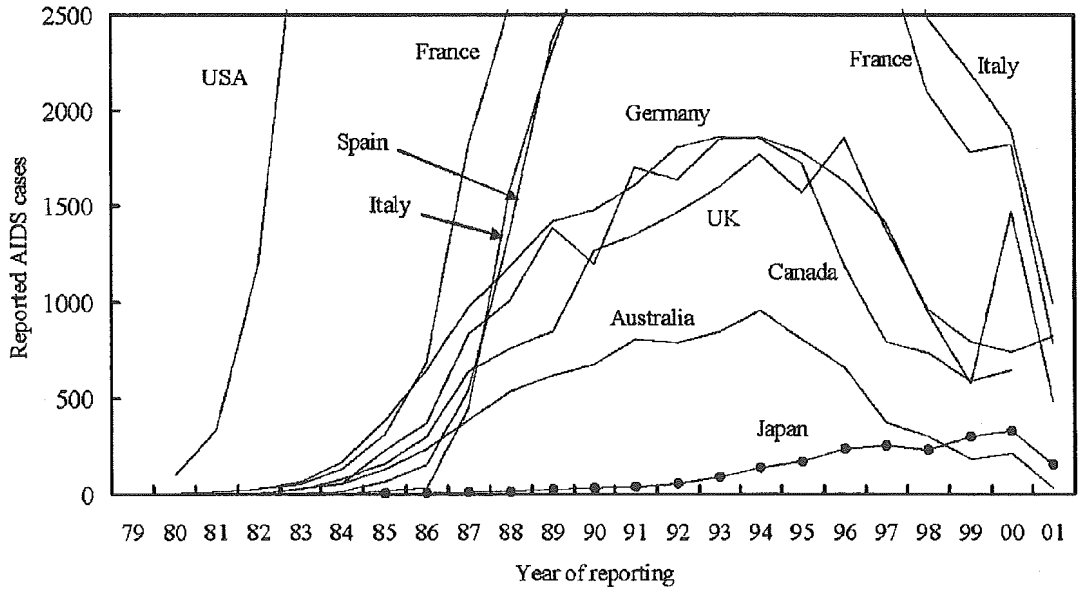
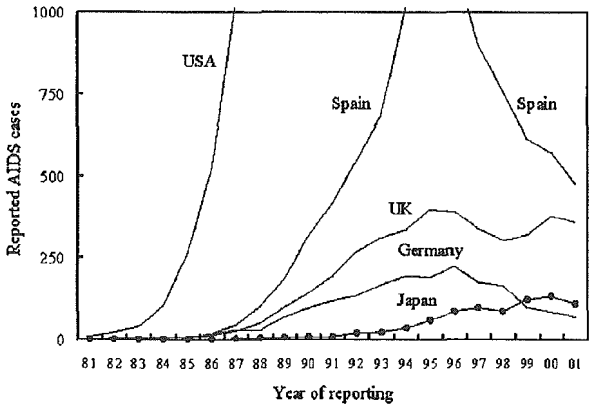
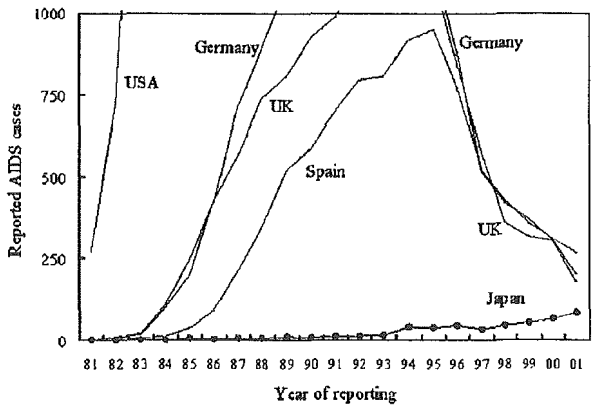


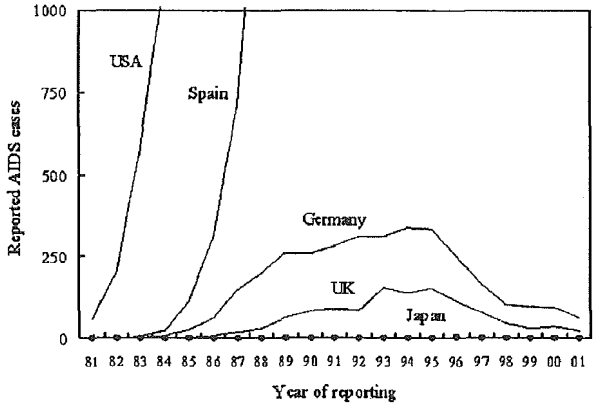
Figure 2 Increasing trends at the onset of the AIDS epidemic in each country.



