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Future Long-Term Care Setting Preferences and Related Factors among Japanese Middle-Aged and Older People Living with HIV

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Abstract

Since the introduction of antiretroviral therapy, the life expectancy of people living with human immunodeficiency virus (PLWH) has extended. This extension has led to an increase in the aging population in Japan and globally. Providing appropriate long-term care (LTC) for PLWH has thus become increasingly critical. Our study aimed to describe LTC setting preferences and related factors among middle-aged and older Japanese people living with HIV. A cross-sectional survey was conducted at two hospitals in Tokyo. One hundred seventy-five outpatients aged 40 years and above participated in this study. Participants completed an anonymous self-administered questionnaire to assess where they wanted to live once they could no longer care for themselves. Approximately 52.0% preferred a designated facility for older adults or LTC, while 30.3% preferred their home or living with family, a partner, or a friend ("familiar housing"). Bivariate analyses revealed that LTC setting preference was significantly associated with marital status, whether or not the participant had at least one child, and household composition. Furthermore, logistic regression analysis revealed that participants living with non-kin were less likely to prefer living in designated housing facilities for older adults or LTC (adjusted odds ratio = 0.17, 95% confidence interval: 0.05 - 0.63). The study findings suggest that family make-up and composition of cohabiters are critical indicators for LTC setting preference in this population. These find-

ings can be the foundation for future care planning and delivery to meet the unique LTC needs and expectations of the aging population with HIV in Japan and similar global settings.

Keywords

Aging, Cross-Sectional Studies, HIV Infections, Patient Preference, Residence Characteristics

1. Introduction

Though human immunodeficiency virus (HIV) infection was once considered a death sentence, with shifts in the treatment landscape, the life expectancy of people living with HIV (PLWH) has increased worldwide, and consequently increasing the global aging population. Antiretroviral therapy (ART), introduced in the mid-1990s, and other measures for HIV infection have effectively decreased the onset of acquired immune deficiency syndrome (AIDS) and AIDS-related fatalities [1] [2]. These changes have contributed to prolonged treatment, which in turn, has extended the life expectancy of PLWH [3] [4]. By 2030, the proportion of PLWH receiving treatment for HIV older than 60 years is predicted to increase by approximately 40% [5]. Accordingly, it has now become a chronic illness with appropriate treatment. However, problems stemming from such prolonged treatments have emerged, including higher incidences of multiple premature noninfectious chronic comorbidities and non-AIDS-defining types of cancer [6] [7] [8] [9]. These conditions are linked to factors like chronic elevations in systemic inflammation and immune activation levels [10]. Therefore, measures to provide appropriate long-term care (LTC) for PLWH have become increasingly critical. However, LTC for older PLWH remains poorly understood.

Previous studies have offered insights into LTC service use plans, preferences, and patterns in general populations. Some have reported that such LTC usage variables are correlated with sociodemographic characteristics, including sex [11] [12] [13], marital status [12] [14] [15], education [13] [16], household composition [11] [13] [17], and financial status [13] [18]. Health status factors like cognitive impairment [12] [16] [19], physical impairment [12] [16] [20], and medical care needs [12] [21] have also been indicated as correlates of LTC service use measures. Other reports have suggested that support from family and social relationships may also be associated with such measures [13] [14] [22] [23] [24]. Certain psychosocial factors specific to minority groups (defined by their race/ethnicity), like the role of choice, may potentially be germane to LTC service use choices [25] [26].

In Japan, as in other countries, PLHW are now aging [1]; however, previous LTC surveys on PLWH were limited to the period when LTC was primarily due

to the ongoing after-effects of AIDS and prior to and around the introduction of ART. These surveys identified issues that complicated LTC for PLWH, which included long-term inpatient care for those who no longer needed hospitalization [27]. It is assumed that the hospitalizations resulted from the low acceptance of PLWH by general LTC facilities due to insufficient personnel and medical environment, a lack of knowledge about HIV infection [28], and difficulties related to home care with informal caregivers [29]. Based on these findings, specific measures have been taken to facilitate better coping, like the development of a tool for discharge support [30] and the implementation of training programs targeting social welfare facilities for general populations, including LTC facilities [31] [32]. Furthermore, the Japanese guidelines on preventing AIDS were recently revised. Issues like environmental arrangements for LTC for older adults and the security of accessing appropriate medical care and welfare were newly incorporated [33]. Thus, the challenges and steps necessary to improve Japan's formal caregiving structure have been elucidated to an extent.

