

対象および方法

1. 調査対象者

日本の都市部にあるエイズ拠点病院の4医療施設（関東地方が2施設、近畿地方が1施設、その他の地方が1施設）を対象施設とした。調査対象施設を2002年11月～2003年4月に受診したHIV感染者・AIDS患者の中で、性的接触が感染経路である定期的な通院者全員を調査対象者とした。ただし、HIV感染告知から1か月未満の者および外国人は、それぞれ倫理的配慮と日本語理解力の懸念から対象外とした。調査対象者は各施設の報告から603人であった。

2. 調査方法

各調査対象者に対して、2002年11月～2003年4月に、各医療施設において同施設の医師または看護師を通じて無記名自記式調査票を配布し、郵送にて回収した。調査票の配布の際に、調査主旨とプライバシー保護、とくに各医療施設のスタッフが回答済みの調査票を見ないことを調査対象者に十分説明した。調査票の配布人数は299人であり、その中で回収された人数は170人（57%）であった。

調査票の内容としては、性、年齢、AIDS発病の有無、感染経路、感染場所、感染時期、感染自覚時期、医療施設受診時期などとした。AIDS患者に対しては、AIDS発病前のHIV検査の受診状況と未受診理由も含めた。質問文として、感染時期は「あなたが実際にHIV感染したのは、いつ頃だと思いますか」、感染自覚時期は「あなたがご自分のHIV感染を初めて知ったのは、いつですか」、医療施設受診時期は「あなたがご自分のHIV感染を知った後、その治療のために医療機関（今の医療機関でなくともよい）を受診したのは、いつですか」であり、回答はいずれも年月とした。

3. 解析方法

調査票の回収者170人について、HIV感染からその自覚までの期間、および、自覚から医療施設受診までの期間について、その分布を求めた。HIV感染から自覚までの期間は感染時期と感染自覚時期の差とし、両方の時期が回答された者を集計した。HIV感染の自覚から医療施設受診までの期間は感染自覚時期と医療施設受診時期の差とし、両方の時期が回答された者を集計した。いずれの期間ともに1か月未満、1～2月、3～5月、6～8月、9～11月、1年、2年、3年以上に区分した。

AIDS患者について、AIDS発症前のHIV検査の受診状況、および、その未受診者では未受診理由を集計した。未受診理由は「HIV感染を思いもなかった」と「それ以外」に区分した。

結 果

1. 対象者の属性

表1に対象者170人の属性を示す。HIV感染者が130人、AIDS患者が35人、不明が5人であった。男がほとんどであり、30～39歳が49%であった。感染経路は同性間性的接触が78%であり、感染場所はほとんどが国内であった。

2. HIV感染からその自覚と医療施設受診までの時間的遅れ

図1にHIV感染からその自覚までの時間的遅れを示す。この集計はHIV感染時期と自覚時期の両方の回答者66人（39%）が対象であった。なお、集計対象外の104人の中で、103人はHIV感染時期が不明であった。この集計対象者の中で、HIV感染から自覚までの遅れは1か月未満が62%、1～2年が21%、3年以上が17%であった。

図2にHIV感染の自覚から医療施設受診までの時間的遅れを示す。この集計はHIV感染自覚時期と医療施設受診時期の両方の回答者163人（96%）が対象であった。この集計対象者の中で、HIV感染の自覚から医療施設受診までの時間的遅れは1か月未満が69%、1～11月が

表 1 対象者の属性

		人数	%
AIDS 発病	あり	35	20.6
	なし	130	76.5
	不明	5	2.9
性	男	161	94.7
	女	7	4.1
	不明	2	1.2
年齢	20～29 歳	27	15.9
	30～39	84	49.4
	40～49	31	18.2
	50～59	18	10.6
	60～69	8	4.7
	不明	2	1.2
感染経路	異性間性的接触	16	9.4
	同性間性的接触	133	78.2
	その他	2	1.2
	不明	19	11.2
感染場所	国内	142	83.5
	国外	10	5.9
	不明	18	10.6