(a) Heterosexual contact

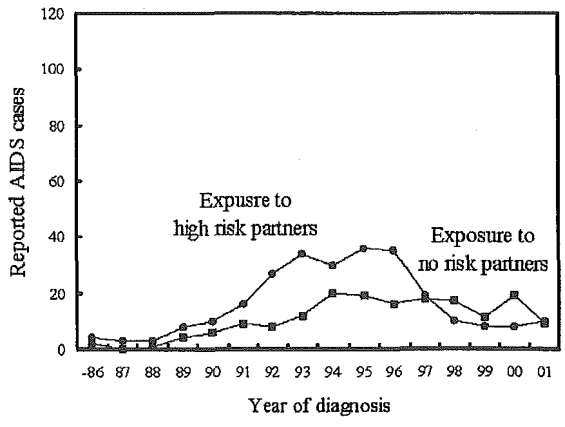


(b) MSM (men who have sex with men) /Bisexual contact

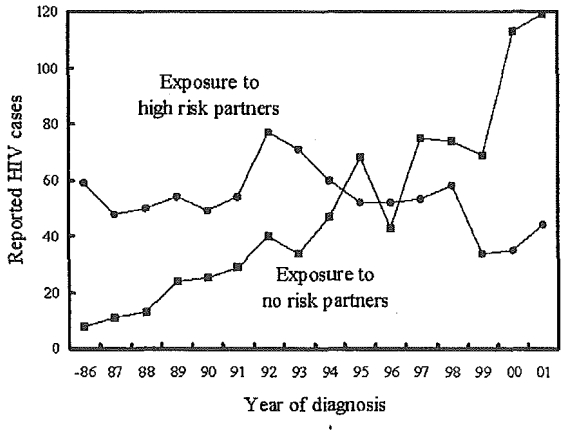


(c) IDU (injecting drug use)

Figure 3 Increasing trends at the onset of the AIDS epidemic according to the route of infection.



(a) AIDS cases



(b) HIV-infected cases

Figure 4 Annual trends in the number of women infected through heterosexual contact in the UK[16] according to the risk of partners.

The proportion of AIDS cases whose risk was not reported was extremely high in Japan. This is due to the fact that, in Japan, the physician in charge investigates the route of infection only at the time of diagnosis, and further inquiries are not conducted. For HIV-infected cases, the proportions were also substantially high in other countries. However, it should be noted that, in all countries, except Japan, this exposure category included cases that were currently being followed up by local health department officials. Individuals whose routes of infection are identified in the follow-up will be reclassified into the appropriate exposure categories.

Increasing trends at the onset of the epidemic

The increasing trend in Japan at the onset of the epidemic was extremely slow compared to other industrialized countries. This was due to the fact that, in Japan, there were few cases infected through MSM and/or IDU. The increasing trend in the number of cases infected through heterosexual contact was also relatively slow in Japan. The reason for this seems to be that in Japan those who tested positive were older as shown in Table 3. It is assumed that the sexual activity of such individuals is lower than that of individuals in their 20's and 30's. Information regarding heterosexual contact according to the exposure risk of partners was obtained from the UK surveillance[16]. Figure 4[16] shows the trends for the number of women infected through heterosexual contact. At the onset of the epidemic, there were more cases with partners at high risk such as IDU and MSM, and the cases whose partners were not at high risk began to increase thereafter. This result suggests that, in Japan, it might be necessary to examine trends in the number of reported cases through heterosexual contact according to the risk of partners. Such analysis will be possible if such information is added to the current surveillance report forms in the future.

Acknowledgements

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Sexual activities and social relationships of people with HIV in Japan

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Abstract *Sixty-one Japanese with sexually transmitted HIV were investigated to clarify the state of, and difficulties in, their sexual activities and social relationships. The study revealed the following difficulties in social relationships due to HIV infection. Thirty-one per cent had experienced discrimination or breach of confidentiality. Self-restriction due to anxiety over discrimination was observed in approximately 90%, and the self-restriction score tended to be higher in those who were not employed, those with economic problems, those who were in a relatively poor state of health, those who had developed AIDS and those who had previously experienced discrimination or breach of confidentiality. The experience of discrimination or breach of confidentiality, and the experience of receiving negative support tended to increase as the respondents had a wider emotional support network. About 60% were dissatisfied with their sex lives, and the degree of satisfaction was significantly lower in those who had fewer sexual contacts and those who had a suppressive attitude toward sexual contacts. A low degree of satisfaction with sex life was found to be an important factor that escalates the level of depression or anxiety.*