Further, it has been reported that Japanese PLWH receiving support services may feel anxious about whether they could move into LTC facilities given their HIV seropositivity [34]. A study found that approximately half of the PLWH did not inform the medical staff of their HIV seropositivity at general medical facilities other than AIDS Core Hospitals because of a higher HIV-related stigma [35]. They might not necessarily discuss their HIV status, even with their significant others, who could become informal caregivers as they age. In a nationwide survey conducted in Japan, the proportion of PLWH who disclosed their status to a partner or spouse was 68.0% and 47.4%, respectively. Contrastingly, the proportion of those who disclosed to parents or siblings was less than 40% [36]. In the context of possible home care environments, Japanese PLWH generally have distinct household compositions compared to the general population, like more single households (47.1% of all PLWH) and non-kinship-based households (e.g., partners/lovers or friends) (17.4% of all PLWH) [36]. Generally, PLWH face circumstances, concerns, and motivations unique to their experience of living with HIV, which may critically affect planning, preferences, and actions related to using LTC services.

Existing studies have identified healthcare aspects valued by PLWH in the context of their aging [37] [38]. However, views and attitudes regarding LTC services, such as use plans, preferences, and patterns among PLWH as care recipients, have not yet been sufficiently documented. Thus, a better understanding of their views and attitudes will help inform future LTC service use planning and actions that maintain PLWH satisfaction and engagement, owing to their unique experiences regarding HIV infection. Therefore, considering the current situation of PLWH, it is imperative to examine issues regarding their preferences for residence when they require LTC due to aging. Thus, our study aimed to identify the preferences for LTC settings among middle-aged and older Japanese people living with HIV and to describe factors related to such preferences.

2. Methods

2.1. Design

A cross-sectional survey was conducted using an anonymous self-administered questionnaire.

2.2. Participants

Eligible participants for this study were HIV-seropositive outpatients from two of the 42 designated AIDS Core Hospitals in Tokyo. The AIDS Core Hospitals are designed to provide high-quality, specialized medical care and services for HIV and AIDS cases, with at least two facilities in each prefecture.

Outpatients meeting the following criteria were recruited: aged 40 years or older, literate in Japanese, and medically assessed as physically and mentally fit by medical staff. Outpatients were excluded from participation if they met one or more of the following criteria: living with hemophilia and those with LTC certification or support from the LTC Approval Board at the time of survey. All outpatients who visited hospitals on outpatient consultation days during the study period and met the criteria were recruited.

2.3. Procedure

The primary doctors and coordinator nurses selected participants based on the above-mentioned criteria. The coordinator nurses or researcher then explained the study details and ethical considerations in writing and orally. The questionnaires were then distributed to those who expressed a willingness to participate after their hospital consultations. The survey period at both hospitals was October-November 2014 and June 2015, respectively.

The ease of use and face validity of the questionnaire used in this study had been confirmed previously through interviews with three male PLWH aged 40 years or older and two consultants of a support organization for PLWH in Tokyo.

2.4. Measures (See Appendix)

- **Dependent variable:** The questionnaire item used to measure preference for LTC setting was generated based on the one used in a previous national survey of Japanese adult citizens on attitude toward life in retirement and social security [39]. This survey was conducted by the Ministry of Health, Labour and Welfare to obtain basic data for planning future health and labor management policies. The statistics by sex and age category have been published and are available online. This study's participants were asked questions, with reference to a hypothetical question based on an imagined future, following the item in the national survey [39]. The question concerned their preferred living arrangements, where they wanted to live once they could no longer care for themselves and needed assistance with daily life activities. They were asked to choose one response from the following options: "remain at home,"

"live with family," "live with partner," "live with a friend," "live in a paid home for older adults," "live in a group home for older adults," "live in a facility such as social welfare facility or health service facility for older adults," "live in a medical institution such as hospital," "do not know," or "other." We had added "live with partner" and "live with a friend" in our study, compared to the national survey [39], considering the variety of household compositions among PLWH.

