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Acceptance situation of HIV patients in Japanese dialysis facilities—questionnaire survey by the Infection Survey Subcommittee

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Abstract

Background: A newspaper article in August 2016 reported that about 40 medical facilities refused dialysis to a human immunodeficiency virus (HIV) patient. Infection Survey Subcommittee in the Japanese Society for Dialysis Therapy investigated this situation.

Methods: An anonymous questionnaire survey about the acceptance of HIV-positive patients was sent to 4039 dialysis institutions. The questionnaire included a number of HIV-positive patients on dialysis currently and in the last 5 years, details on whether the institution received requests to perform dialysis on HIV-positive patients, the responses to these requests, the preparation system for acceptance, the reasons for refusal of dialysis of HIV-positive patients, knowledge of HIV-related guidelines in use, and the considerations for the acceptance of dialysis for HIV-positive patients. We evaluated answers to these questions from the institutions.

Results: Two thousand five hundred eighty-three facilities (64.0%) responded to the survey questions. In the past 5 years, 215 facilities (8.3%) were requested to accept HIV patients for dialysis and 40.1% of these refused acceptance. Although manuals, written policy and procedure, for a needle piercing accident existed in most of the facilities that accepted the patients, many facilities did neither prepare the stocks of anti-HIV drugs nor cooperate with HIV core hospitals. Principal reasons for the refusal were listed as the lack of medical experience with HIV patients, anxiety of healthcare providers with regard to HIV infection risk, lack of stocks of anti-HIV drugs for needle piercing accidents, and the lack of cooperation with HIV core hospitals. The proportion of facilities expected to accept HIV patients in the future was as low as 16.9% among all facilities that responded to the survey.

Conclusions: The Japanese Society for Dialysis Therapy will need to strengthen the cooperation with other academic societies and disseminate basic knowledge on HIV and infection control measures to develop and establish the acceptance system of maintenance dialysis for HIV patients.

Keywords: HIV, Maintenance dialysis, Acceptance, Refusal, Infection control

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Background

The AIDS Surveillance Committee of Ministry of Health, Labour and Welfare in Japan reported that the cumulative number of patients infected with human immunodeficiency virus (HIV) was 27,443 in 2016, which is increasing with new registrations of approximately 1500 patients every year [1]. Due to the progress of antiviral agents, HIV-positive patients today are expected to have nearly the same life prognosis as that of non-HIV patients. The consideration of HIV infection has changed from “a deadly illness” to “a treatable chronic disease” in recent years. Therefore, various chronic diseases associated with HIV infection have drawn attention. Chronic kidney disease in HIV patients, also known as HIV-CKD, is also considered one of these examples. Though the proportion of patients requiring the maintenance dialysis is still unknown, it is reported to be 0.5–1.0% in the Western countries [2, 3]. The increase in number of HIV-CKD patients is predicted to result in an increase in number of patients requiring maintenance dialysis in near future. The shocking article from the “Tokyo Shimbun” on 30th of August in 2016 reported that a HIV-positive patient requiring hemodialysis was refused maintenance dialysis by about 40 medical institutions.

Therefore, the Infection Survey Subcommittee in the Japanese Society for Dialysis Therapy conducted a questionnaire survey for secure healthcare access at the member institutions.

Methods

An anonymous questionnaire survey about the acceptance of HIV-positive patients was sent to 4039 dialysis institutions including hospitals and clinics, which were registered as member institutions of the Japanese Society for Dialysis Therapy in November 2016.

The questionnaire included the location, type, and number of dialysis patients as well as number of HIV-positive patients on dialysis currently and in the last 5 years at an institution as of 1st of November in 2016. Details on whether the institution received requests to perform dialysis on HIV-positive patients, the responses to these requests, the preparation system for acceptance (manuals, written policy and procedure, for a needle piercing accident, cooperation with HIV core hospitals, preparation of the stocks of anti-HIV drugs, and the payments for these drugs), the rate of needle piercing accidents at the accepting institution, the reasons for refusal of dialysis of individual HIV-positive patients, the general reasons to refuse dialysis of HIV-positive patients, knowledge of HIV-related guidelines in use (“the Guidelines for Dialysis of HIV Positive Patients” published by [Japanese Association of Dialysis Physicians](#) and [Japanese Society for Dialysis Therapy](#) in 2010, “the Guidelines for Fundamental Handling and Infection

Control in Dialysis Facilities in the fourth revised edition” published in 2015, and “Treatment guidelines for HIV” published by the [research division of Ministry of Health, Labour and Welfare](#) in 2016), the considerations for the acceptance of dialysis for HIV-positive patients, and the pros and cons of the transfer of results of this questionnaire to the HIV core hospitals.