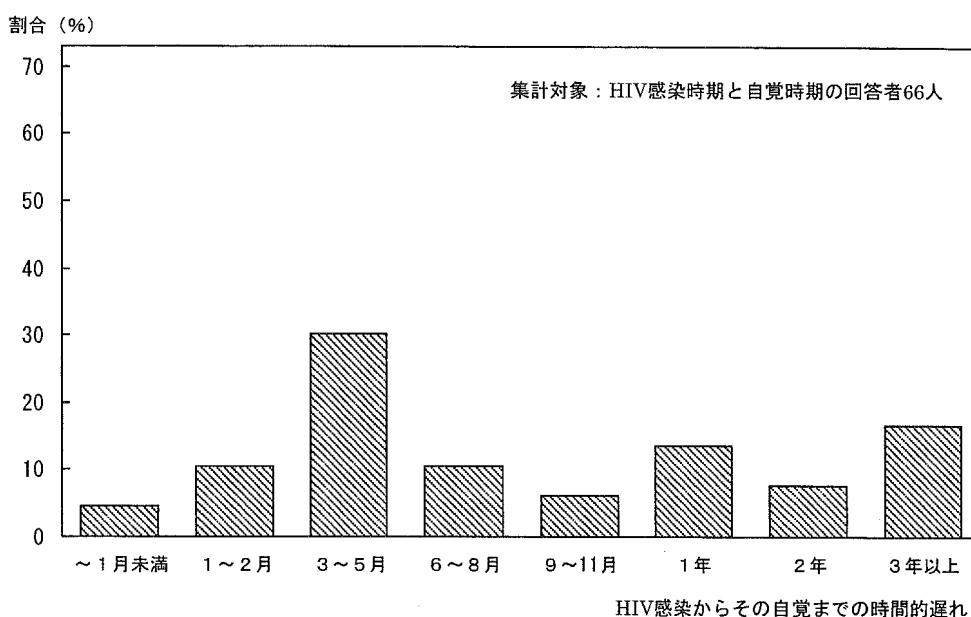


図 1 HIV 感染からその自覚までの時間的遅れ

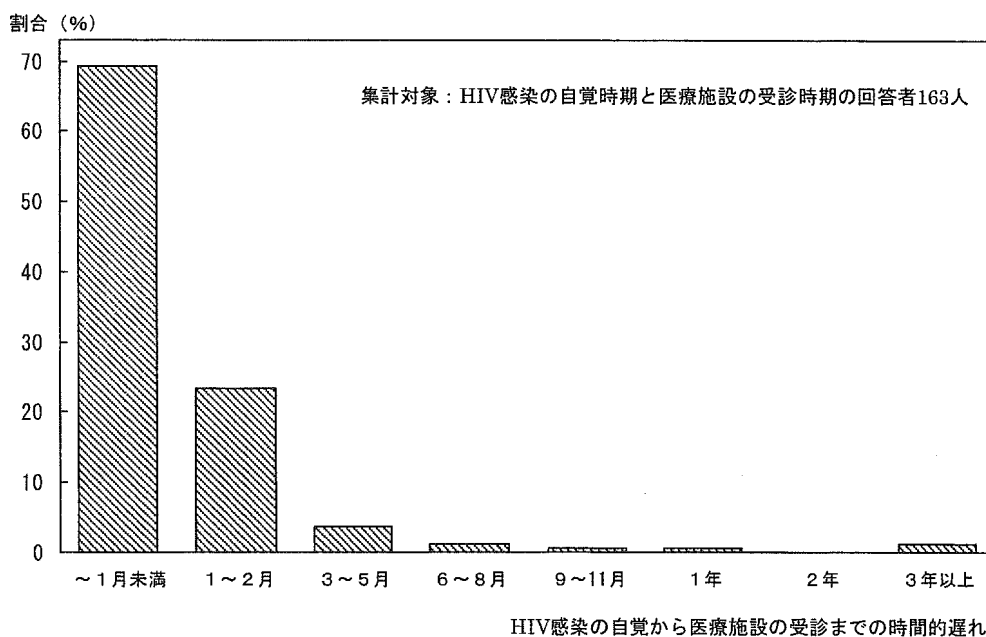


図 2 HIV 感染の自覚から医療施設の受診までの時間的遅れ

29%、1年以上が2%であった。

3. AIDS 発病前の HIV 検査受診状況

図 3 に AIDS 発病前の HIV 検査受診状況を示す。AIDS 発病者 34 人の中で、AIDS 発病前の HIV 検査は受診が 24%、未受診が 76%であった。未受診者 26 人の中で、未受診理由は「HIV 感染を思いもしなかった」が 69%であった。