The facility options are provided or underwritten by the public LTC insurance system in Japan, which covers requisite care and services, for home-dwelling and institutionalized individuals aged 65 years and above, and for those aged 40 - 64 years requiring care owing to specific age-related diseases, based on a care manager's comprehensive assessment. There are different types of facilities providing LTC under the program: "paid homes for older adults" (this type of facility comprises fee-based homes for older adults in need of LTC), "group homes for older adults" (this type of facility provides care, including daily life activities, in a homely atmosphere and group-living format), "social welfare facilities for older adults" (these facilities are for those in need of continuous care and who find it challenging to live at home), and "health service facilities for older adults" (facilities assisting those who leave hospital rehabilitation to independently handle everyday challenges) [40] [41].

- **Independent variables:** Perceived family support was measured using the Japanese version of the Family APGAR Scale [42]. This scale measures satisfaction with support from family based on five items: *Adaptation*, *Partnership*, *Growth*, *Affection*, and *Resolve*. Three responses were possible for each of the five items. Higher scores indicate greater satisfaction with family support (score range = 0 - 10). *Family* was defined as "people you consider family, regardless of actual kinship, any relationship, or living together" in the included instructions. Cronbach's α of the Family APGAR scale was 0.941.

  The Internalized AIDS-Related Stigma Scale (IA-RSS) [43] was used to measure internalized stigma of PLWH. This psychometric scale measures self-defacing beliefs and negative perceptions of PLWH based on six dichotomous response items. Higher scores indicate greater internalized stigma (score range = 0 - 6). Because a Japanese version of this scale had not yet been developed, we developed one through forward and back translations. The original author verified the back translation, and permission was duly acquired to use the Japanese version of the IA-RSS. Cronbach's α of the IA-RSS was 0.821.

  Other assessed factors included: age, gender, sexual orientation, marital status, having children, household composition, education, employment, financial status, living on welfare, the role of choice in determining LTC setting, HIV-related health status, and HIV infection disclosure and self-rated health statuses.

2.5. Data Analyses

The data collection periods were different for the two selected hospitals. Howev-

er, few differences were found in the participant characteristics of each hospital. Thus, the data were analyzed together.

The responses were coded into two categories in bivariate and multivariate analyses to clarify factors related to preferences for LTC settings: *living in familiar housing* (remaining at home/living with family, partner/lover, or friend) versus *living in a designated housing facility for older adults/LTC* (living in a paid home for older persons/group home for older adults/facility such as social welfare facility or health service facility for older persons/medical institution such as a hospital).

Fisher's exact tests were used to compare the characteristics of participants and their preferences for LTC settings. A logistic regression analysis was performed with a coded preference for LTC settings as the dependent variable. Independent variables included age, sexual orientation, having a spouse/partner, having a child, household composition, HIV infection disclosure, self-rated health, self-rated financial circumstance, role of choice in determining LTC setting, family support, and internalized AIDS-related stigma. The total scores for family support and internalized AIDS-related stigma were dichotomized at the median to create "high-" and "low-" scoring groups for analyses.

All data analyses were conducted with IBM SPSS Version 24.0 for Windows (IBM SPSS, Inc., Chicago, IL, USA). The significance threshold was set at 0.05.

2.6. Ethical Considerations

Our study was approved by the appropriate ethics committee and the institutional review boards of the hospitals where the survey was conducted. All procedures and study details were explained to the participants, in writing and orally, along with assurances of anonymity and that participation was voluntary. Return of the questionnaire was regarded as consent to participate. A 500-yen gift card was enclosed with questionnaires as compensation.

3. Results

Of 331 outpatients, 230 returned completed questionnaires (69.5%). We excluded 55 questionnaires because of missing values for the dependent variable or based on inclusion/exclusion criteria. Thus, we analyzed data from 175 participants' questionnaires (52.9%).