Results

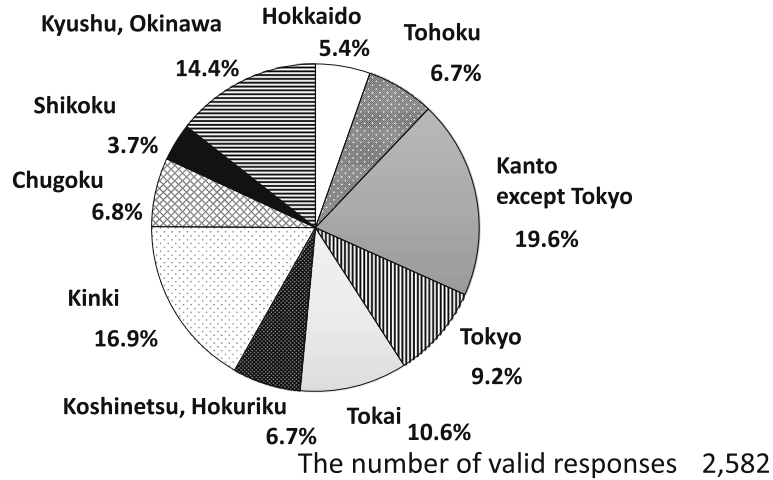
The anonymous questionnaire was sent to 4039 dialysis institutions registered as member institutions of the Japanese Society for Dialysis therapy, and 2583 facilities (64.0%) answered the questionnaire. With respect to the types of institutions, hospitals accounted for 47.7% (1232 facilities), hemodialysis clinics accounted for 35.1% (907 facilities), and university hospitals accounted for 3.8% (98 facilities). The locations of the facilities and the number of patients in each are shown in Fig. 1.

The number of HIV-positive patients currently on dialysis in these facilities was 87 (Table 1). The number of HIV-positive patients on dialysis in the past 5 years was 228 (Table 2). The facilities which received requests to accept dialysis for HIV-positive patients among member institutions in the past 5 years accounted for 8.3% (215 facilities). 40.1% of these refused acceptance although 52.5% of these accepted (Table 3).

When facilities accept HIV-positive patients, it is recommended to prepare a manual for needle piercing accidents, cooperation with HIV core hospitals, and the stocks of anti-HIV drugs. 96.6% (200 facilities) of the accepting facilities prepared the manual for a needle piercing accident. However, among these, only 59.6% (124 facilities) directly cooperated with HIV core hospitals and only 51.1% (121 facilities) prepared the stocks of anti-HIV drugs for a needle piercing accident (Table 4). 78.8% (93 facilities) with the stocks of anti-HIV drugs pay their expenses by themselves, 7.6% (9 facilities) request the expenses to be paid by the HIV core hospitals, and 2.5% request the expense to be paid by the staff. In fact, a needle piercing accident occurred in 12.9% (27 facilities) of these facilities. Although 96.3% of these managed the accident as per the existing manual, 3.7% (1 facility) experienced difficulties to deal with the accident due to panic among healthcare providers. With respect to the time to administer the anti-HIV drugs after the accident, the proportion of facilities “within 3 h” accounted for 66.7% (14 facilities), followed by “within 6 h—9.5% (2 facilities), and “within 12 h”—14.3% (3 facilities). This implies that every person in each facility received the preventive medicine within 12 h, except for personnel in facilities (9.5%; 2 facilities) which did not select the preventive medicine. With respect to the time to the consultation with a HIV specialist in the respective HIV core hospital, 71.4% (10 facilities) consulted

