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Psychological support for people with hemophilia and HIV who suffer from cancer: A first national survey

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Abstract: Psychological support is necessary for people with hemophilia and HIV (PHH) who suffer from cancers. Most PHH are infected with not only HIV but also hepatitis C virus due to non-heat-treated blood coagulation factor products. PHH have a high risk of carcinogenesis, including liver cancer. Furthermore, many PHH present psychological problems, due to the great stress resulting from carcinogenesis and which impedes their cancer treatment. This study aimed to assess the psychological support system through a nationwide survey of healthcare workers caring for PHH at HIV care hospitals in Japan. The response rate was 49.1% (194/395), with a coverage rate of 74% (516/697) for PHH. Our findings indicated that psychologists were the most likely to be "coordinated" or "expected to coordinate" when PHH suffered from cancer (74%, multiple responses allowed). The most common reason for rating the adequacy of psychological support as "very good" or "good" was "easy collaboration with various professionals and medical teams". The number of HIV coordinator nurses and clinical psychologists per facility was 1.06 and 2.56, respectively. Our findings indicated more psychological support systems should be established in Japan, including reimbursement for psychological support for PHH.

***Keywords*:** HIV, hemophilia, cancers, psychologists, psychological support

Introduction

In the early 1980s, there were reported outbreaks of human immunodeficiency virus (HIV) infection among patients with hemophilia due to imported unheated blood coagulation products (*1-3*). There are currently estimated to be 697 people with HIV and hemophilia (PHH) in Japan (*2*). Improvements in antiretroviral therapy and dissemination of knowledge have dramatically decreased the incidence of acquired immune deficiency syndrome (AIDS) (*3-5*). As a result, however, there has been an increasing incidence of non-AIDS-defining malignancy (NADM) among patients with HIV, which may occur approximately 40 years after infection (*4,6*). Moreover, approximately 99% of PHH have co-infections with hepatitis B and C viruses and are at high risk of developing liver cancer (*4,6*). Among these patients, the standardized cancer incidence ratio (SCIR) is 2.08 (95% confidence interval [CI]: 1.48-2.90) for all malignancies, with liver cancer accounting for most NADMs (43%, SCIR: 23.09 [95% CI: 13.92-38.30]) (*6*).

The HIV medical care system in Japan was established in 1993 at the request of PHH members and is described in Hazardous AIDS Trial History (*7*). It is based on the notification from the Director-General of the Health and Medical Service Bureau of the Ministry of Health and Welfare, "Development of Regional Block Core Hospitals for AIDS Treatment", and is centered at the AIDS Clinical Center (ACC) established at the National Center for Global Health and Medicine (*7*). There are 14 block core hospitals in eight regional blocks, 54 core base hospitals representing each prefecture, and designated independent support medical institutions (the immune system outpatient care) throughout the country (*8*). The main support staff in those hospitals are HIV coordinator nurses (HIVCNs) who care for patients through a team approach in the comprehensive medical system; furthermore, they coordinate between departments as well as provide advice for the patient's understanding (*8*). "Senjuu Nurses" are those who spend at least 80% of their working hours engaged in HIV medical treatment. "Sennin Nurses" are those qualified to oversee both HIV and other medical treatment and spend at least 50% of their working time engaged in HIV treatment.

Generally, patients with cancers have a relatively high prevalence of depression and anxiety (*9,10*). Even

without meeting the diagnostic criteria for depression, the process of psychological acceptance of a cancer diagnosis involves gradual psychological distress, including denial, anger, bargaining, depression, and acceptance (*11*). Cognitive-behavioral formulations are useful tools for understanding the thoughts, feelings, and behaviors that can cause or maintain symptoms of depression or anxiety in patients such as treatment refusal, avoidance behavior, or excessive reassurance seeking (*10*). In Japan, some centers have recently established psycho-oncology teams that consist of psychiatrists, palliative care physicians, oncology nurses, and oncology pharmacists. Additionally, starting in 2022, the occupation of a certified public psychologist was updated with the calculation of guidance and management fees for patients with cancer; as such, they are very much expected to provide psychological care to these patients (*12*).