The participants' characteristics are shown in Table 1. A majority of the participants were in their 40 s (n = 87, 49.7%), men (n = 154, 94.5%), and self-identified as homosexual or bisexual (n = 135, 79.0%). Approximately two-thirds (n = 116, 66.3%) were single, almost half (n = 80, 45.7%) had no spouse or partner, less than a quarter (n = 40, 23.0%) had children, and almost half (n = 84, 48.0%) lived alone at the time of the survey. Nearly all participants (n = 172, 98.3%) had started ART. A majority (n = 117, 67.6%) rated their health as good or relatively good. Twenty-four (13.9%) had not disclosed their HIV status to anyone. The median (IQR) of the Family APGAR score was 5 (2 - 8).

Table 1. Participants' sociodemographic, clinical, and psychosocial characteristics (n = 175).

Variables		n or Median	% or IQR
Age (in years)	40 - 49	87	49.7
	50 - 59	49	28.0
	60 - 69	33	18.9
	≥70	6	3.4
Gender	Man	154	94.5
	Woman	8	4.9
	Other	1	0.6
Sexual orientation	Homosexual	100	58.5
	Bisexual	35	20.5
	Heterosexual	30	17.5
	Do not know	6	3.5
Marital status	Single	116	66.3
	Married	36	20.6
	Divorced/widowed	21	12.0
	Other	2	1.1
Having spouse/partner	Yes-Spouse	36	20.6
	Yes-Partner (unmarried)	59	33.7
	No	80	45.7
Having any children	Yes	40	23.0
	No	134	77.0
Education	≤High school	50	29.1
	College/junior college	36	20.9
	≥Undergraduate school	86	50.0
Employment status	Employed	120	69.4
	Unemployed	53	30.6
On welfare	Yes	22	12.6
	No	153	87.4
Self-rated financial circumstance	Well-off/quite well-off	49	28.0
	Neutral	55	31.4
	Quite bad/bad	71	40.6
On ART	Yes	172	98.3
	No	3	1.7
CD4 count (cells/μl)	Less than 200	23	13.2
	200 - 349	23	13.2
	350 - 499	44	25.3
	More than 499	79	45.4
	Do not know	5	2.9

Continued

Self-rated health	Good/relatively good	117	67.6
	Usual	40	23.1
	Relatively bad/bad	16	9.2
Household composition	Living alone	84	48.0
	Living with kin	53	30.3
	Living with non-kin	32	18.3
	Living with both kin and non-kin	2	1.1
	Other	4	2.3
Family APGAR score[a]	(Minimum: 0, Maximum: 10)	5	2-8
HIV infection disclosure status[b]	To at least one person	149	86.1
	To no one	24	13.9
IA-RSS score[c]	(Minimum: 0, Maximum: 6)	4	2 - 6

Totals for each variable may not add up to 175 due to missing data; ART = antiretroviral therapy; CD4 = cluster of differentiation 4; IQR = Interquartile range; a. Family APGAR: higher score indicated higher satisfaction with family support (range: 0 - 10); b. HIV infection disclosure status to member of personal social/family network. Categories include spouse, partner/lover, ex-partner/ex-lover, child, father, mother, sibling, friend, coworker, and other; c. IA-RSS = Internalized AIDS-Related Stigma Scale: higher scores demonstrate greater internalized stigma (range: 0 - 6).

3.1. Preference for an LTC Setting

Participants' overall LTC setting preferences are shown in Table 2. Approximately half (52.0%) preferred to live in a designated housing facility for older adults/LTC, given the imagined future scenario, while roughly one-third (30.3%) preferred to live in familiar housing.

3.2. Factors Associated with Preferences for LTC Settings

In the bivariate analyses (Table 3), preference for LTC settings (living in familiar housing versus living in a designated housing facility for older adults/LTC) was significantly associated with marital status ($p = 0.02$), having any children ($p < 0.001$), self-rated health status ($p = 0.01$), household composition ($p = 0.01$), and role of choice in determining LTC setting ($p = 0.01$). Participants who had at least one child and those who lived with any kin were likely to prefer to live in familiar housing as opposed to living in a designated housing facility for older adults/LTC. Participants who lived alone were likely to prefer to live in a designated housing facility for older adults/LTC as opposed to living in familiar housing.