The general description of dialysis facilities that responded to the questionnaire survey

a The locations of dialysis facilities



b The number of dialysis patients in these facilities

the number of patients	the number of responses	%
1-9	86	3.3 %
10-49	772	29.9 %
50-99	944	36.5 %
100-199	595	23.0 %
200-299	82	3.2 %
300-399	25	1.0 %
400-499	5	0.2 %
500-	7	0.3 %
No response	67	2.6 %

Fig. 1 The general description of dialysis facilities that responded to the questionnaire survey. The regions of dialysis facilities that responded to the questionnaire survey are shown in Fig. 1a. We divided them into 10 regions from north to south, i.e., Hokkaido, Tohoku, Kanto except Tokyo, Tokyo, Tokai, Koshinetsu/Hokuriku, Kinki, Chugoku, Shikoku, and Kyushu/Okinawa. We received similar rate of responses from each region. The number of dialysis patients in these facilities is shown in Fig. 1b

immediately, 21.4% (3 facilities) on the next day, and 7.1% (1 facility) after 2 days (Fig. 2).

About 40.1% of the facilities refused acceptance of HIV-positive patients due to the following reasons: no experience in the practice of HIV-positive patients, anxiety among the healthcare providers with respect to HIV infection risk, lack of anti-HIV drug stocks for a needle piercing accident, lack of cooperation with the HIV core hospitals, insufficient standard precautions in medical facilities, lack of knowledge on the required measures during a needle piercing accident, and insufficient beds for dialysis (Table 5). Moreover, the general reasons for

refusing healthcare to HIV-positive patients, which were evaluated at all facilities, were similar to those listed above (Table 6).

With respect to cooperation with facilities that have experiences accepting HIV-positive patients or with HIV core hospitals, only 8.9% (221) of the facilities have cooperated in the past and 17.9% (443 facilities) plan to cooperate in future (Table 7).

Three guidelines are known for performing dialysis of HIV-positive patients, which include “the Guidelines for Dialysis of HIV Positive Patients” published by [Japanese Association of Dialysis Physicians](#) and [Japanese Society](#)

Table 1 The number of HIV positive patients on dialysis in a facility

(No. of persons)	The number of responses	%
0	2483	96.1%
1	58	2.2%
2	13	0.5%
3	1	0.0%
No answer	28	1.1%

for [Dialysis Therapy](#) in 2010, “the Guidelines on Fundamental Handling and Infection Control in Dialysis Facilities in the fourth revised edition” published in 2015, and “Treatment Guidelines for HIV” published by the [Research Division of Ministry of Health, Labour and Welfare](#) in 2016 [4–6]. The actual compliance of these guidelines was really low based on the high frequencies of facilities unfamiliar, vaguely familiar, or familiar without practice of these guidelines, as shown in [Table 8](#). The proportion of the facilities that never knew about all these guidelines accounted for 3.8% (98 facilities).

The proportion of facilities intending to accept HIV-positive patients for dialysis in future was as low as 16.9% (436 facilities), while the proportion of facilities intending to refuse it was 38.3% (988 facilities). Furthermore, the proportion of facilities selecting “others” accounted for 43.1% (1114 facilities) ([Fig. 3](#)). 20.4% of the facilities with the intention to accept refused to transfer the results of our questionnaire survey to HIV core hospitals ([Fig. 4](#)). Considering the opinions from all facilities, 65.9% (460 facilities) accepted to transfer the results of this questionnaire survey and 26.1% refused (data not shown).

Discussion

The current questionnaire survey, performed in response to the shocking article published in the “Tokyo Shimbun” in 2016 reporting that maintenance hemodialysis in a HIV-positive patient was refused by a series of 40 medical institutions, demonstrated that 40.1% of the dialysis facilities refuse dialysis for HIV-positive patients and 38.3%

Table 2 The number of HIV positive patients on dialysis in a facility in the past five years

(No. of persons)	The number of responses	%
0	2404	93.1%
1	107	4.1%
2	32	1.2%
3	5	0.2%
4	3	0.1%
More than 4	6	0.2%
No response	26	1.0%

Table 3 Responses of the request to accept the HIV positive patients

	The number of responses	%
Accepted	114	52.5%
Tried to accept, but refused by a patient	17	7.8%
Refused	87	40.1%
number of valid responses	217	–

would not intend to accept them in future. This shocking result closely matches with the report by Yanagisawa et al. showing that 55.3% of the facilities will not be willing to accept HIV-positive patients in future [3].