考 察

調査対象者は受療中の HIV 感染者・AIDS 患者であった。HIV 検査の未受診者などは含まれていないが、前述の通り、その把握自体が現実にはきわめて困難なためである。調査対象の医療施設は 4 つのエイズ拠点病院とした。受療

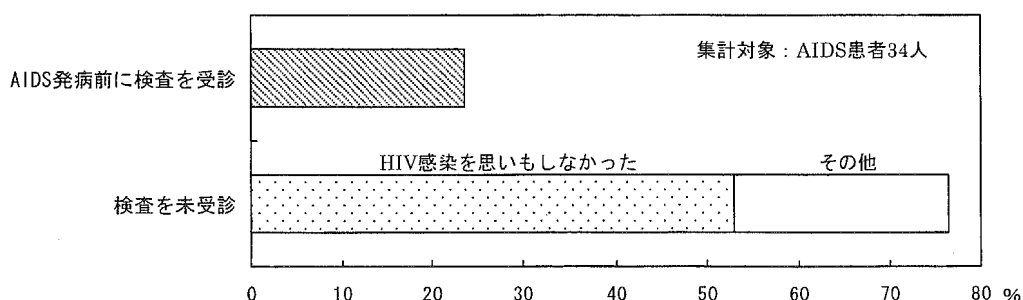


図3 AIDS発病前のHIV検査の受診状況

中のHIV感染者・AIDS患者の全体において、そのほとんどはエイズ拠点病院で受療し、また、その多くは比較的少数の医療施設であると指摘されている^{11,12)}。本調査対象の医療施設はその中に含まれている。

本解析は調査票を配布・回収できた者に限られている。調査票の配布者は調査対象者の50% (299人/603人)、回収者は配布者の57% (170人/299人)であった。前者は主として医療施設の協力状況、後者は調査対象者の協力状況が関係していたと考えられる。前述の通り、調査方法上の配慮を行ったものの、配布率・回収率ともに必ずしも高くなく、この点は本研究の問題である。

本解析の対象者の属性として、男がほとんど、30歳代が49%、国内感染がほとんど、同性間性的接触による感染が78%であった。エイズ発生動向調査によれば¹³⁾、最近の日本国籍HIV感染者・AIDS患者の報告数では、男がほとんど、30歳代が多いものの、20歳代も少なくなく、国内感染がほとんどである。同性間性的接触による感染が多いものの、異性間性的接触による感染も少なくない。これと比較すると、本対象者は性別と感染場所が比較的類似し、一方、年齢がやや高く、同性間性的接触が多い傾向であった。これらの相違による本結果への影響は明らかではないが、本結果をみるときに念頭におくことが重要であろう。

HIV感染から自覚までの遅れについては、1~3年未満が21%、3年以上が17%であった。これは、HIV感染時点と感染自覚時点の両方が回答された者(解析対象者の39%)に限られたが、この遅れがかなり長いことを示唆していると考えられる。HIV感染時点については、頻回な性的接触を行っている者では時点の特定が困難なために、不明回答が多かったと考えられる。また、その回答された感染時点の正確性は必ずしも高くないかもしれない。

HIV感染の自覚から医療施設を受診までの遅れについては、1か月未満が69%であり、1年以上は2%であった。この遅れについては比較的短いことが示唆された。これは、対象者のほとんどを集計対象とし、しかも、感染の自覚時点と医療施設を受診時点が明確であることから、ある

