

End-of-life care for HIV-infected patients with malignancies: A questionnaire-based survey

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Abstract

Background: The number of HIV-infected patients who require palliative or end-of-life care is increasing, and the status of end-of-life care for HIV patients with malignancies is unclear.

Aim: This study aimed to evaluate the end-of-life care provided to HIV patients with malignancies in Japan.

Design: National cross-sectional questionnaire-based survey.

Setting/participants: Questionnaires were delivered to the medical staff of 378 regional core hospitals/core hospitals for AIDS and 285 palliative care units in Japan. Data were collected between August and October 2013.

Results: Overall, 226 regional core hospitals/core hospitals for AIDS (59.8%) responded. A total of 55 institutions (24.3%) provided end-of-life care to HIV patients with malignancies. Regarding the place of death of the patients, 69.1% died at the institution whereas 18.2% were transferred to palliative care units. The requests of 16 (29.1%) institutions to transfer patients to palliative care units were rejected. Of the 378 palliative care units, 179 (62.8%) responded. While 13 palliative care units (4.6%) provided care to hospitalized HIV patients with malignancies, 20 (11.2%) refused to accept these patients for treatment because of a lack of experience in treating these patients and a lack of knowledge regarding HIV infection.

Conclusion: Our findings suggest that in Japan, HIV patients with malignancies have difficulties obtaining hospitalization at a palliative care unit, which is likely due to a lack of experience among the professionals in treating such patients as well as a lack of knowledge about HIV.

Keywords

Palliative care, terminal care, AIDS, HIV, neoplasms, hospice

What is already known about the subject?

- The number of HIV-infected patients with malignancies who require palliative or end-of-life care is increasing.
- No study has described how end-of-life care is currently being provided for HIV patients with malignancies.

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What this paper adds?

- This study found that the place of death of HIV patients with malignancies was most often regional core hospitals/core hospitals for AIDS, and only a small percentage of patients died in a palliative care unit (PCU).
- HIV patients with malignancies have difficulties obtaining hospitalization at PCUs in Japan, which is likely due to a lack of experience among the professionals in treating such patients as well as a lack of knowledge about HIV.

Implications for practice, theory, or policy

- Efforts to improve the understanding of the management of patients with HIV infection and to understand their most common concerns, including requests for concealment of HIV status from family, should be prioritized.
- Educational programs focused on HIV infection should be designed to educate PCU staff nationally.

Introduction

The institution of combination anti-retroviral therapy (cART) has transformed HIV infection into a chronic disease and has resulted in a reduction in AIDS-related morbidity in developed countries. Furthermore, cART has resulted in a decrease in the incidence of AIDS-defining cancers, including Kaposi sarcoma, non-Hodgkin lymphoma, and cervical cancer.¹⁻⁴ In contrast, the incidence of non-AIDS-defining cancers (NADCs), including lung, liver, and anal cancer, has increased with the prolongation of patient's life expectancy.^{2,4-9} Furthermore, elevated mortality rates for NADCs have been reported for HIV patients.¹⁰

Symptom control, end-of-life care (EOLC), and quality of life (QOL) of patients with malignancies are extremely important. Palliative care for patients with advanced malignancies should be considered early in the course of the illness. Palliative care has been associated with improvements in QOL, mood, and survival.¹¹ The Japanese Ministry of Health, Labor, and Welfare (MHLW) has supported institutional palliative care services, which are called palliative care units (PCUs). As the importance of palliative care has spread, the number of PCUs in Japan has increased yearly. However, there are not enough PCUs; therefore, most terminal patients with malignancies have died in a general hospital. Furthermore, we have often found that HIV patients with malignancies experienced difficulties in transferring to different hospitals and home care, except if they transferred to hospitals that specialized in HIV infection. Therefore, HIV patients with malignancies may not receive sufficient palliative care or EOLC from palliative care specialists or specialized palliative care services.

In Japan, the MHLW has supported the HIV/AIDS core hospital system, which includes the AIDS Clinical Center, 14 regional core hospitals located throughout 8 regional blocks, and approximately 380 core hospitals. Since April 1999, all support has been provided in accordance with the Infectious Disease Control Law, which requires doctors to notify the MHLW of patients diagnosed with HIV and AIDS. The number of Japanese patients with HIV and AIDS has continued to increase. As of 2012, 14,706 patients with HIV infection and 6719 patients with AIDS

have been reported.¹² In addition, an increased prevalence of AIDS-related non-Hodgkin lymphoma has been reported.¹³ In the past decade, the incidence of non-AIDS-defining lung cancer has also increased.¹⁴ Thus, the number of HIV patients who require palliative care or EOLC is thought to be increasing. However, no systematic survey of EOLC for HIV patients with malignancies has been conducted, and the status of EOLC for HIV patients with malignancies is unclear. Therefore, we administered a cross-sectional questionnaire to evaluate the EOLC provided to HIV patients with malignancies in regional core hospitals/core hospitals for AIDS (RCHAs) and in PCUs.