In the past, HIV infection caused patient death within a few years unless they were treated with the appropriate anti-HIV drugs. Multiple anti-HIV drugs have been developed and applied in the clinical practice since the latter half of 1990s. Subsequently, the prognosis of the HIV-positive patients dramatically improved to nearly the same as non-HIV patients. Along with improvements in life prognosis, we need to not only control the AIDS defining illnesses and malignant tumors, that are the principle causes of death in HIV patients, but also the comorbid chronic diseases such as diabetes mellitus, dyslipidemia, chronic kidney disease, and cardiovascular disease [2]. It has been reported that the prevalence of chronic kidney disease in HIV-positive patients in Japan is 15.4% [7]. Hara et al. reported that chronic kidney disease in HIV-positive patients progresses more rapidly than that in non-HIV patients [8]. Rasch et al. reported that the introduction rate of hemodialysis in HIV positive patients is 3.6 times higher than that of non-HIV patients [9]. Yanagisawa et al. reported in 2014 that the frequency of HIV-positive patients among those treated with hemodialysis is as low as 0.024% in Japan, which is significantly lower than the frequencies of 1% in the USA and 0.67% in France [3]. Our data from the survey estimated that the proportion of HIV-positive patients treated with dialysis (87) among all dialysis patients treated in the facilities that responded to the questionnaire (217,429) was as low as 0.04%. Consequently, these

Table 4 The situation at facilities with respect to preparation for accepting HIV positive patients

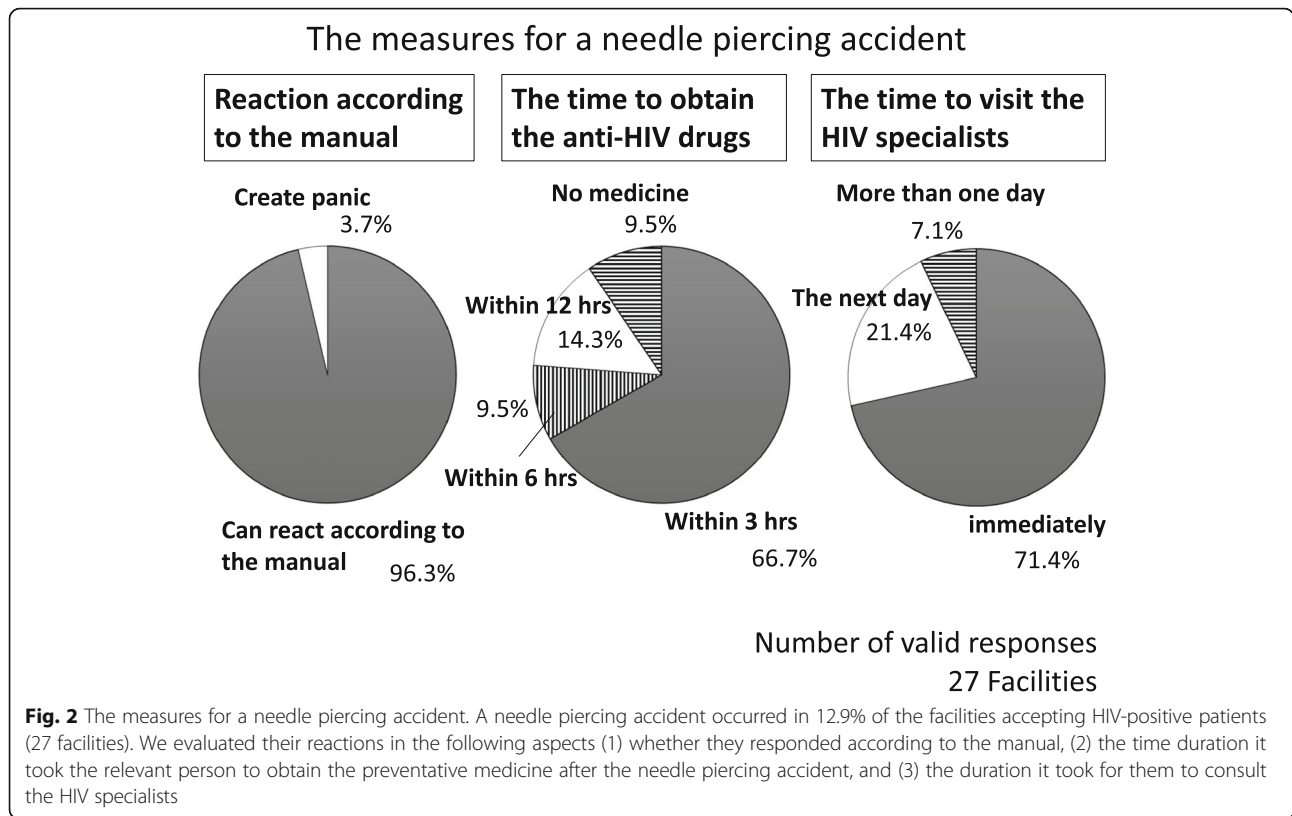
	Yes	No
A manual for needle piercing accidents ¹	96.6%	3.4%
Cooperation with HIV core hospitals ²	59.6%	40.4%
Stocks of anti-HIV drugs ³	51.1% ^a	48.9%