It is apparent that PHH have higher levels of psychological distress than people with hemophilia without HIV (*1,13*), indicating that many PHH may present mental health problems. A recent study showed that compared with people with HIV without hemophilia, PHH had a significantly lower prevalence of tension–anxiety and a significantly higher prevalence of low vigor (*14*). PHH who are suffering from cancer may experience further stress and significant psychological reactions. Additionally, their physical health may be affected by refusal to seek medical treatment due to reduced motivation. Counseling interventions by psychologists have been reported to help PHH gain self-awareness (*15*) and are of critical importance in major events such as cancer complications. However, such psycho-oncological interventions, treatments, or support systems for PHH have not been established. Additionally, there remain challenges in ensuring medical cooperation between hemophilia/HIV care professionals and cancer care professionals.

Accordingly, this study aimed to conduct a nationwide questionnaire survey among core hospitals providing HIV treatment to ascertain the status of their psychological support systems for PHH, especially those suffering from cancers.

Materials and Methods

Study design

A nationwide questionnaire survey was conducted in June 2023 among 395 HIV core hospitals and clinics providing HIV care (Table 1). The questionnaire included items regarding the number of PHH who visited each facility between January 1 and December 31, 2022, the number of cancer cases among them, the number of workers within each profession who cared for PHH, the degree of "psychological support" for PHH who were suffering from cancer, and the level of "mental care representing psychological support" at their facilities. Regarding "psychological support", we also included free-answer items, followed by after-coding using keywords and similar content. The questions regarding "psychological support" (Questions 3 and 4) were targeted to healthcare professionals at

Table 1. Questionnaire items

Question 1 How many people with hemophilia and HIV (PHH) visited the hospitals between January 1 and December 31, 2022? How many PHH were newly diagnosed with cancer?
Question 2 Tell us about the medical service system for people with hemophilia and HIV (PHH). Number of workers of each profession and employment status (number of full-time and part-time workers). HIV/AIDS practitioner, Board-certified member of the Japanese Society for AIDS Research, The Japanese Society of Psychosomatic Medicine specialist physician, The Japanese Society of Psychiatry and Neurology specialist physician, Board-certified consultation-liaison psychiatrist by the Japanese Society of General Hospital Psychiatry, Board-certified member of the Japan Psycho-Oncology Society, HIV coordinator nurse, Certified HIV infection nurse of the Japanese Society for AIDS Research, Clinical psychologist, Certified public psychologist, Other counselors, Certified social worker, and Mental health social worker. "Number of HIV coordinator nurses" is the total number of full-time nurses including Senjyuu or Sennin. For questions 3-5, there are some notes as follows: No answer is required if no PHH visits your facility. The respondent should be a medical professional who is involved in PHH treatment.
Question 3 If PHH are affected with cancer, what worker profession do you coordinate (or expect to coordinate) with in your facility on "mental care (psychological support)"? Please select the profession below (multiple answers allowed): (a) Certified nurse in palliative care (b) Oncology-certified nurse specialist (c) Certified nurse in cancer-related nursing (d) Certified social worker (e) Mental health social worker (f) Psychiatrist (g) Psychologist (h) Others (free description)
Question 4 Please assess the fulfillment level of the "mental care (psychological support)" system for PLWHH affected with cancer. Please select one and give the reason in free description. (a) Very good (b) Good (c) Neither good nor bad (d) Bad (e) Very bad

medical institutions attended by PHH.

Analysis

Fisher's exact test was used to assess the significance of the level of "psychological support" and the employment status of psychologists. A *p*-value of less than 0.05 was considered statistically significant.

Ethical considerations

The study protocol was approved by the Ethics Board of the Institute of Medical Science, University of Tokyo (approval no. 2021-71-1216) and adhered to the principles of the Declaration of Helsinki. The requirement for consent to participate was waived by the Institutional Review Board of the Institute of Medical Science, University of Tokyo, following national regulations.