The multivariate analysis (Table 4) revealed that participants who rated their perceived financial circumstances as "neutral/quite bad/bad" as opposed to "well off/quite well off" (adjusted odds ratio [AOR] = 0.10, 95% confidence interval [CI]: 0.03 - 0.40) and those who lived with non-kin as opposed to living alone (AOR = 0.17, 95% CI: 0.05 - 0.63), were less likely to prefer to live in a designated housing facility for older adults/LTC.

Table 2. Distribution of preference for LTC setting (n = 175).

Variables	n	%
Live in familiar housing	53	30.3
Remain at home	35	20.0
Live with partner	10	5.7
Live with family	7	4.0
Live with friend	1	0.6
Live in designated housing facility for older adults or for LTC	91	52.0
Live in facility like social welfare facility or health service facility	33	18.9
Live in medical institution like hospitals	31	17.7
Live in paid home for older adults	21	12.0
Live in group home for older adults	6	3.4
Do not know	24	13.7
Other	7	4.0

LTC = long-term care.

4. Discussion

4.1. Preferences for LTC Settings among Japanese PLWH

In our study, 30.3% of the surveyed PLWH in Japan preferred living in *familiar housing*. According to a national survey of Japanese citizens conducted by the Ministry of Health, Labour and Welfare, 21.6% of the population indicated a preference for remaining at home and living with family when we calculated the values standardized for age and gender among a sample of those aged 40 years or older based on the published statistics [39]. Conversely, 52.0% of study participants preferred living in *designated housing facilities*, compared to 60.0% of the age- and gender-standardized population in the national survey [39].

It was found that the PLWH are more likely to prefer familiar housing compared to the general population for various reasons. First, PLWH may be anxious about whether appropriate LTC services or facilities will be available to them as they age [34] [38] [44] [45]. Specifically, PLWH aged 50 years and above recognize themselves as the first vanguard cohort to experience growing into older adults living with HIV [45] [46]. Thus, this population had concerns about whether necessary mechanisms will be available to allow them to receive age-related care specific to HIV and about the potential HIV-related stigma and discrimination in designated housing facilities. Such concerns might cause them to feel uneasy about the perceived lack of suitable future housing prospects [44] [45]. Subsequently, it is assumed that PLWH prefer to remain in familiar environments compared to the general population.

4.2. Factors Associated with Preferences for LTC Settings

Participants having at least one child and living with any kin were more likely to

Table 3. Comparison of participants' characteristics by preference for LTC setting[a] (n = 144).

		LTC setting				
		Live in familiar housing[b]		Live in designated housing facility for older adults for LTC[c]		
Variable	n	n	%	n	%	p-value[d]
Age (in years)						
40 - 64	124	43	34.7	81	65.3	0.21
65 and older	20	10	50.0	10	50.0	
Gender						
Man	130	48	36.9	82	63.1	0.65
Woman	5	1	20.0	4	80.0	
Sexual orientation						
Homosexual	82	27	32.9	55	67.1	0.51
Bisexual	26	10	38.5	16	61.5	
Heterosexual	28	12	42.9	16	57.1	
Do not know	5	3	60.0	2	40.0	
Marital status						
Single	95	28	29.5	67	70.5	0.02
Married	30	15	50.0	15	50.0	
Divorced/widowed	17	10	58.8	7	41.2	
Other	2	0	0.0	2	100.0	
Having spouse or partner						
Spouse	30	15	50.0	15	50.0	0.19
Partner (unmarried)	50	15	30.0	35	70.0	
No	64	23	35.9	41	64.1	
Having any children						
Yes	35	20	57.1	15	42.9	<0.001
No	108	33	30.6	75	69.4	
Education						
≤High school	42	16	38.1	26	61.9	0.37
College/junior college	26	12	46.2	14	53.8	
≥Undergraduate schooling	74	23	31.1	51	68.9	
On ART						
Yes	142	51	35.9	91	64.1	0.13
No	2	2	100.0	0	0.0	
Self-rated health						
Usual/relatively bad/bad	46	10	21.7	36	78.3	0.01
Good/relatively good	96	41	42.7	55	57.3	