Introduction

HIV infection has social aspects such as stigma (Alonzo & Reynolds, 1995; Crawford, 1994) and these may greatly affect the social relationships of people with HIV (Pierret, 2000). For example, expectation of, and anxiety over, discrimination leads to hiding of the disease as a stigma-coping response (Schneider & Conrad, 1983), increased cautiousness and wariness, and prevention of the formation of support networks, and these in turn reinforce internalization of stigma, development of felt-stigma (Scambler & Hopkins, 1986) and self-restriction of daily activities (Green, 1995). In addition, these aspects of the illness experience have been suggested to have major effects on quality of life (QoL) (Weitz, 1997). HIV

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infection has also been reported to induce suppression of sexual activities and prevention of the development of intimate relationships such as marriage and love affairs (Rhodes & Cusick, 2000). While marked increases in survival have been observed as a consequence of effective HAART (highly active antiretroviral therapy), clarification of the state of social relationships has emerged as an increasingly important problem related to social support for people with HIV.

According to WHOQoL-100, advocated in 1998 by the WHOQOL Group, QoL is composed of four domains: physical health, psychological health, social relationships and environment. Social relationships are divided into three facets: personal relationships, social support and sexual activity, with the emphasis on the importance of attention to social relationships for QoL of not only people with HIV but also people in general (WHOQOL Group, 1998).

In Japan, however, people with HIV have been studied primarily with regard to their physical or psychological health management, and few studies have been conducted to evaluate their social relationships. For this reason, there is no clear strategy for the arrangement of a supportive environment for people with HIV.

Therefore, we focused on (1) stigmatization and felt-stigma, which have serious effects on personal relationships, and stigma coping, (2) social support and negative support, and (3) sexual activities and satisfaction with sex life, which were derived from the three facets of social relationships described in WHOQOL-100. This study attempted to clarify the state of social relationships in people with HIV and relevant problems, as well as to identify conditions and factors leading to such problems. Relationships were also investigated between the state of social relationships and mental health, which is in the psychological health domain of WHOQOL-100.

Methods

Samples and procedures

Prior to the survey, a research group named the 'STI & HIV Survey Group' consisting of medical staff of HIV care units, researchers and people with HIV was established in July 1999 in Tokyo, and a questionnaire was prepared in collaboration. The group also interviewed eight HIV-positive persons as preparatory work.

Participants in the study were recruited from September to November 2000 at one major hospital in Tokyo. Approximately 100 patients with sexually transmitted HIV regularly visited the hospital in April–September 2000. Criteria for the participants were as follows: (1) Japanese with sexually transmitted HIV, and(2) those who visited the hospital regularly in April–September 2000. Those patients who had received notification of HIV infection within the previous month were excluded with ethical considerations. A total of 93 patients who met the criteria were recruited and approached by the physicians or nurses directly involved in their care. Anonymous self-completion questionnaires were handed to 84 patients individually and collected by mail in sealed envelopes over a three-month period, addressed directly to the author, who was not involved in their direct medical care. Valid replies came from 61 and were used for the analyses presented in this paper. Although little information is available for those who failed to respond to this survey, we speculate that non-respondents had more complicating life problems than respondents, including worse health status and no support network.

Sociodemographic characteristics

The respondents were asked their gender, age, educational background, gender of their sexual partners, employment status and self-rated economic status.

Health status

Respondents were questioned regarding self-rated health, CD4 cell count, plasma HIV-RNA level, whether they had developed AIDS or not, and the HADS was administered.

The self-rated health item concerned the state of health during the previous month and used a five-point scale from 'very bad' to 'very good'.

HADS is the Hospital Anxiety and Depression Scale, consisting of 14 items (each item is scored 0–3), developed by Zigmond and Snaith (1983). The original HADS is considered to allow simple self-measurement of the tendency for depression and anxiety without being markedly affected by physical symptoms (Savard *et al.*, 1998) and is reported to correlate well with the HIV-related QoL scale (Burgess *et al.*, 1993). Its Japanese version was introduced by Kitamura (1993) and its reliability and validity in Japanese people have been evaluated (Hatta *et al.*, 1998; Higashi *et al.*, 1998; Kugaya *et al.*, 2000). The possible range of the score is 0–42, and the score is higher as depression and anxiety is more severe. In this study, the mean HADS score was 11.1 ± 8.0, and Cronbach's alpha coefficient was 0.91.

Difficulties in personal relationships

Whether the respondents had experienced breach of confidentiality related to HIV status was asked as 'experienced breach of confidentiality', and whether the respondents had been discriminated against or treated discriminatorily for being or being suspected of being HIV-positive was asked as the 'experience of discrimination'. Concerning 'way of hiding HIV status at the workplace', respondents were asked how they had informed colleagues at the workplace that they were HIV-positive.