Results

Questionnaire collection rate and coverage rate of people with hemophilia and HIV

Among 395 facilities that received questionnaires, 194 facilities responded (response rate 49.1%), of which 59 (30.4%) were medical facilities attended by PHH. The total number of PHH attending these hospitals was 516, representing a capture rate of 74.0% (516/697). Among them, 228 were attending ACCs and block core hospitals (22.8 PHH/facility, 44.2% [228/516], 10 facilities), 158 were attending core hospitals (6.07 PHH/facility, 30.6% [158/516], 26 facilities), and 130 were attending other medical institutions (5.65 PHH/facility, 25.2% [130/516], 23 facilities) (Figure 1). Moreover, eight PHH had been newly diagnosed with cancer in 2022 (1.6%, 8/516).

Medical service system for people with hemophilia and HIV

Table 2 shows the total number of healthcare workers involved in caring for PHH, their employment status, and the total and average number of workers per medical facility. The average number of HIV practitioners per facility was 4.63 persons, with 1.66 persons/facility being board-certified members of the Japanese Society for AIDS Research (JSAR), 4.11 persons/facility being specialists of the Japanese Society of Psychiatry and Neurology (JSPN), 2.56 persons/facility being Clinical psychologists, 2.38 persons/facility being certified public psychologists, 4.88 persons/facility being social workers, 1.06 persons/facility being HIVCNs, and 0.78 persons/facility being a certified HIV infection nurse of JSAR. HIVCNs were very few, and certified HIV infection nurses of JSAR were even fewer, with approximately three nurses assigned to four facilities. Among HIV clinicians, 35.3% (66/187, 47 valid responses) were certified by JSAR.

Regarding full-time workers, the average number of HIV practitioners per facility was 3.85 persons, with 2.79 persons/facility being specialists of JSPN,

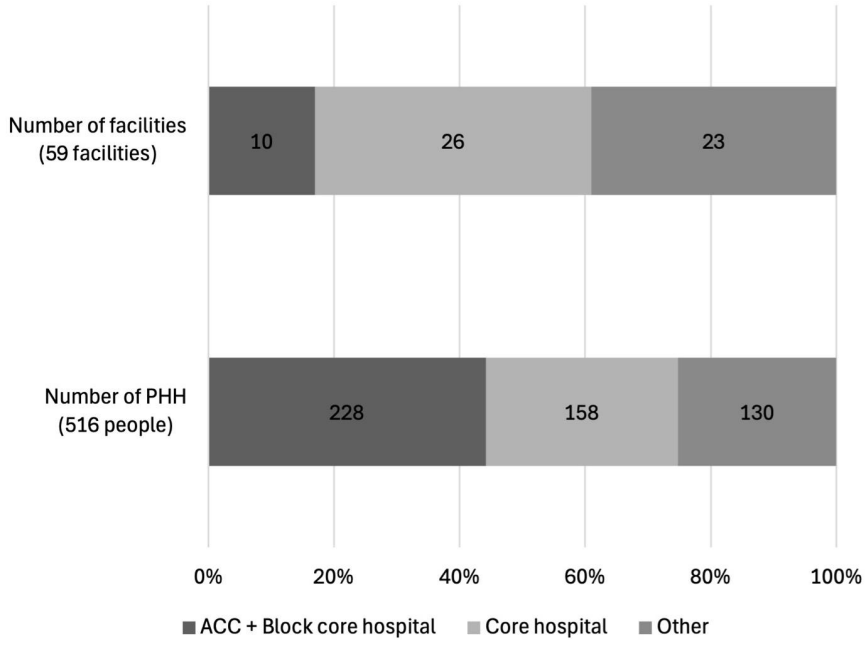

Figure 1. Number of facilities with valid responses and the number of outpatient PHH. ACC, AIDS Clinical Center; PHH, people with hemophilia and HIV.