^a78.8% of the facilities pay their expenses themselves

¹:number of valid responses 207

²:number of valid responses 208

³:number of valid responses237



fewer number of HIV-positive patients among all dialysis patients compared to Western countries could cause a delay in the treatment plan for these patients in Japan because of the lack of interest and awareness.

As shown in this study, the principle reasons for the refusing healthcare to HIV-positive patients were the lack of basic knowledge on HIV infection among healthcare providers including insufficient experience of

doctors with HIV-infected individuals, leading to a biased impression, such as the fear of transmitting HIV infection. Our results suggest that the basic knowledge on infection control and prevention of HIV infection are not fully understood in these facilities. These include lower infection rates of HIV than HBV and HCV, (e.g., 0.09% infection rate after hematic mucosal exposure) and a low infectiousness of HIV-positive patients under

Table 5 The reasons for refusal at facilities that requested to accept

	number of responses	%
Not enough beds	19	17.4%
No experience of the practice	62	56.9%
No acceptance of outpatients	6	5.5%
No cooperation with HIV specialists (HIV core hospitals)	9	8.3%
No cooperation with HIV core hospitals	43	39.4%
Insufficient standard precautions in the facility	39	35.8%
No knowledge of needle piercing accidents	19	17.4%
No stocks of anti HIV drugs	57	52.3%
Anxiety of HIV infection risk	60	55.0%
Others	26	23.9%
Number of valid responses	109	-

Table 6 The general reasons for refusal in all facilities

	number of responses	%
Not enough beds	362	14.4%
No experience of the practice	1915	76.3%
No acceptance of outpatients	148	5.9%
No cooperation with HIV specialists (HIV core hospitals)	305	12.2%
No cooperation with HIV core hospitals	1130	45.0%
Insufficient standard precautions in the facility	645	25.7%
No knowledge of needle piercing accidents	730	29.1%
No stocks of anti HIV drugs	1280	51.0%
Anxiety of HIV infection risk	1630	63.9%
Others	176	7.0%
Number of valid responses	2510	-

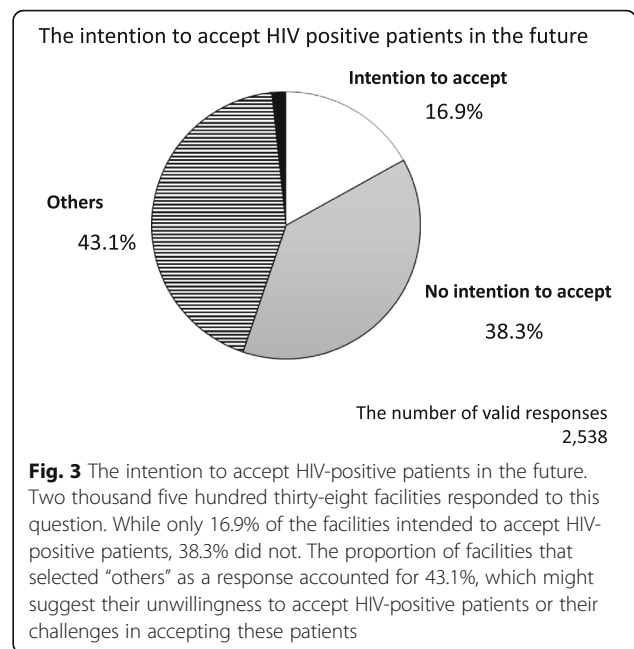
Table 7 Cooperation with facilities that have experiences of accepting HIV positive patients, or with HIV core hospitals