Methods**Study design**

We developed two types of questionnaires to evaluate the EOLC of HIV patients with malignancies. The first was directed toward medical staff at RCHAs and was designed to evaluate the EOLC provided to HIV patients with malignancies (see Appendix 1). The second questionnaire was designed for medical staff at PCUs and aimed to evaluate the EOLC provided to HIV patients with malignancies and the eligibility of patients for admission to the hospital at each PCU (see Appendix 2).

This study followed the ethical guidelines for epidemiological research by the MHLW, and this guideline does not require the ethical approval of institutes for the questionnaires to medical staff without individual chart reviews.

Study participants

A total of 285 RCHAs and 378 PCUs were identified as of 2013 in Japan. RCHAs and PCUs that were not active were excluded. The target sample included the medical staff of all RCHAs and PCUs in Japan. Self-reporting questionnaires were sent to each institution in August 2013, along with a cover letter explaining the purpose of the study. Data were collected between August and October

2013. This study was allowed to be done without informed consents of patients according to ethical guidelines for epidemiological research by the MHLW.

Results

Questionnaire responses

A total of 226 RCHAs submitted responses to the questionnaire (response rate of 59.8%). The respondents included 212 medical doctors, 7 medical clerks, 6 nurses, and 1 medical pharmacist. In addition, a total of 179 PCUs (response rate of 62.8%) responded to the questionnaire. The respondents included 168 medical doctors, 10 nurses, and 1 medical clerk.

EOLC at RCHAs

Of the 226 RCHAs that responded to the questionnaires, 55 institutions (24.3%) provided palliative care to HIV patients with malignancies. Regarding the place of death, 69.1% of patients died at the institution and 18.2% died at home or at PCUs (Table 1). The total length of hospitalization, transition from a hospital to a different institution or to home care, patient requests for concealment of HIV status from family, treatment period for anti-retroviral (ARV) agents, and psychological support for patients were difficulties associated with providing EOLC to HIV patients with malignancies.

Of the 55 institutions with experience in providing palliative care, 16 (29.1%) respondents reported rejected requests for transfer to PCUs and 10 (18.3%) reported rejected requests for transfer to home care. The major causes of rejection of PCU transfer requests were that the medical professionals had a lack of experience and knowledge regarding the treatment of HIV infection (52.6%) and because they preferred to avoid continuing ARV therapy after hospital transfer (26.3%). The major causes of rejected requests to transfer the patient to home care were also a lack of experience and knowledge regarding medical treatment of HIV infection (69.2%), limited experience with providing psychological support to the families of HIV patients (46.2%), and issues with continued administration of ARV therapy after hospital transfer (30.8%).

EOLC at PCUs

Of the 179 PCUs that responded to the questionnaire, 13 (4.6%) had experience providing care to hospitalized HIV patients with malignancies (Table 2). Some institutions reported difficulties that were experienced when providing EOLC to HIV patients with malignancies. These included difficulties in providing psychological support for the families of the patients, difficulties with the use of ARVs, difficulties related to patient requests to conceal HIV infection status from the family, and difficulties providing psychological support to patients.

Table 1. End-of-life care for patients at regional core hospitals/core hospitals for AIDS in Japan.

	N	%
Experience providing end-of-life care for AIDS patients with malignancies		
Yes	55	24.3
No	171	75.7
Number of patients who received end-of-life care		
1–5	46	83.6
6–10	4	7.3
11–20	2	3.6
>20	2	3.6
No data	1	1.8
Place of patient death		
At the institution	38	69.1
At home	10	18.2
PCU	10	18.2
Another hospital	9	16.4
Difficulty in providing end-of-life care		
Total length of hospitalization	21	38.2
Transition from the hospital to a different institution or home care	15	27.3
The patient requested concealment of HIV status from family	15	27.3
Treatment period for ARVs	15	27.3
Psychological support of patients	13	23.6
Welfare system and medical expenses	5	9.1
How to use ARVs	4	7.3
Opportunistic disease	1	1.8
Medical staff providing care for HIV patients with malignancies at the end of life ^a		
Medical doctor	52	100
Nurse	50	96.2
Medical pharmacist	36	69.2
Dentist	7	13.5
Dietician	14	26.9
Social worker	44	84.6
Clinical psychologist	26	50.0
Physical therapist	10	19.2
Occupational therapist	4	7.7
Speech-language-hearing therapist	3	5.8
Religionist	0	0
Support of the specialty palliative care team and medical staff		
Yes	13	23.6
No	6	11.0
Yes/No ^b	32	58.2
No data	4	7.3
Request to transfer to PCUs rejected		
Yes	16	29.1
No	39	70.9
Rejection of the request to transfer to home care		
Yes	10	18.2
No	45	71.8

N: number of institutions; PCU: palliative care unit; ARVs: anti-retroviral agents.