Table 2. Medical service system for people with haemophilia and HIV

Professions	Number of facilities with valid responses	Number of full-time workers (person)	Number of part-time workers (person)	Average number of full-time workers (person/facility)	Average number of part-time workers (person/facility)	Average number of workers (person/facility)	Full-time work rate (%)
HIV practitioner	54	208	42	3.85	0.78	4.63	83.2
Board-certified member of the Japanese Society for AIDS Research	47	66	12	1.40	0.26	1.66	84.6
The Japanese Society of Psychosomatic Medicine specialist physician	35	1	1	0.03	0.03	0.06	50.0
The Japanese Society of Psychiatry and Neurology specialist physician	38	106	50	2.79	1.32	4.11	67.9
Board-certified psychiatrist by the Japanese Society of General Hospital Psychiatry	38	18	1	0.47	0.03	0.50	94.7
Board-certified member of the Japan Psycho-Oncology Society	35	3	0	0.09	0.00	0.09	100.0
Clinical psychologist	52	73	60	1.40	1.15	2.56	54.9
Certified public psychologist	47	60	52	1.28	1.11	2.38	53.6
Other counselor	36	8	20	0.22	0.56	0.78	28.6
Certified social worker	48	216	18	4.50	0.38	4.88	92.3
Mental health social worker	40	95	9	2.38	0.23	2.60	91.3

Professions	Number of facilities with valid responses	Number of Senjyuu HIVCNs (person)	Number of Sennin HIVCNs (person)	Average number of Senjyuu HIVCNs per facility (person/facility)	Average number of Sennin HIVCNs per facility (person/facility)	Average number of total Senjyuu and Sennin HIVCNs per facility (person/facility)	Senjyuu work rate (%)
HIV coordinator nurse	48	30	21	0.63	0.44	1.06	58.8
Certified HIV infection nurse of the Japanese Society for AIDS Research	48	16	21	0.33	0.44	0.78	43.2

Abbreviations: HIVCNs, HIV coordinator nurses.

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1.40 persons/facility being clinical psychologists, 1.28 persons/facility being certified public psychologists, and 4.50 persons/facility being certified social workers. Regarding the percentage of full-time workers (full-time work rate), 83.2% were HIV clinicians, 67.9% were specialists of JSPN, 54.9% were clinical psychologists, and 92.3% were certified social workers. Comparing the number of full-time workers per facility, it was found that the number of HIVCNs and clinical or public psychologists was less than one-third of the number of certified social workers.

As shown in Figure 1, the total number of PHH attending facilities differed across facilities; therefore, the average number of HIV practitioners, JSPN specialists, clinical psychologists, certified social workers, and HIVCNs working per facility was calculated separately for each medical facility category (Figure 2). The average number of JSPN specialists (3.13-4.64) and certified social workers (4.73-5.22) working per facility did not significantly differ among the three facility categories. However, HIV practitioners and HIVCNs working per facility were relatively higher in ACCs and block core hospitals (7.50 HIV practitioners and 4.63 HIVCNs) than in core hospitals (4.26 HIV practitioners and 0.57 HIVCNs) and other medical institutions (4.00 HIV practitioners and 0.11 HIVCNs). The average number of clinical psychologists (2.40-3.00) working per facility did not significantly