Whether the respondents voluntarily restricted daily activities due to anxiety over discrimination or not was asked as 'self-restriction due to anxiety over discrimination'. More specifically, six statements including 'I am always cautious not to have my HIV infection known to people around me' and 'I am treated at a hospital where I am unlikely to see my neighbours or acquaintances' were prepared, which had previously been used in the survey of HIV-infected haemophiliacs named 'Comprehensive basic survey on health, medical treatment, life and welfare' conducted in 1998 in Japan (Seki *et al.*, 2002). The self-restriction score was calculated by summing all six items, coded 1 for 'yes' and 0 for 'no' (see Appendix A). The possible score was 0–6, and the score was higher as the degree of self-restriction was greater. In this study, the mean score was 2.5 ± 1.7 and Cronbach's alpha coefficient was 0.69.

Items related to social support

Of the four functional attributes of social support, i.e. emotional, instrumental, informational and appraisal (Langford *et al.*, 1997), support with emotional functions was selected and its extent as perceived by the recipients, and whether or not there were emotional support providers were assessed in this study. Concerning 'emotional support providers', we asked the respondents to select the persons who listened to and understood their worries and troubles including HIV infection from 14 items including 'parents', 'spouse, partner, lover' and

'doctors and nurses at the hospital', which were also adopted from the Seki *et al.* (2002) survey mentioned above. The 'extent of emotional support network' was scored on the basis of the number of items selected by the respondent as providers of such support (see Appendix B).

Social support is considered to include negative support, or support that is undesirable for the recipient (Revenson *et al.*, 1991), and Pakenham suggested over-protectiveness as ineffective support (1998). In this study, support that was considered 'good' by its providers and 'ineffective' by the recipient was defined as negative support. More specifically, 'being unnecessarily taken care of for being HIV-positive' was defined as 'over-interference', and 'being more than necessarily worried about or sympathized with for being HIV-positive' was defined as 'over-protectiveness'. We asked respectively whether the respondents had such an experience or not, and if they had such experiences, we asked the respondents to select the persons who over-interfered with or over-protected them from the 14 items in the aforementioned emotional support network. Negative support was assessed to be present when there was either over-interference or over-protectiveness, or both.

Sexual activities

The 'frequency of sexual contact' was evaluated by asking the mean current frequency of sexual contact using a ten-point scale from 'no contact' to 'five times or more per week'. Concerning the 'suppressive attitude toward sexual contact', respondents were asked whether or not they reduced the frequency of sexual contacts, number of partners and type of sexual contact, and respondents were regarded to have a suppressive attitude toward sexual contact when they answered that they reduced any of them due to HIV status. Concerning the 'suppressive attitude toward marriage, having partners or having lovers', respondents were asked if they avoided involvement in intimate relationships such as spouses, partners or lovers due to their HIV status. Respondents used a four-point scale and we considered that they did not have a 'suppressive attitude' when they answered 'not at all' or 'not very much' and that they had a 'suppressive attitude' when they answered 'fairly' or 'very much'. Respondents were also asked if they had spouses or partners. Concerning the 'degree of satisfaction with sex life', respondents were asked whether they were generally satisfied with their sexual activities using a four-point scale from 'totally dissatisfied' to 'very satisfied'.

Statistical analysis

We primarily performed the following four analyses using SPSS 10.0J software.

1. One-way ANOVA (analysis of variance) using the self-restriction score as the dependent variable and the attributes, characteristics, health status, experience of breach of confidentiality or discrimination and way of hiding of HIV infection at the workplace as the independent variables.
2. One-way ANOVA using the extent of the emotional support network as the dependent variable and the self-restriction score and negative support in addition to the items shown in (1) as the independent variables.
3. Logistic regression analysis of each of the major items related to sexual activities by applying them one by one as independent variables using the degree of satisfaction with sex life as the dependent variable and the gender and age as the control variables.

4. Multiple regression analysis using the HADS score as the dependent variable and gender, age and educational background as the control variables, and by simultaneously applying the CD4 cell count, self-rated health, self-rated economic status (which were shown by one-way ANOVA to be significantly related), the self-restriction score, extent of emotional support network and degree of satisfaction with sex life as the independent variables.

Results

Sociodemographic characteristics and their health status

As shown in Table 1, males accounted for 85.2% and females for 14.8% of the respondents. They were aged 26–64 years of age, with a mean of 39.6 ± 9.9 years. Men who had sex with men accounted for 70.5%. Eighty-two per cent were employed and the self-rated economic status was 'very bad' or 'bad' in 42.7%. The self-rated health was 'very bad' or 'bad' in 19.7%, the CD4 cell count was less than 200/μl in 18.0%, and 18.0% had developed AIDS. The plasma HIV-RNA was undetectable in 55.7%. The mean HADS score was 11.1 ± 8.0.