^aThree institutions did not respond to the question.

^bAt some institutions, the specialty palliative care team and medical staff were combined.

Table 2. End-of-life care for patients at palliative care units in Japan.

	N	%
Experience providing end-of-life care for HIV patients with malignancies		
Yes	13	4.6
No	163	95.4
Difficulty in providing end-of-life care		
Psychological support for the families of patients	5	38.7
How to use ARVs	4	30.8
The patient requested concealment of HIV status from family	4	30.8
Psychological support of patients	4	30.8
The welfare system and medical expenses	2	15.4
Opportunistic disease	1	7.7
Medical staff providing care for HIV patients with malignancies ^a		
Medical doctor	15	100.0
Nurse	15	100.0
Medical pharmacist	6	40.0
Dentist	2	13.3
Dietician	4	26.7
Social worker	8	53.3
Clinical psychologist	5	33.3
Physical therapist	3	20.0
Occupational therapist	1	6.7
Speech-language-hearing therapist	0	0
Religionist	0	0
Rejection of the request to accept transfer to PCUs		
Yes	20	11.2
No	159	88.8

N: number of institutions; ARVs: anti-retroviral agents; PCU: palliative care unit.

^aTwo institutions did not respond to the question.

Of the 179 PCUs, 20 (11.2%) experienced rejection of requests to transfer HIV patients with malignancies to the PCU. Transfers to the PCU were rejected due to several causes, including limited experience and knowledge regarding the medical treatment of HIV infection (60.0%), difficulties in continuing the ARV therapy after hospital transfer (60.0%), prejudice of the medical staff against HIV-infected patients (20%), opportunistic disease (15.0%), and patient requests to conceal HIV infection status from the family (10.0%).

The eligibility of HIV patients with malignancies for admission into PCUs

The eligibility criteria of each PCU for the admission of HIV patients with malignancies are shown in Figure 1. Many survey respondents stated that continuing ARV

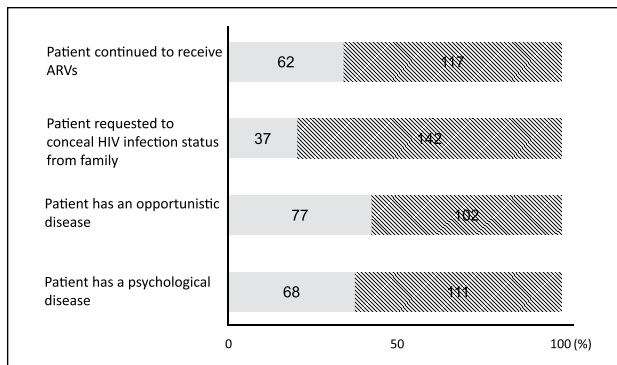


Figure 1. Eligibility criteria for each palliative care unit (PCU) for admission of HIV-infected patients with malignancies. Survey respondents answered questions as to whether patients meeting specific criteria would be eligible (gray columns) or ineligible (dashed columns) for treatment at the PCU. ARV: anti-retroviral agent.

therapy after hospital transfer, requests to conceal the HIV infection status from family, and opportunistic or psychological diseases prevented consideration for hospitalization in the PCU (65.4%, 79.3%, 57.0%, and 62.0% of respondents, respectively).

Discussion

Following the introduction of ARV therapy, the incidence of several non-AIDS disorders, including cardiovascular disease, cancer, kidney disease, liver disease, osteopenia or osteoporosis, and neurocognitive disease, has increased with the prolongation of the life expectancy of HIV patients.¹⁵ In a 20-year cohort study of extended follow-up of cART, it was demonstrated that the rates of NADCs have continued to increase over time.⁴ In addition, the incidence of NADCs, in particular viral infection and smoking-associated cancer, was significantly higher than expected among HIV patients.¹⁶ Furthermore, elevated mortality rates for NADCs have been reported for HIV patients.¹⁰ Therefore, HIV patients with malignancies who reach the end-of-life stage require palliative care and EOLC at an appropriate place.