程度、その回答の正確性も高いと考えられる。

HIV感染から医療施設を受診までの遅れについて、先行研究をみると⁷⁾、受療中の日本国籍HIV感染者では、1~2年が36%、3年以上が28%であった。本結果におけるHIV感染から自覚まで、および、自覚から医療施設を受診までを加えた遅れは、それよりもかなり短い傾向であった。この相違にはいくつかの理由が考えられる。対象施設は先行研究が東京都内の多くの病院、本研究が4つのエイズ拠点病院であった。HIV感染時点の得られた割合は先行研究が41%、本研究が39%と類似していた。同性間性的接触の割合は先行研究が41%、本研究が78%とかなり異なった。本結果の遅れが先行研究よりも短いことに対して、この対象施設や調査対象者の属性の違いが関係していたのかもしれない。また、調査時期の違いから、先行研究は1991~1997年の受診者、本研究は2002~2003年の受診者であった。この間において、抗HIV治療法やHIV検査の体制は大きく進展・普及した⁸⁻¹⁰⁾。これらの違いによって、この遅れが短縮していたのかもしれないが、さらに研究を進める必要がある。

AIDS発病者において、AIDS発病前のHIV検査の未受診者が76%を占めており、また、未受診理由は「HIV感染を思いもしなかった」が多かった。これは、HIV感染から医療施設を受診までの遅れがかなり長いことを示唆している。AIDS発病の潜伏期間の中央値は10年程度と指摘されていることから¹⁴⁾、AIDS発病者の多くはかなり以前にHIV感染した者と考えられる。これより、以前のHIV感染者はHIV感染から医療施設を受診までの遅れが長かったことを示唆しているのかもしれない。

以上、本研究には多くの制限と問題があり、今後、さらに研究を進める必要があると考えられる。本結果からは、HIV感染から自覚までの遅れがかなり長く、自覚から医療施設を受診までの遅れは比較的短いことが示唆された。この遅れの短縮のためには、とくに、潜在しているHIV感染者に対してHIV検査の受診をより促進することが重要であろう。

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Sexual activities and social relationships of people with HIV in Japan

Y. INOUE,¹ Y. YAMAZAKI,¹ Y. SEKI,² C. WAKABAYASHI³ & M. KIHARA⁴

¹Department of Health Sociology, School of Health Sciences and Nursing, University of Tokyo, Tokyo, ²Department of Nursing Administration, School of Health Sciences, Gunma University of Prefecture, Gunma, ³Department of Social Work, School of Health and Social Services, Saitama Prefectural University, Saitama & ⁴Department of Global Health and Socio-epidemiology, School of Public Health, University of Kyoto, Kyoto, Japan

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

Address for correspondence: Yoji Inoue, Department of Health Sociology, School of Health Sciences and Nursing, University of Tokyo, 3-1, Hongo 7-chome, Bunkyo-ku, 113-0033, Tokyo, Japan. Tel: +81 (0)3 5841 3514; Fax: +81 (0)3 5684 6083; E-mail: ship@oak.ocn.ne.jp

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/ μ l 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/μl	11 (18.0)
200–500/μl	28 (45.9)
> 500/μl	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: ¹Undetectable means less than 400/mm³.

Table 2. Items related to difficulties in personal relationships

	<i>n</i> (%)
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	<i>n</i>	Average	SD	<i>F</i> value	<i>p</i>
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 data 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	
	<i>n</i> (%)	Over-interference <i>n</i> (%)	Over-protectiveness <i>n</i> (%)
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	<i>n</i>	Average	SD	<i>F</i> value	<i>p</i>
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 data 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	<i>p</i>
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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Appendix A

Measure of self-restriction score

Respondents were asked to answer each item 'yes' or 'no'. The score was calculated by adding 1 for 'yes' and 0 for 'no' concerning the six items.

1. I am always cautious not to have my HIV infection known to people around me.
2. I am treated at a hospital where I am unlikely to see my neighbours or acquaintances.
3. I avoid health checks at my workplace or school.
4. I avoid close human relations at my workplace, school or in the neighbourhood.
5. I try to avoid contact with relatives.
6. I have moved, because it was difficult to stay in the same neighbourhood.