Difficulties in human relationships

As shown in Table 2, 21.3% and 21.3% of the respondents had experienced discrimination and breach of confidentiality, respectively, and 31.1% had either or both experiences.

Concerning self-restriction due to anxiety over discrimination, 68.9% were 'always cautious not to have my HIV infection known to people around me', 49.2% were 'treated at a hospital where I am unlikely to see my neighbours or acquaintances' and 44.3% avoided 'health checks at my workplace or school'. At least one of the six items were answered affirmatively by 90.2%.

Although not shown in the table, 47.5% hid their HIV infection from their colleagues at the workplace by 'not telling or answering anything' and 44.3% indirectly denied their HIV infection by giving different explanations such as 'delicate constitution', 'liver disease', 'diabetes', 'anaemia', 'refractory disease' and 'leukemia'. Only 6.6% informed colleagues about their serostatus.

On one-way ANOVA (Table 3), the self-restriction score was significantly higher in those who were not employed, those who were in poor self-rated health, those who had developed AIDS and those who had experienced breach of confidentiality or discrimination than in those who were in the opposite situation. It was also significantly higher in those who self-rated their economic status as 'very bad' or 'bad' than in those who rated it as 'average'.

Social support

As indicated in Table 4, friends or acquaintances (HIV-negative), HIV-positive friends or acquaintances, physicians or nurses at the hospital and hospital counsellors were frequently mentioned as emotional support providers in addition to parents, spouse, partner and lover. The mean number of items of emotional support providers, i.e. the extent of the emotional support network score (possible range = 0–14), was 2.5 ± 2.1. It was 0 (no support network) in 11.5% and 4 or greater (wide support network) in 23.0%.

As for negative support, 13.1% and 16.4% of the respondents had experienced over-interference and over-protectiveness, respectively, and 19.7% had either or both experiences

Table 1. *Sociodemographic characteristics and health status*

Characteristic	*n* (%)
Gender	
Male	52 (85.2)
Female	9 (14.8)
Age(years)	
26–34	23 (37.7)
35–44	18 (29.5)
45–54	14 (23.0)
55–64	6 (9.8)
Educational background	
Junior or senior high school	23 (37.7)
Junior college/professional school	11 (18.0)
University/graduate school	25 (44.2)
Gender of sexual partner	
Opposite	16 (26.2)
Same	33 (54.1)
Opposite and same	11 (18.0)
NA	1 (1.6)
Employment	
Employed	50 (82.0)
Unemployed	11 (18.0)
Self-rated economic status	
Very good/good	11 (18.0)
Average	24 (39.3)
Very bad/bad	26 (42.7)
Self-rated health	
Very good/good	20 (32.8)
Average	29 (47.5)
Very bad/bad	12 (19.7)
CD4 cell count	
$< 200/\mu l$	11 (18.0)
$200–500/\mu l$	28 (45.9)
$> 500/\mu l$	17 (27.9)
NA	5 (8.2)
Plasma HIV-RNA level	
Undetectable[1]	34 (55.7)
Detectable	20 (32.8)
NA	7 (11.5)
AIDS	
Developed	11 (18.0)
Not developed	46 (75.4)
NA	4 (6.6)
HADS	
< 10	35 (57.4)
10–20	18 (29.5)
> 20	8 (13.1)

Note: [1]Undetectable means less than $400/mm^3$.

Table 2. *Items related to difficulties in personal relationships*

	n (%)
Experience of discrimination or breach of confidentiality	19 (31.1)
Experience of discrimination	13 (21.3)
Experience of breach of confidentiality	13 (21.3)
Self-restriction due to anxiety over discrimination	55 (90.2)
I am always cautious not to have my HIV infection known to people around me.	42 (68.9)
I am treated at a hospital where I am unlikely to meet my neighbours or acquaintances.	30 (49.2)
I avoid health checks at my workplace or school.	27 (44.3)
I avoid close human relations at my workplace, school, or in the neighbourhood.	20 (32.8)
I try to avoid contact with relatives.	16 (26.2)
I have moved, because it was difficult to stay in the same neighbourhood.	6 (9.8)

Note: Total does not come to 100% since multiple choice method was applied. NA = 1 (1.7%).