The place of death of people with cancer varies widely across countries, and these differences are influenced by the countries' healthcare resources.¹⁷ In Japan, approximately 40% and 20% of people preferred to receive EOLC and die at home and in the PCU, respectively.¹⁸ However, almost 80% of terminal Japanese patients died in a general hospital, and a total of 350,000 cancer patients died during the fiscal year 2011, of which 9% made use of a PCU.¹⁹ In addition, this study has shown that HIV patients with malignancies have difficulties obtaining hospitalization at a PCU or transitioning to home care for several reasons, including a lack of experience in treating these patients and a lack of knowledge of HIV infection. Moreover, in this study, the opinions of the PCU staff regarding admission of

HIV patients with malignancies into PCUs differed based on whether the patients continued treatment with ARVs and whether the patients requested concealment of their HIV status from family (Figure 1). Treatment with ARVs and concealment of HIV infection from family are important concerns when caring for HIV patients, although medical staff who lack experience in treating patients with HIV may not understand these issues. Therefore, to promote the EOLC of HIV patients at PCUs and at home, educational programs and management guidelines that compensate for the lack of experience with HIV infection are needed.

The American Society of Clinical Oncology Provisional Clinical Opinion has recommended that combined standard oncology care and palliative care be considered early in the course of illness for any patient with metastatic cancer and/or a high symptom burden.²⁰ This opinion was based on a phase III randomized controlled trial performed by Temel et al.,¹¹ which demonstrated that palliative care was associated with improvements in QOL, mood, and survival. HIV patients with malignancies are considered for early palliative care; however, there may be issues accessing this care as a result of the difficult treatment of these patients. In this study, palliative care staff responded that psychological support for patients and their families and notification of the families of patients about the HIV infection status were difficulties experienced when providing EOLC to HIV patients with malignancies.

Patients with HIV infection have multidimensional problems,²¹ including physical pain²² and psychological symptoms such as depression,²³ social isolation,²⁴ and spiritual distress.²⁵ Therefore, the QOL of patients with HIV infection is lower compared to that of the general public and patients with other diseases. Differences in QOL between patients with advanced AIDS and cancer have also been demonstrated. Indeed, patients with AIDS had lower total and psychological QOL scores than patients with advanced cancer; however, patients with AIDS had higher physical QOL scores.²⁶ The effects of advanced cancer and HIV infection on the QOL of patients are unknown. Because these patients may experience increased pain, palliative care should be provided for total pain, including pain related to HIV infection.

Palliative care must never be a substitute for anti-retroviral therapy (ART) but rather these two services should be integrated.^{27,28} HIV patients with complex problems should be referred to a palliative care specialist for follow-up and management. However, the results of our study indicated that PCU staff generally had insufficient knowledge regarding HIV infection including the use of ARTs and that patients experienced difficulties in transferring to a PCU. The role of medical pharmacists in the care of HIV patients with malignancies has always been important for providing palliative care to patients while continuing appropriate ART. However, PCU pharmacists have participated in only 40% of this study. In addition, in this study,

we evaluated medical staff who care for HIV patients with malignancies at the end of life and found that the participation of medical staff, with the exception of medical doctors and nurses, was low. Patients with HIV and their families require the support of medical, psychological, and social specialists. Specifically, care for most HIV patients is provided by family, which decreases psychological stress substantially.²⁷ However, in our study, the patients often did not want to tell their families that they are infected with HIV. Therefore, providing psychological care for the patient becomes more difficult. The fact that patients frequently did not want to disclose their HIV status to their families was found to prevent transfer to PCUs. In addition, providing psychological support for patients and their families was found to be a common difficulty with EOLC; therefore, a team of clinicians including a clinical psychologist or nurse should provide more aggressive psychological care to both patients and their families.

In conclusion, we showed that in Japan, HIV patients with malignancies had difficulty obtaining hospitalization at a PCU. This is likely a consequence of the lack of experience of the staff in treating these types of patients and a lack of knowledge about HIV. Educational programs focused on HIV infection should therefore be designed in order to educate PCU staff nationally.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Appendix I

Questionnaire regarding end-of-life care for patients with AIDS at regional core hospitals/core hospitals for AIDS in Japan

1. Does your institution have experience with providing end-of-life care to HIV-infected patients with malignancies?

Yes

No

If “no,” please skip to Q2.

1-1. How many HIV patients with malignancies have received end-of-life care your institution?

1–5 patients

6–10 patients

11–20 patients

21 patients or more

1-2. Where did your patients with HIV die? (multiple choice)

Your institution

Another hospital

At home

At a palliative care unit

1-3. Did you experience difficulties with providing end-of-life care for HIV patients with malignancies?