Continued

Self-rated financial circumstance						
Neutral/quite bad/bad	102	43	42.2	59	57.8	0.05
Well off/quite well off	42	10	23.8	32	76.2	
Household composition						
Living with any kin	43	21	48.8	22	51.2	0.01
Living with non-kin	29	14	48.3	15	51.7	
Living alone	72	18	25.0	54	75.0	
Family APGAR score[e]						
High score (6 and over)	59	25	42.2	34	57.6	0.28
Low score (≤5)	77	25	32.5	52	67.5	
HIV infection disclosure status[f]						
To no one	17	5	29.4	12	70.6	0.59
To at least one person	125	48	38.4	77	61.6	
Role of choice in determining LTC setting						
Choice is my own	89	26	29.2	63	70.8	0.01
Choice is someone else's	48	25	52.1	23	47.9	
IA-RSS score[g]						
High score (5 and over)	59	21	35.6	38	64.4	1.0
Low score (≤4)	81	29	35.8	52	64.2	

Total for each variable may not add up to 130 due to missing data; LTC = long-term care; ART = antiretroviral therapy; a. Responses of "Do not know" and "Other" were excluded from these analyses; b. Living in familiar housing included options of remaining at home, living with family, partner/lover, or friend; c. Living in a designated housing facility for older adults or for LTC included options of living in paid home for older adults, group home for older adults, facility such as social welfare facility or health service facility, and medical institution such as hospital; d. Calculated by Fisher's exact test; e. Family APGAR: Higher score indicates higher satisfaction with family support (range: 0 - 10). Dichotomized at median: 5; f. HIV infection disclosure status to member of personal social/family network. Categories include spouse, partner/lover, ex-partner/ex-lover, child, father, mother, sibling, friend, coworker, and other; g. IA-RSS = Internalized AIDS-Related Stigma Scale: Higher score demonstrates greater internalized stigma (range: 0 - 6). Dichotomized at median: 4.

prefer to live in familiar housing (vs. a designated housing for older adults/LTC), and those living alone were more likely to prefer to live in designated housing for older adults/LTC. Our findings emphasize family, like children or any other kin, as crucial providers of LTC services for PLWH, while supporting and expanding upon the previous literature about LTC service use plans, preferences, and patterns in the general population [13] [20] [47]. It was found that PLWH, however, frequently had cohabiters or partners. Notably, participants living with non-kin, compared with those living alone, were less likely to prefer to live in a designated housing facility for older adults/LTC.

In summary, family structure and composition of cohabiters are meaningful indicators of LTC setting preference for PLWH. A previous study about resilience in aging with HIV [48] showed that social connectedness is a source of

Table 4. Logistic regression analysis of factors associated with preference for living in designated housing facility for older adults or for LTC[a] (n = 110).

Variables	AOR	95% CI for AOR		p-value
		Lower	Upper	
Age (in years)				
65 and older	0.42	0.06	3.00	0.39
40 - 64 (reference)	1.00			
Gender				
Man	0.60	0.01	34.34	0.80
Woman (reference)	1.00			
Sexual orientation				
Homosexual	0.75	0.13	4.37	0.75
Bisexual	2.67	0.53	13.52	0.24
Heterosexual (reference)	1.00			
Having spouse/partner				
Yes-Spouse	0.61	0.08	4.75	0.64
Yes-Partner (unmarried)	1.08	0.30	3.93	0.91
No (reference)	1.00			
Having child				
Yes	0.26	0.05	1.33	0.10
No (reference)	1.00			
Self-rated financial circumstance				
Neutral/quite bad/bad	0.10	0.03	0.40	<0.001
Well off/quite well off (reference)	1.00			
Self-rated health				
Usual/relatively bad/bad	2.53	0.81	7.88	0.11
Good/relatively good (reference)	1.00			
Household composition				
Living with any kin	0.33	0.08	1.39	0.13
Living with non-kin	0.17	0.05	0.63	0.01
Living alone (reference)	1.00			
Family APGAR score[b]				
High score (6 and over)	0.61	0.20	1.88	0.39
Low score (≤5) (reference)	1.00			
HIV infection disclosure status[c]				
To at least one person	0.31	0.04	2.52	0.27
To no one (reference)	1.00			