Table 3. *One-way ANOVA of the self-restriction score*

Independent variables	*n*	Average	SD	*F* value	*p*
Gender				$F(1,58) = 0.78$	0.381
Age				$F(3,56) = 2.53$	0.066
Gender of sexual partners				$F(2,57) = 0.68$	0.509
Employment				$F(1,58) = 16.66$	0.000
Employed	52	2.0	1.5		
Unemployed	8	4.4	1.5		
Self-rated economic status				$F(2,57) = 3.75$	0.029
Very good/good	11	2.0	1.3		
Average	23	1.8	1.2]*		
Very bad/bad	26	3.0	2.0]		
Self-rated health				$F(2,57) = 4.43$	0.016
Very good/good	19	2.1	1.4 ┐		
Average	29	2.0	1.7]*		
Very bad/bad	12	3.6	1.6 ┘ *		
CD4 cell count				$F(2,52) = 1.79$	0.176
Plasma HIV-RNA level				$F(1,51) = 0.45$	0.503
AIDS				$F(1,55) = 4.32$	0.042
Developed	11	3.3	1.6		
Not developed	46	2.1	1.7		
Experience of discrimination or breach of confidentiality				$F(1,58) = 6.95$	0.011
Yes	19	3.2	1.6		
No	41	2.0	1.6		
Way of hiding HIV infection at the workplace				$F(1,53) = 1.13$	0.294

Note: (1) Categories, average and SD are shown only when p values are less than 0.05;
(2) missing date are excluded from the analysis;
(3) as for gender, age, gender of sexual partners, CD4 cell count, plasma HIV-RNA level, the same categories are used with Table 1, after excluded NA;
(4) 'way of hiding HIV infection at the workplace' has two categories: 'not telling or answering anything' and 'giving a different explanation';
(5) $*p < 0.05$ by Tukey's multiple comparison test.

Table 4. *Providers of emotional and negative support*

	Emotional support	Negative support	
	n (%)	Over-interference *n* (%)	Over-protectiveness *n* (%)
Existing support network	53 (86.9)	8 (13.1)	10 (16.4)
Parents	13 (21.3)	3 (4.9)	2 (3.3)
Spouse, partner, lover	28 (45.9)	2 (3.3)	3 (4.9)
Brothers, sisters	6 (9.8)	0 (0.0)	0 (0.0)
Relatives	3 (4.9)	0 (0.0)	0 (0.0)
Colleagues at the workplace	4 (6.6)	0 (0.0)	0 (0.0)
Teachers, students	1 (1.6)	0 (0.0)	0 (0.0)
Friends or acquaintances (HIV-negative)	26 (42.6)	3 (4.9)	4 (6.6)
HIV-positive friends or acquaintances	11 (18.0)	1 (1.6)	1 (1.6)
Doctors and nurses at the hospital	27 (44.2)	1 (1.6)	0 (0.0)
Hospital counsellors	23 (37.7)	0 (0.0)	0 (0.0)
NGO members	2 (3.3)	2 (3.3)	1 (1.6)
Governmental office	4 (6.6)	0 (0.0)	0 (0.0)
HIV-related group	3 (4.9)	0 (0.0)	1 (1.6)
Other	1 (1.6)	0 (0.0)	0 (0.0)
No support network	7 (11.5)	52 (85.2)	50 (82.0)

Note: Total does not come to 100% since multiple choice method was applied. NA = 1 (1.7%).

(Table 4). Negative support was frequently offered by parents, spouse, partner, lover, friends or acquaintances (HIV-negative) who were often mentioned as emotional support providers.

One-way ANOVA showed the following tendencies in the emotional support network (Table 5). The emotional support network was significantly wider in females than in males, in those who had experienced breach of confidentiality or discrimination than in those who had not, in those who hid HIV infection by giving explanations other than HIV than in those who hid it by not telling or answering anything, and in those who had received negative support than in those who had not.

Sexual activities and the degree of satisfaction with sex life

Although not shown in the table, the frequency of sexual contact was 'less than once a month' in 42.6%, suggested to be lower than the results of surveys in the age-matched general Japanese public (Kihara *et al.*, 2000). Also 75.4% had a suppressive attitude toward sexual contact due to HIV status. A suppressive attitude toward marriage, having partners or having lovers due to HIV status was observed in 68.9%. Concerning the degree of satisfaction with sex life, 24.6% were 'totally dissatisfied' and 34.4% were 'not satisfied very much'.

Logistic regression analysis using the degree of satisfaction with sex life as the dependent variable showed that it was significantly lower in those with a low frequency of sexual contact, those with a suppressive attitude toward sexual contact and those with a suppressive attitude toward marriage, having partners or having lovers (Table 6).

Factors related to depression and anxiety

The HADS score was significantly increased as the CD4 cell count was smaller, the self-rated health was poorer, the self-rated economic status was worse and the degree of satisfaction with sex life was lower (Table 7).