Yes

No

If “no,” please skip to Q1-4.

1-3-1. How did you experience difficulties with end-of-life care for HIV patients with malignancies? (multiple choice)

The use of anti-retroviral agents (i.e. interactions and side effects)

The treatment period for anti-retroviral agents (the duration for which anti-retroviral agents were administered to HIV patients)

The patient had opportunistic disease

The transition from the hospital to a different institution or home care

The total length of hospitalization

Psychological support for patients

Patient requests for concealment of HIV infection status from family

The welfare system and medical expenses

Other

1-4. What type of medical professional administered palliative care to HIV patients with malignancies? (multiple choice)

Medical doctor

Nurse

Medical pharmacist

Dentist

Dietician

Social worker

Clinical psychologist

Physical therapist

Occupational therapist

Speech-language-hearing therapist

Religionist

Other

1-5. Please select the policy of the palliative care team at your institution for the treatment of HIV patients with malignancies.

There are no palliative care teams in my institution

A palliative care team exists at my institution, but the team is not commissioned to participate in palliative care for HIV patients with malignancies

A palliative care team exists at my institution and the team participates in palliative care for all HIV patients with malignancies

A palliative care team exists at my institution and the team occasionally participates in palliative care for HIV patients with malignancies

Other

2. Did you experience a refusal of a request to transfer a patient from the hospital to a palliative care unit for patients with HIV and malignancies?

Yes

No

If “no,” please skip to Q3.

2-1. If “no,” please select the reason: (multiple choice)

Poor experience and knowledge regarding the medical treatment of patients with HIV

The patient continued to receive anti-retroviral agents after hospital transfer

The patient had opportunistic disease

There were difficulties in providing psychological support to patients

Poor experience supporting patient families

Other

3. Did you experience any refusals of requests to transfer HIV patients with malignancies from the hospital to home care?

Yes

No

If “no,” please skip to Q3-1.

3-1. If “no,” please select the reason: (multiple choice)

Poor experience and knowledge regarding the medical treatment of patients with HIV

The patient continued to receive anti-retroviral agents after hospital transfer

The patient had opportunistic disease

There were difficulties in providing psychological support to patients
 There was poor experience in providing psychological support to the families of HIV patients
 Other

Dietician
 Social worker
 Clinical psychologist
 Physical therapist
 Occupational therapist
 Speech-language-hearing therapist
 Religionist
 Other

Appendix 2

Questionnaire regarding end-of-life care for patients at palliative care units

1. Does your institution have experience providing end-of-life care to HIV-infected patients with malignancies?

Yes
 No

If "no," please skip to Q2.

1-1. How many HIV patients with malignancies have received end-of-life care at your institution?

()patients

1-2. Have you experienced difficulty providing end-of-life care to HIV patients with malignancies?

Yes
 No

If "no," please skip to Q1-3.

1-2-1. How have you experienced difficulty in providing end-of-life care to HIV patients with malignancies? (multiple choice)

In the use of anti-retroviral agents
 Management and treatment of HIV infection and HIV infection-related opportunistic disease
 Psychological support for patients
 The welfare system and medical expenses
 Patient requests to conceal HIV infection status from family
 Psychological support for the families of patients
 Other

1-3. What type of medical professional administered palliative care to HIV patients with malignancies? (multiple choice)

Medical doctor
 Nurse
 Medical pharmacist
 Dentist

2. Did you experience any rejections of requests for hospital transfers to palliative care units for HIV patients with malignancies?

Yes
 No

If "no," please skip to Q3.

2-1. If "no," please select the reason(s): (multiple choice)

Poor experience and knowledge regarding the management and medical treatment of patients with HIV infection
 The patient continued to receive anti-retroviral agents after hospital transfer
 The patient had opportunistic disease
 There were difficulties providing psychological support to patients
 The patient requested concealment of HIV infection status from the family
 Prejudice of the staff of the palliative care unit
 Other

3. Please choose a policy of eligibility with respect to the hospitalization of HIV and AIDS patients at your institution. (multiple choice)

Even if HIV patients have to continue the anti-retroviral agents after hospital transfer, the patients are eligible for hospitalization in the palliative care unit.
 Even if HIV patients request concealment of the HIV infection status from family members, the patients are eligible for hospitalization in the palliative care unit.
 Even if HIV patients have opportunistic disease (hepatitis, encephalopathy, etc.), the patients are eligible for hospitalization in the palliative care unit.
 Even if HIV patients have psychological disease (adjustment disorder, depression, etc.), the patients are eligible for hospitalization in the palliative care unit.
 None of the above is relevant.