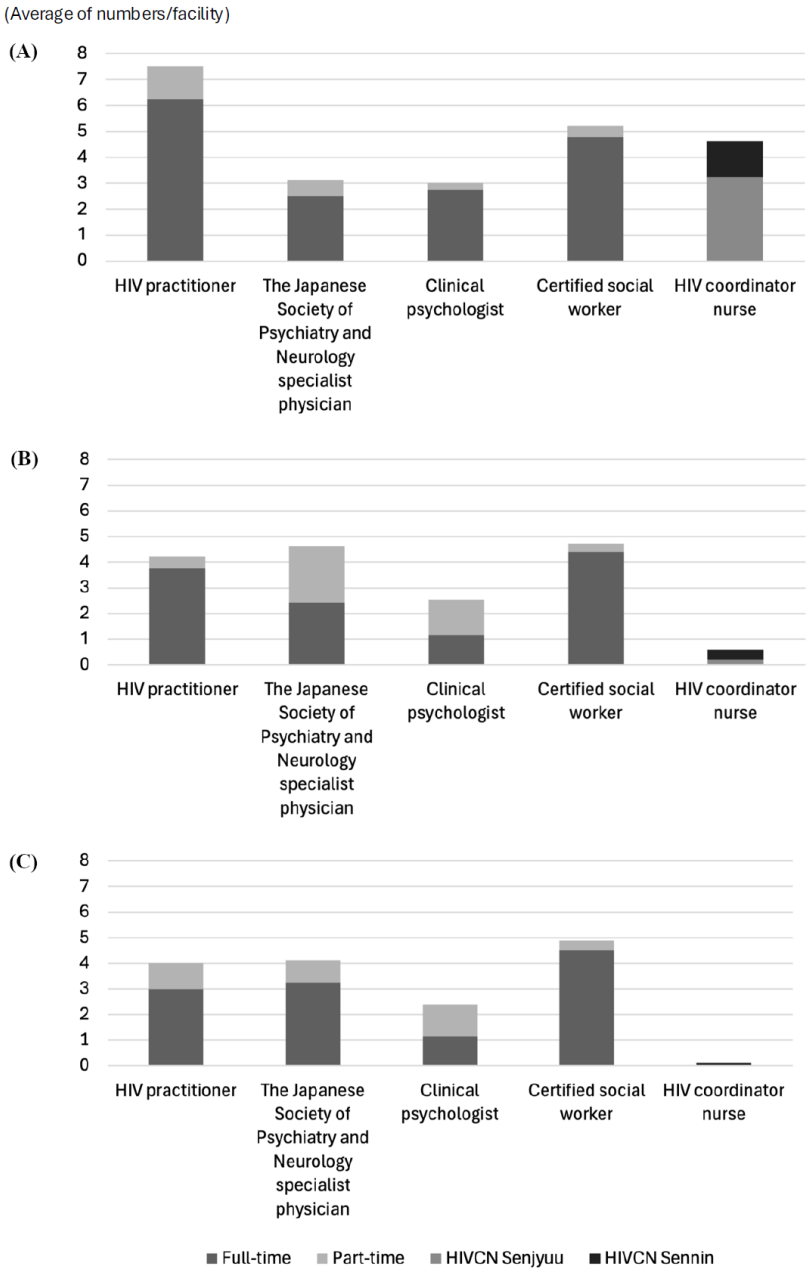

Figure 2. The average number of specialist workers. (**A**) ACC and nine block core hospitals, (**B**) Twenty-six core hospitals, **(C)** Twenty other hospitals. ACC, AIDS Clinical Center; HIVCNs, HIV coordinator nurse.

differ among the three categories; however, there were fewer full-time clinical psychologists in core hospitals and other medical institutions than in ACCs and block core hospitals.

System of coordination between professions in "psychological support" and the level of satisfaction at their own facilities

According to the responses, in cases of PHH with cancers, the most common occupations who coordinated (or expected to coordinate) in "psychological support" were psychologists (74.0%, 37/50), certified social workers (64.0%, 32/50), oncology-certified nurse specialists (58.0%, 29/50), certified nurses in palliative care (58.0%, 29/50), psychiatrists (52.0%, 26/50), certified nurses in cancer-related nursing (40.0%, 20/50), and "mental health social workers" (20.0%, 26/50) (Figure 3A). Only one medical facility listed the occupation as HIVCN. Despite the low average number of psychologists working per facility (2.56 for clinical psychologists, 2.38 for certified public psychologists, and 0.78 for other counselors), 74% of the facilities indicated psychologists as the profession with which they worked or expected to work with.