Table 5. *One-way ANOVA of the extent of emotional support network*

Independent variables	*n*	Average	SD	*F* value	*p*
Gender				$F(1,58) = 7.03$	0.010
Male	51	2.2	1.9		
Female	9	4.1	2.1		
Age				$F(3,56) = 0.77$	0.515
Gender of sexual partners				$F(2,57) = 0.10$	0.905
Employment				$F(1,58) = 0.33$	0.567
Self-rated economic status				$F(2,57) = 0.59$	0.555
Self-rated health				$F(2,57) = 1.24$	0.297
CD4 cell count				$F(2,52) = 0.58$	0.561
Plasma HIV-RNA level				$F(1,51) = 0.68$	0.415
AIDS				$F(1,55) = 0.83$	0.775
Experience of discrimination or breach of confidentiality				$F(1,58) = 6.61$	0.013
Yes	19	3.5	1.9		
No	41	2.1	2.0		
Self-restriction score				$F(2,57) = 1.07$	0.349
Way of hiding HIV infection at the workplace				$F(1,53) = 8.45$	0.005
Giving a different explanation	26	3.0	1.9		
Not telling or answering anything	29	1.7	1.3		
Negative support				$F(1,58) = 5.85$	0.019
Yes	12	3.8	2.7		
No	48	2.2	1.8		

Note: (1) Categories, average and SD are shown only when p values are less than 0.05;
(2) missing date are excluded from the analysis;
(3) as for age, gender of sexual partners, CD4 cell count, plasma HIV-RNA level, AIDS, the same categories are used with Table 1, after excluded NA;
(4) as for employment, two categories are used for this analysis, i.e. employed and unemployed, as for the self-restriction score, three, i.e. 0, 1–3 and more than 3, as for self-rated economic status, three, i.e. very good/good, average and bad/very bad, and as for self-rated health, three, i.e. very good/good, average and bad/very bad.

Table 6. *Logistic regression analysis of the degree of satisfaction with sex life*

Independent variable	OR	*p*
Frequency of sexual contact (less than once a month = 1, once a month or more = 0)	0.185	0.018
Suppressive attitude toward sexual contact (yes = 1, no = 0)	0.311	0.084
Suppressive attitude toward marriage, having partners or having lovers (yes = 1, no = 0)	0.227	0.023
Gender of sexual partners (including same gender = 1, opposite gender only = 0)	1.196	0.822
Having spouse, partners, lovers (yes = 1, no = 0)	1.174	0.779

Note: (1) Each of the independent variables are applied one by one, using the gender and age as control variables;
(2) as for the dependent variable, two categories are used, i.e. totally dissatisfied/dissatisfied and satisfied/very satisfied.

Discussion

Wide presence of difficulties in social relationships

Difficulties in social relationships encountered by people with HIV tend to be overlooked, because they are not as apparent as their physical difficulties such as symptoms of illness and

Table 7. *Multiple regression analysis of the HADS score*

Independent variable	Category/score	β
Gender	(0 = female, 1 = male)	0.008
Age		0.054
Educational background	(reference category = junior/senior high school)	
	junior college/professional school (0 = no, 1 = yes)	−0.051
	university/graduate school (0 = no, 1 = yes)	−0.032
CD4 cell count		−0.229*
Self-rated health	(1 = very bad, 5 = very good)	−0.318**
Self-rated economic status	(1 = very bad, 5 = very good)	−0.246*
Self-restriction score	(0 ~ 6)	0.140
Extent of emotional support network	(0 ~ 14)	−0.074
Satisfaction with sex life	(0 = totally dissatisfied/not satisfied very much, 1 = satisfied very much/totally satisfied)	−0.354***
Adjusted R^2		0.556***

Note: *$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

decline in physical abilities. However, this study suggested that people with HIV in Japan have a wide range of difficulties in social relationships. It showed that more than 90% self-restricted their social activities and that 60% of them were dissatisfied with their sex life. Attention to such difficulties is considered to be extremely important for understanding QoL of people with HIV in Japan and improving the environment of their support.

Stigma, self-restriction and support network

Thirty-one per cent had experienced either breach of confidentiality or discrimination. Also, most of them were found to hide the fact of HIV infection from colleagues at the workplace. These results suggest that discrimination against people with HIV and breach of confidentiality are not overt in Japan, because they conceal their HIV status for fear of stigmatization or discrimination by people around them.

Also, more than 90% answered that they self-restricted some activities of daily life due to anxiety over discrimination. Routine restriction of activities and behaviour, such as avoiding intimate human relations in the workplace, school or neighbourhood and always being cautious, is considered in itself to be withdrawal from, and difficulty in, human relations.