	number of responses	%
Experience of cooperation	221	8.9%
No experience of cooperation	1612	65.2%
Intention of cooperation	443	17.9%
No intention of cooperation	651	26.3%
Others	140	5.7%
number of valid responses	2472	-

good control with regular antiviral treatment [10]. In addition, appropriate measures after a needle piercing accident are not recognized in these facilities. Infection control for the HIV-infected, as per “the guidelines on fundamental handling and infection control in dialysis facilities in the fourth revised edition,” does not ask for patient isolation or fixed position of beds, but only for standard precautions such as hand hygiene and individual protection for healthcare providers [5]. Moreover, our analysis indicated a serious problem that the institution members are not familiar with currently available guidelines. It is an urgent task to disseminate the above described guidelines available at present. Taken together, our association with the help of guidelines needs to disseminate basic knowledge such as the infection rate, and the strategies for infection control in HIV, and provide the appropriate environment for imagery rehearsal through educational lectures, a symposium or lectures by the facilities that have accepted HIV-positive patients.

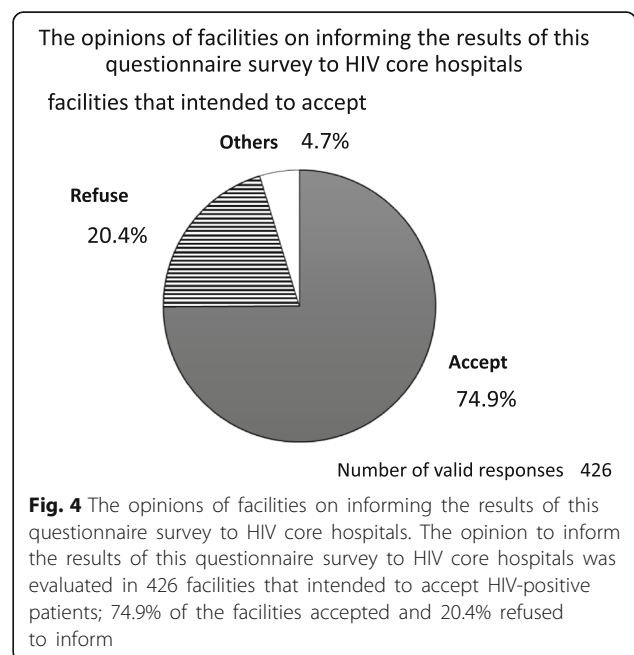
Table 8 Knowledge of HIV related guidelines

‘The Guidelines for Dialysis of HIV Positive Patients’ published by Japanese Association of Dialysis Physicians and Japanese Society for Dialysis Therapy in 2010			
Very familiar	Aware without practice	Vaguely familiar	Unknown
11.3%	43.2%	38.6%	7.4%
Number of valid responses 2552 (some facilities selected several answers at the same time)			
‘The Guidelines on Fundamental Handling and Infection Control in Dialysis Facilities in the fourth revised edition’ published in 2015			
Very familiar	Aware without practice	Vaguely familiar	Unknown
20.2%	46.7%	26.7%	6.7%
Number of valid responses 2553 (some facilities selected several answers at the same time)			
‘Treatment Guidelines for HIV’ published by research division of Ministry of Health, Labour and Welfare in 2016			
Very familiar	Aware without practice	Vaguely familiar	Unknown
6.1%	27.7%	42.8%	23.6%
Number of valid responses 2546 (some facilities selected several answers at the same time)			



Furthermore, our association could set up a support section for the acceptance of HIV patients requiring dialysis.