Figure 3B shows the level of "psychological support" for PHH with cancers at each facility. "Physiological support" was rated as "very good", "good", "Neither good nor bad", and "poor" in 7 (12%), 20 (34%), 21 (36%), and 2 (3%) facilities, respectively. Among institutions that rated "psychological support" as "very good", the most frequent reason for this rating was "Easy to cooperate with other professionals and medical teams" (42.9%, 3/7), followed by "Well-staffed for psychological support" (28.6%, 2/7). In institutions that responded as "Neither good nor bad", the most common reason was "Lack of experience" (23.8%, 5/21), followed by "Due to part-time psychologists" and "Difficulty in responding to sudden needs", both at 14.2% (3/21). There was one institution that cited, "We believe that support can be provided through the existing cancer patient support system, and there is no specialized system for PHH". The institutions that rated "psychological support" as "poor" tended

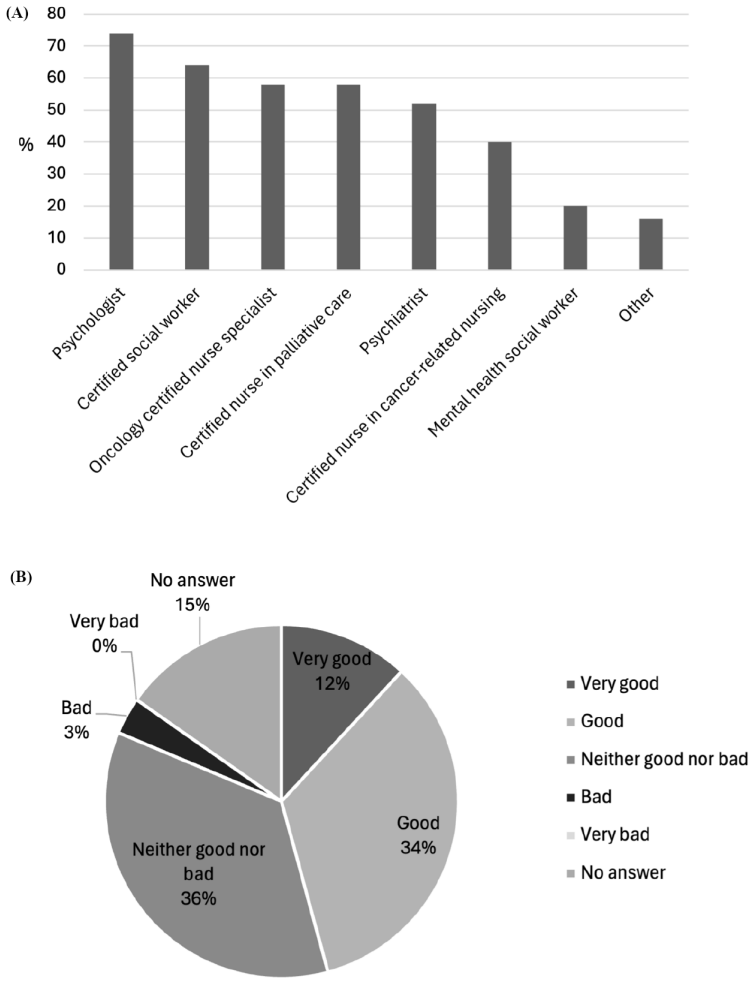

Figure 3. System of coordination among healthcare professionals working within an institution when PHH are affected by cancer. (A) Profession that coordinates with your facility (or expects to coordinate), multiple answers were allowed; 50 hospitals responded. **(B)** Fulfillment level of psychological care (psychological support).

to have "no access to counselors" and "no system for PHH". Moreover, institutions that rated "psychological support" as "very good" tended to have more full-time psychologists than the "undecided" institutions. Still, this difference was not significant ($p = 0.19$).