Continued

Role of choice in determining LTC setting				
Choice is my own	1.88	0.65	5.46	0.24
Choice is someone else's (reference)	1.00			
IA-RSS score[d]				
High score (5 and over)	0.94	0.33	2.69	0.91
Low score (≤4) (reference)	1.00			

Missing data were excluded listwise; AOR = adjusted odds ratio; CI = confidence interval; HIV = Human immunodeficiency virus; a. Living in designated housing facility for older adults or for LTC includes options of living in paid home for older adults, group home for older adults, facility such as social welfare facility or health service facility, and medical institution such as hospital. Reference category is preference for remaining at home or living with family, a partner/lover, or a friend. Responses of "Do not know" and "Other" were excluded from this logistic regression model; b. Family APGAR: Higher scores indicate higher satisfaction with family support. Dichotomized at median: 5; c. HIV infection disclosure status to member of personal social/family network. Categories include spouse, partner/lover, ex-partner/ex-lover, child, father, mother, sibling, friend, coworker, and other; d. IA-RSS = Internalized AIDS-Related Stigma Scale: Higher scores demonstrate greater internalized stigma. Dichotomized at median: 4.

comfort and support in managing the challenges of living with HIV. Our findings suggest that PLWH who live with non-kin are less likely to prefer to live in a designated housing facility when they age and must shoulder the double burden of LTC needs and HIV. They may prefer to avoid concerns about potential HIV-related stigma and discrimination in the LTC setting [44] [45]. These results confirm the perspective that long-term social relationships can serve to buffer damaging societal interactions [48].

4.3. Strengths and Limitations

To the best of our knowledge, this study offers a novel perspective on preferences for LTC settings among middle-aged and older people living with HIV globally, in areas where aging with HIV is prevalent, along with the related demographic and psychosocial factors. Additionally, it focused on salient features stemming from the experience of aging with HIV. The survey method included an operational definition of family and various LTC setting options that considered the background of PLWH in Japan, and our findings have supported and expanded upon the previous knowledge in the general population.

Our study also had some limitations that should be considered. First, PLWH who participated in this study were relatively healthy, because those who were physically or mentally unstable were excluded. However, we understand that such individuals may have especially felt the pressing need for LTC. Furthermore, our study was conducted at only two facilities located in Tokyo, both of which are widely regarded as state-of-the-art AIDS Core Hospitals. Preference for LTC settings may differ among PLWH attending other hospitals with diverse care frameworks or among those living in other regions of Japan. Therefore, the results need to be generalized prudently, and future studies should incorporate a united sampling scheme among hospitals and a larger sample size.

Furthermore, our methods of measuring certain variables should be noted. We assessed the extent of disclosure based solely on whether participants had disclosed their HIV status to at least one person. However, disclosure in practice encompasses various concepts beyond this simplistic interpretation. Hence, future studies should clarify the specific dimensions of disclosure that affect the health or preferences for LTC settings of PLWH. Similarly, there are various stigma dimensions, which have not been focused on in our study. Future studies should thus elucidate these dimensions and their impact on preferences for LTC settings.

5. Conclusion

Our study described preferences for LTC settings among Japanese middle-aged and older people living with HIV and the related factors, focusing on the unique experience of aging with HIV. We found that PLWH were more likely to prefer to remain at home or live with family, a partner, or a friend, compared to Japan's general population. Thus, household composition, defined without reference to biological or legal relationships, emerged as a central element influencing these people's preferences to age in place. Our findings have critical implications for the design of future service delivery to accommodate unique LTC needs and expectations of aging populations of PLWH in Japan and similar settings globally.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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Appendix

Measure—Dependent Variable

Where would you like to live, once you can no longer care for yourself and need assistance with daily tasks such as eating and excretion?

☐ remain at home ☐ live with family ☐ live with partner ☐ live with a friend ☐ live in a paid home for older adults ☐live in a group home for older adults ☐ live in a facility, such as social welfare facility or health service facility for older adults ☐ live in a medical institution such as a hospital ☐ do not know ☐ other, to be specified ( )