Our questionnaire survey highlighted that many dialysis facilities did not have a system for accepting HIV-positive patients including a manual for needle piercing accidents, stocks of anti-HIV drugs, or develop cooperation with HIV core hospitals. While the manual for a needle piercing accident was prepared at more than 95% of the facilities that accept HIV patients, the figure



was not 100% (Table 4). It is desirable to establish a cooperative relationship between the dialysis facilities and HIV core hospitals to accept HIV patients, allowing the latter to help the former by providing useful information in an emergent situation. Another reason why dialysis facilities may not be willing to accept HIV patients is the economic burden of stocking anti-HIV drugs for needle piercing accidents. In fact, 51.1% of the facilities stock anti-HIV drugs and 78.8% of these pay for it themselves. The currently recommended preventative medicine for a needle piercing accident is a combination of twice a day Raltegravir (Isentress[®]) and once a day Truvada (Truvada[®] Combination Tablet). In an emergency situation, it is recommended that the person with exposure takes each tablet with their own consent and visit for consultation to a HIV core hospital. However, they generally leave the cost for preventative therapy to the dialysis facilities. This is not preferable for the dialysis facilities because these medicines are expensive (1510.4 yen/tablet for Raltegravir and 3756.3 yen/tablet for Truvada) and have a limited expiration date (30 months for Raltegravir and 3 years for Truvada). However, this problem could be solved by sharing of anti-HIV drug stocks through a collaborative group purchase by the HIV core hospitals. Thus, constructive discussions between the Japanese Society for AIDS Research and Japanese Society for Dialysis Therapy are needed to build an effective bounty system to reduce the economic burden on dialysis facilities.

The third problem is the low cooperation rate (8.9%) with HIV core hospitals among all concerned facilities (Table 7). "Treatment Guidelines for HIV" published by the [Research Division of Ministry of Health, Labour and Welfare](#) describes that HIV core hospitals need to cooperate with medical facilities in advance [6]. Though some facilities refused to transfer the results of this questionnaire survey to the HIV core hospitals, it may be useful to generate a list of dialysis facilities that have already accepted the transfer and distribute it to the HIV core hospitals. Moreover, a collaborative meeting between the facilities and HIV core hospitals to accept patients, led by our association could help to expand the acceptance rate by exchanging information not only between dialysis facilities and HIV core hospitals, but also among the dialysis facilities. The cooperation with HIV core hospitals is considered important as this would allow healthcare providers in the dialysis facilities to work in safer environments by access to updated information on preventative medicine and appropriate measures for a needle piercing accident from specialists at the HIV core hospitals. To solve these problems, we need to open the dialog with the Japanese Association for Infectious Diseases and the relevant academic societies. On the other hand, the fact that the frequency of facilities with intention to cooperate (17.9%) was lower than that of facilities without intention to cooperate

(26.3%) (Table 7), the fact that 45.0% of them pointed out the reason for refusal as lack of cooperation with HIV core hospitals (Table 6), and the fact that 20.4% of these refused to transfer the results of this questionnaire survey to HIV core hospitals (Fig. 4) suggest the difficulties behind the current approaches. Considering these points, member institutions may want to consider a more cautious approach rather than the traditional top-down approach through discussions and mutual understanding with the associated academic societies.

Though this questionnaire survey had a high response rate (64.0%), suggesting a high interest in this theme by member institutions, 36.0% of these could be considered less interested or to have no plan to accept HIV-positive patients. These facilities might not only lack the experience practicing with HIV-positive patients but also the basic knowledge. It is quite important to proceed with the establishment of educational and medical systems to expand dialysis facilities that are willing to accept HIV patients by challenging the problems clarified through this questionnaire survey.

Conclusion

In Japan, improvements in the prognosis of HIV patients have led to an increase in the number of patients requiring maintenance dialysis. Our questionnaire survey clarifies the lack of sufficient preparation and social support system for accepting HIV-positive patients in dialysis centers. The spread of knowledge on HIV, the establishment of a support system, and the cooperation of HIV core hospitals are the urgent needs, which will undoubtedly lead the progress on increased acceptance of HIV-positive patients for dialysis.

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Availability of data and materials

All data generated or analyzed during this study are included in this published article.

Authors' contributions

AY and MR analyzed the questionnaire survey and wrote the draft of this paper. YI, NO, YK, TS, YTakano, IT, KH, YN, NH, TY, SW, YTakemoto, and HN modified the draft. All authors read and approved the final manuscript.

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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