Discussion

This is the first national questionnaire survey regarding the psychological support system in medical institutions handling PHH affected by cancer. In our survey, the capture rate for PHH was 74%, suggesting a high level of interest among healthcare professionals involved in the psychological care of PHH patients with malignancy. Additionally, psychologists were the most common profession (74%) that medical workers would coordinate with in cases of PHH affected by cancer, suggesting that healthcare professionals treating PHH trust and expect psychologists to provide "psychological support".

In the 1990s, countries such as France, Germany, Switzerland, Canada, Italy and the USA established reimbursement programs for PHH (*16*). Sulser emphasized the need for physicians, government agencies, and industry to complement policy decisions with considerations of medical ethics, psychosocial factors, and quality of life. He also stressed that vigilance regarding the safety of therapy for PHH must be maintained (*17*). In the Netherlands, the treatment of hemophilia became increasingly centralized from the early 2000s. By 2013, standard criteria were introduced in hemophilia treatment centers, treatment guidelines were revised, and in 2014, all patients infected with HCV were treated with direct-acting antiviral drugs, achieving complete eradication of the virus (*18*). However, many countries have yet to identify all PHH. Moreover, no country has reported successfully implementing comprehensive psychological support for PHH. It has been suggested that Japan faces similar challenges, where not all PHH are adequately identified or treated uniformly. Psychological support, particularly for aging PHH who may develop malignancies, is likely a global concern but has not been thoroughly investigated or reported.

As mentioned above, HIV care is provided by three medical systems in Japan (*7,8*). In our study, the largest proportion of PHH attended ACCs and block core hospitals (44.2%), followed by core hospitals (30.6%) and other medical hospitals (25.2%). This could be assumed to represent the current situation regarding hospital attendance by PHH throughout Japan. The average number of staff working per facility was very low for HIVCNs (1.06 people/facility) compared with those for HIV practitioners (4.63 people/facility) and JSAR-certified doctors (1.66 people/facility). This also indicates that 64.7% of HIV practitioners at each facility were not JSAR-certified doctors (Table 2). HIV practitioners and HIVCNs working per facility were relatively higher in ACCs and block core hospitals (7.50 HIV practitioners and 4.63 HIVCNs) than in core hospitals (4.23 HIV practitioners and 0.57 HIVCNs) and other medical institutions (4.00 HIV practitioners and 0.11 HIVCNs) (Figure 2). These results suggest that the burden on HIVCNs and HIV practitioners at facilities other than ACCs and block core hospitals was relatively high. However, it should be noted that there are differences in the number of PHH attendees at different facilities. Even considering these factors, our findings may indicate an extremely low number of assigned HIVCNs, especially in core hospitals and other medical hospitals.

As earlier mentioned, mental health issues are more prevalent among PHH than in the general population. It has been estimated that approximately 50% of PHH have neurocognitive dysfunction (*19*). Moreover, Komatsu *et al.* reported a high prevalence of "low vigor" among PHH, leading to impaired executive and social functioning. Therefore, healthcare professionals should pay attention to the vigor, executive functioning, and social functioning in PHH (*14*). Moreover, in addition to HIV infection, many PHH have suffered from other chronic complications such as type 2 diabetes and cardiovascular disease. Generally, depression is correlated with chronic illness and affects treatment adherence, so that patients with depression are three times more likely to be non-compliant to treatment than patients without depression (*20*). Psychological support of patients with chronic illness requires the intervention.

In our study, psychologists were the most common profession (74%) that workers would coordinate with in cases of PHH affected by cancer. Further, medical institutions with "very good" psychological care tended to have full-time psychologists; however, there was no significant difference compared with institutions with "neither good nor poor" psychological support. In facilities with "very good" psychological care, this is attributed to the relative ease of coordination between the various professionals and healthcare teams. The National Institute for Health and Clinical Excellence practice guidelines in the UK include a recommended "stepped care model" (*21*). This is a useful model for depression and palliative care in patients with cancer. In the beginning, a liaison team of psychologists, psychiatrists, and psychiatric liaison nurses provide support through supervision, while doctors and nurses in each department provide screening and preventive intervention. The model shows the hierarchy of the level of intervention required; for example, psychologists and other professionals coordinate to intervene when depression becomes apparent. As mentioned earlier, facilities with "very good" psychological have relatively easy coordination among the various professionals and healthcare teams, thus these facilities may be capable of

establishing such a system.