The deterioration of the physical or economic condition of the HIV-positive respondent and the experience of discrimination or breach of confidentiality were shown to be factors that increase such self-restriction. Although evaluation of the cause-effect relationship is difficult from the results of this study alone, it is likely that for people with HIV, as it progresses to advanced stage disease, it becomes more difficult to hide their HIV infection, which leads them to decrease social activities and become isolated (Betsy & Eric, 2000). Disadvantage of economic conditions which can threaten future life are also considered to increase self-restriction, in order to prevent suffering from the additional social disadvantage. People with HIV with the experience of discrimination or breach of confidentiality may intensify their self-restriction so that they do not place themselves in even worse situations.

As for the support network, a previous study showed that the support network for people with HIV has been limited to family members and medical professionals (Pakenham, 1998).

In this study, family members, physicians and nurses at the hospital and hospital counsellors were often mentioned as emotional support providers as had been expected, but friends and acquaintances were also raised frequently. However, about 20%, a percentage that cannot be ignored, had experienced negative support. Detailed evaluation of what support is likely to be perceived as negative by what type of people is needed in the future.

Since the extent of the emotional support network was related to the experience of breach of confidentiality or discrimination and negative support, expansion of the emotional support network is considered to increase the group of confided people and, thus, to increase the chances of experiencing breach of confidentiality or discrimination and negative support. Therefore, sufficient precautions to prevent such negative aspects are needed when people with HIV try to expand their support network.

Overall, these findings strongly suggest that people with HIV in Japan have difficulty in keeping up social support networks. It is therefore important to stress that there is a pressing need to improve the social environment, to establish a society in which the general public better understands HIV and the need for support networks for people with HIV, a society in which people with HIV do not feel stigmatized in their daily lives. These may be achieved partly by public education and support for people who may experience prejudice and discrimination.

Sexual activities and degree of satisfaction with sex life

The frequency of sexual contact in people with HIV was found to be generally lower than the results of a national survey of the Japanese general public. Also, the degree of satisfaction with sex life was significantly lower in those who had sexual contact less frequently, those who had a suppressive attitude toward sexual contact and those who had a suppressive attitude toward marriage, having partners or having lovers. They are considered to avoid sexual contact and not to be able to develop intimate relationships with others due to worries about the risk of transmitting HIV to others and having to disclose the fact of HIV infection, and these factors are estimated to reduce the degree of satisfaction with sex life.

In addition, the degree of satisfaction with sex life was related to the degree of depression or anxiety even after controlling for the effects of gender, age, educational background, CD4 cell count, self-rated health and self-rated economic status, so that the degree of satisfaction with sex life is considered to be an important factor related to the degree of depression or anxiety. The results strongly suggested that sexuality is an important part of everyday life for Japanese people with HIV. However, in Japan, discussion of sexual life of people with HIV has been treated as a taboo, even among physicians and other staff of HIV care teams. Patients and physicians do not routinely talk about sex life and, when they do, the topics have usually been limited to HIV risk management.

The American Cancer Society has written in their booklets that cancer patients have a right to know the facts about sexual health to enrich their lives (1999), stressing that even for people with severe disease, staying sexually healthy is important. Although not so many studies have been conducted with regard to people with HIV on this issue, some studies suggest that sexual functioning or sexual satisfaction are important aspects in their daily lives (Newshan *et al.*, 1998; Norman *et al.*, 1998). In the USA, re-evaluation of sexual activities from the viewpoint of QoL has been presented as an important issue for the support of people with HIV (Schiltz, 2000). The results of this study suggested that this approach is valid in Japan also. The future task for Japanese people with HIV should be to establish strategies for sexuality of people with HIV, not only to give information on HIV prevention but also to pay

attention to their sexual health or sexual wellbeing, with the collaboration of physicians, nurses, researchers, other medical staff and people with HIV.

Limitations of this study

This was the first survey to our knowledge on social relationships including sexual behaviours of people with HIV in Japan. Since there are few studies on these aspects of people with HIV in Japan, this study may deepen our understanding; however, there are several limitations to this study. First, as the participants were recruited in only one hospital in Tokyo, problems unique to that hospital may be reflected in the results. In the future, it is important to conduct a survey including those in other areas or visiting other hospitals. Second, since 27% failed to return the questionnaires and unfortunately little information about them could be obtained, it is necessary to conduct a survey of these patients as well to see if they differ substantially from those that did return them. Third, as this study was cross-sectional, judgement concerning the cause-effect relationship was sometimes difficult. Surveys including longitudinal programmes must be carried out, to confirm the results of this study.

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