Appendix B

Measure of extent of emotional support network score

Respondents were asked to select from the 14 items. The score was calculated by adding 1 for 'selected' and 0 for 'not selected' concerning the 14 items.

1. Parents
2. Spouse, partner, lover
3. Brothers, sisters
4. Relatives
5. Colleagues at the workplace
6. Teachers, students
7. Friends or acquaintances (HIV-negative)
8. HIV-positive friends or acquaintances
9. Doctors and nurses at the hospital
10. Hospital counsellors
11. NGO members
12. Governmental office
13. HIV-related group
14. Other

Research Report

Epidemiological Characteristics of HIV and AIDS in Japan based on HIV/AIDS Surveillance Data : An International Comparison

Yutaka MATSUYAMA¹⁾, Takuhiro YAMAGUCHI¹⁾, Shuji HASHIMOTO²⁾, Miyuki KAWADO²⁾,
Seiichi ICHIKAWA³⁾, Tamami UMEDA⁴⁾ and Masahiro KIHARA⁵⁾

¹⁾ Department of Biostatistics, School of Health Sciences and Nursing, University of Tokyo,

²⁾ Department of Hygiene, Fujita Health University School of Medicine,

³⁾ Nagoya City University School of Nursing,

⁴⁾ Human Space Technology and Astronauts Department, Japan Aerospace Exploration Agency,

⁵⁾ Department of Social Epidemiology, Kyoto University School of Public Health

Objective : The aim of this study was to compare the annual trends in the reported number of Japanese HIV/AIDS cases, and the distribution of sex, age and route of infection. The increasing trend of reported AIDS cases at the onset of the Japan epidemic was also compared with those of other industrialized countries.

Materials and Methods : HIV/AIDS surveillance data through December 2001 were utilized. As for the comparison of increasing trends at the onset of the epidemic, the Epidemiological Facts Sheets organized by the UNAIDS/WHO (United Nations Programme on AIDS/World Health Organization) were used. Nine industrialized countries, the USA, EU (European Union) (51 countries of the WHO European Region), Canada, Australia, UK, Germany, Italy, Spain, and France were selected for comparisons.

Results : Comparisons of Japanese HIV/AIDS with other industrialized countries revealed that the annual trend in reported cases was still increasing. The proportion of people with HIV aged 40 or above was high, and the proportion of males with HIV infected through heterosexual contact was extremely high. The increasing trend in reported AIDS cases at the onset of the Japan epidemic was extremely slow compared to that in other countries. In particular, there were differences in the number of cases infected through MSM (men who have sex with men), including bisexual contact, and or IDU (injecting drug use).

Conclusion : The epidemiological characteristics of HIV/AIDS in Japan, such as annual trends, and the distribution of sex, age and route of infection were revealed by comparisons with the surveillance data from nine other countries.

Key words : HIV, AIDS, surveillance, international comparison

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Introduction

HIV/AIDS surveillance systems have been established in many countries¹⁻⁵⁾ to estimate the prevalence and incidence of

Corresponding Author : Yutaka Matsuyama (Department of Biostatistics, School of Health Sciences and Nursing, University of Tokyo, Hongo 7-3-1, Bunkyo-ku, Tokyo 113-0033, JAPAN
E-mail : matuyama@epistat.m.u-tokyo.ac.jp
Fax : +81-3-5841-3527

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HIV/AIDS. They have provided some of the most important data available for determining the course of the epidemic and identifying high-risk population subgroups.

In Japan, HIV/AIDS surveillance has been fully operational since 1984, and several studies have been conducted to facilitate the interpretation and understanding of the surveillance data⁶⁻¹⁴⁾. In particular, trends in the number of reported HIV/AIDS cases^{7-9,11)} and reported deaths¹²⁾, the issues related to reporting delays^{9,11)}, estimations of the coverage rate of reported individuals with HIV^{7,9,11)}, and future predictions of the number of people with HIV and AIDS^{6,13)}, have been investigated in detail. However, only few studies have tried to

compare the characteristics of Japan's epidemic with those of the industrialized countries that first encountered the HIV epidemic. Umeda *et al.*¹⁴⁾ compared the epidemiological characteristics of Japanese AIDS cases infected through heterosexual contact with those of the UK (United Kingdom) and the USA (United States of America) based on surveillance data through 1996. Although the number of people with HIV and AIDS in Japan is still low compared to other industrialized countries, it is important to internationally examine the similarities and/or differences in the epidemiological characteristics of HIV/AIDS in Japan.