Moreover, PHH affected by cancer often receive care and treatment in a department and medical facility different from the previously attended ones. Since childhood, PHH have suffered from fatal congenital diseases, endured HIV and HCV infections, and have faced life-threatening illnesses multiple times. Even though many of their peers have passed away, numerous PHH who are battling malignancies sometimes hesitate to seek treatment for these conditions. Accordingly, it is important to address how to maintain continuity of psychological support in such cases. Psychologists who understand the history of PHH, the mental health characteristics of PHH, and the characteristics of patients with chronic illness can provide "psychological support" throughout this transfer across departments/facilities for PHH with cancer.

Currently, certified public psychologists contribute to team medicine as treatment advisors for patients with chronic diseases, including obesity and heart failure (*22,23*). Certified public psychologists are included in the reimbursement of the cancer patient management fee, but not in the calculation of the medical fee (viral disease guidance and management fee) for ordinary medical treatment of PHH. This should be considered in future policy formulations. Taken together, it is important to develop a system for the stable placement of psychologists to allow continuous psychological support for PHH, even with the occurrence of cancer.

Further studies are strongly recommended. This study highlights that only a limited number of psychologists are currently engaged in this field. Therefore, we anticipate that more psychological professionals will enter this area, facilitated by measures such as reimbursement programs. However, prior to the implementation of a comprehensive medical system that includes reimbursement, alternative psychological support systems should be activated using the limited resources available. For instance, group psychotherapies such as mindfulness-based stress reduction and mindfulness-based cognitive therapy, which were originally developed as group interventions, could be employed (*24,25*). Additionally, in response to the challenges posed by COVID-19, various forms of psychotherapy have been successfully adapted for remote delivery through methods such as telephone and internet-based platforms (*26-29*). Furthermore, novel therapies like acceptance and commitment therapy (ACT) have emerged, aiming to enhance an individual's psychological flexibility in addressing difficult thoughts and feelings related to their physical condition. ACT operates through six core processes collectively known as the "ACT Hexaflex": acceptance, cognitive defusion, contact with the present moment, self-as-context, value-driven behavior, and commitment to value-driven behaviors (*30*). Given its adaptability, ACT may represent an ideal strategy for PHH, particularly in institutions where access to psychologists is limited.

This study has several limitations. First, the coverage rate of PHH in our survey was 74%; accordingly, we did not include approximately 200 PHH nationwide. Second, we could not determine the status of "psychological care (psychological support)" in medical institutions that did not respond. Although it can be assumed that "psychological support" may be enhanced by increasing the number of psychologists engaged, further studies are warranted to determine the extent to which the number of psychologists needs to be increased. Third, these issues are somewhat specific to Japanese PHH. Therefore, the psychological care findings from this study might not be generalized to other countries or regions. Finally, the respondents to the questions regarding "psychological support" were healthcare professionals, and it may be important to consider the opinions and needs from the perspective of PHH. Finally, the respondents to the "psychological support" questions were healthcare professionals, so it may be important to explore the opinions and broader needs of PHH themselves for a more comprehensive perspective and better healthcare management.

In conclusion, this is the first nationwide survey of the psychological support system for PHH with cancer. The coverage rate for PHH was 74%, indicating a high level of interest among healthcare workers. The average number of HIVCNs and JSAR-certified doctors per medical facility was low; further, the number of HIVCNs and HIV practitioners was especially low in core base hospitals and other medical facilities compared to ACCs and block core hospitals. Psychologists were the most common profession (74%) that workers would coordinate with in cases of PHH affected by cancer. Psychological support for PHH, many of whom may have psychological problems including stress, should be provided on a regular basis and continued in the event of a cancer.

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