In this study, after examining the situations for surveillance systems in other industrialized countries, we compared the annual trend in the reported number of Japanese HIV/AIDS cases, and the distribution of sex, age and route of infection with those of other industrialized countries based on available HIV/AIDS surveillance data through December 2001. The increasing trends in reported AIDS cases at the onset of the epidemic in each country were also compared.

Materials and Methods

HIV/AIDS surveillance in Japan

AIDS surveillance in Japan began in 1984 and was legalized through the implementation of the "Act of AIDS Prevention" in 1989^{10,15)}. Following enactment of the "Law Concerning the Prevention of Infectious Diseases and Patients with Infectious Diseases" in 1999, the "Act of AIDS Prevention" was abolished and AIDS surveillance was integrated into the "National Epidemiological Surveillance of Infectious Diseases" organized by the Ministry of Health, Labor and Welfare, Japan.

Both AIDS and HIV infections are notifiable conditions and must be reported to the Public Health Center authorities by the diagnosing physician within 7 days. Each Public Health Center reports the information to the Prefectural/Municipal City Health authorities and the Infectious Diseases Surveillance Center (IDSC) through an online system. Two types of notification forms were created: the First Report is utilized when a physician has identified an HIV-positive case or AIDS case for the first time, and the Second Report is used when a physician has recognized a change in the pathological status of a case, such as from HIV-positive to AIDS or from AIDS to death. It should be noted that filing the Second Report was changed to be optional under the "Law Concern-

ing the Prevention of Infectious Diseases and Patients with Infectious Diseases". Both reports are examined and approved every three months by the AIDS Surveillance Committee of the Ministry of Health, Labor and Welfare, Japan. Cases caused by blood-derived coagulation products are not reported.

AIDS notification must indicate the distinction between HIV-positive and AIDS, nationality, route of infection, sex, age at diagnosis, suspected place of infection (in Japan/abroad), place of residence, diagnosis method, symptoms at diagnosis, AIDS indicator diseases, and the date of first HIV or AIDS infection, diagnosis and reporting. The Second Report includes the nationality, sex, age at diagnosis, the date of HIV or AIDS diagnosis and reporting, and any additional information describing the changes that have occurred and the date of occurrence. Neither report includes information regarding the name, address, or date of birth of the patient or any notes that might lead to personal identification.

Surveillance data and analysis method

The number of people reported with HIV or AIDS was calculated based on the annual report of HIV/AIDS surveillance in Japan⁵⁾. Only Japanese individuals with HIV and AIDS were included in this study, because there are known differences in the epidemiological characteristics such as the trend in the number of reported cases, distribution of sex and route of infection between Japanese and non-Japanese residents of Japan^{8,11)}. The cumulative reported number of HIV and AIDS cases among the Japanese through 2001 were 2915 and 1654, respectively. Note that the reported number of AIDS cases does not include the cases from the Second Report after April 1, 1999, as stated above.

Nine industrialized countries/regions, the USA¹⁾, EU (European Union, 51 countries of the WHO European Region)²⁾, Canada³⁾, Australia⁴⁾, UK¹⁶⁾, Germany¹⁷⁾, Italy¹⁸⁾, Spain¹⁹⁾, and France²⁰⁾ were selected for comparisons between countries. About 80% of the AIDS cases reported in the HIV/AIDS Surveillance of Europe²⁾ conducted by the European Centre for Epidemiological Monitoring of AIDS (EuroHIV programme) occurred in five of the selected countries; UK, Germany, Italy, Spain, and France.

The number of people reported with HIV and AIDS by sex, age, route of infection, and the calendar year of diagnosis was calculated based on the annual HIV/AIDS surveillance report from each country through December 2001. Because the surveillance reports from Australia and France did not include the number of cases according to age category, age