Original Article

Preferences Regarding End-of-Life Care Among Adolescents and Young Adults With Cancer: Results From a Comprehensive Multicenter Survey in Japan

Hidekazu Hirano, MD, Chikako Shimizu, MD, PhD, Asuka Kawachi, MD, Miwa Ozawa, MD, PhD, Akiko Higuchi, MSW, Saran Yoshida, PhD, Ken Shimizu, MD, PhD, Ryohei Tatara, MD, and Keizo Horibe, MD, PhD

Department of Breast and Medical Oncology (H.H., A.K.), National Cancer Center Hospital, Tokyo; Department of Gastrointestinal Medical Oncology (H.H.), National Cancer Center Hospital, Tokyo; Department of Medicine (H.H.), Keio University Graduate School of Medicine, Tokyo; Department of Breast Medical Oncology (C.S.), National Center for Global Health and Medicine, Tokyo; Department of Pediatrics (M.O.), St. Luke's International Hospital, Tokyo; Children's Cancer Association of Japan (A.H.), Tokyo; Graduate School of Education (S.Y.), Tohoku University, Sendai, Miyagi; Department of Psycho-oncology (K.S., R.T.), National Cancer Center Hospital, Tokyo; Clinical Department of Palliative Medicine (R.T.), Osaka City General Hospital, Osaka; and Clinical Research Center (K.H.), National Hospital Organization Nagoya Medical Center, Nagoya, Japan

Abstract

Context. Patient preferences influence end-of-life (EOL) care which patients receive. However, preferences regarding EOL care among adolescent and young adult (AYA) cancer population remain unclear.

Objectives. The objective of the study was to evaluate preferences regarding EOL care among AYA cancer population.

Methods. We evaluated preferences regarding EOL care as a part of a comprehensive multicenter questionnaire study investigating the experience and needs of Japanese AYA cancer population.

Results. A total of 349 AYA cancer population (213 AYA cancer patients and 136 AYA cancer survivors) were evaluated. Eighty-six percent (296/344), 53% (180/338), 88% (301/341), and 61% (207/342) of participants with valid response preferred to have prognostic disclosure, receive palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity, actively use palliative care, and stay home at EOL, respectively. In multivariate analysis, the preference regarding prognostic disclosure was associated positively with no child status (odds ratio [OR] = 3.05, $P = 0.003$) and negatively with history of chemotherapy (OR = 0.23, $P = 0.009$), the preference regarding palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity was associated positively with status under active cancer treatment (OR = 1.74, $P = 0.03$), and the preference of staying home at EOL was positively associated with anxiety (OR = 1.72, $P = 0.04$).

Conclusion. This study elucidated preferences regarding EOL care among Japanese AYA cancer population. These findings may help health care practitioners to have better understanding of preferences regarding EOL care among this population. J Pain Symptom Manage 2019;58:235–243. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Adolescent and young adult, cancer, end-of-life care, preference, prognostic disclosure, chemotherapy

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H. H. and C. S. have equal contribution.

Address correspondence to: Chikako Shimizu, MD, PhD, Department of Breast Medical Oncology, National Center for Global Health and Medicine, 1-21-1, Toyama, Shinjuku-ku, Tokyo 162-8655, Japan. E-mail: cshimizu@hosp.ncgm.go.jp

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Introduction

Adolescent and young adult (AYA) cancer patients are defined as individuals who are diagnosed with cancer between the ages of 15 and 39 years.[1] Annually, the incidence of cancer in this population is nearly 70,000 patients in the U.S., and approximately 20,000 patients in Japan.[2] Despite steady progress in cancer treatment, improvement in survival has not been satisfactory in AYA cancer patients compared to populations of other ages, which positions cancer as one of the major causes of death in the AYA population.[1] When cancer becomes a terminal disease, end-of-life (EOL) care is among the important patient care considerations.

As a distinctive feature of EOL care in AYA cancer patients, intensive treatment is implemented in a small but significant proportion of this population. Administration of chemotherapy within 14 days of death, admission to an intensive care unit, and cardiopulmonary resuscitation were observed in 11%–36%, 21%–22%, and 12%–18%, of the AYA cancer patients, respectively.[3–6] Other characteristics regarding EOL care in this population include late timing of EOL discussions (median days before death of less than 7–89 days) and low proportion (16%) of death at home.[7]

Preferences of patients influence what kind of EOL care they actually receive. Previous studies mostly in adult cancer patients demonstrated that patient preferences were associated with EOL care such as prognostic disclosure, intensive EOL care, proactive use of palliative care, and place of death.[8–12] However, preferences regarding EOL care in AYA cancer patients remain to be elucidated. Filling the knowledge gap in this area may help health care practitioners to have in-depth insights into attitude of AYA cancer patients toward EOL care and construct an overarching framework that offers better EOL care for this population.

The primary objective of this study was to assess preferences regarding EOL care in the AYA cancer population by using data from a nationwide study that investigated the experience and needs of AYA cancer treatment in Japan. The secondary objective was to explore if sociodemographic factors were associated with preferences regarding EOL care.

Methods

Sociodemographic Data

A comprehensive nationwide survey to investigate the experience and needs of AYA cancer population was conducted in Japan with the support from Ministry of Health, Labor and Welfare and approval by institutional review boards of all participating institutions. An anonymous self-completion questionnaire was developed and validated in a pilot study in 10 cancer survivors who had cancer of AYA onset. Eligible participants for the survey were patients with any cancer type who had been receiving active cancer treatment at age less than 40 years or cancer survivors who were diagnosed of cancer at age 15–39 years. The following individuals were excluded from the study: 1) individuals who were considered unsuitable candidates with difficulty of completing questionnaires owing to serious physical or psychological symptoms by their physicians and 2) individuals who could not understand Japanese.

Eligible individuals receiving active treatment were screened at regular outpatient visits at 15 participating institutions across Japan and received explanation of the outline of the study orally. Questionnaires were delivered to individuals who were agreed with participation. In addition, 30 patient groups serving for AYA with cancer screened eligible individuals who were cancer survivors and send questionnaires to them.

Participants were asked to return completed questionnaires via mail to the study secretariat office. Return of a completed questionnaire was considered consent to participate in the study. Questionnaires were distributed to 593 AYA cancer patients and 752 AYA cancer survivors from June 2016 to November 2016. Of them, 225 AYA cancer patients (37.9%) and 261 AYA cancer survivors (34.7%) returned questionnaires.

As a part of this comprehensive survey, the present study was held to investigate preferences regarding EOL care in AYA cancer population. This study included a subpopulation of the main study as follows: 1) patients under active cancer treatment who were diagnosed of cancer at the age of 15–39 years and 2) cancer survivors who were diagnosed of cancer at the age of 15–39 years.

Measurements

Sociodemographic Data. Participants' characteristics included treatment status (under active cancer treatment or survivor), gender, cancer type, age at diagnosis of cancer, current age, educational status, working status, marital status, presence of children, and history of chemotherapy.

Hospital Anxiety and Depression Scale. Depression and anxiety have been associated with preferences of care in the setting of EOL.[13–15] The Hospital Anxiety and Depression Scale (HADS) was developed to identify anxiety disorders and depression among patients in nonpsychiatric hospital clinics.[16] The HADS is divided into an anxiety subscale (HADS-A) and a depression subscale (HADS-D). The HADS questionnaire is composed of seven items for HADS-A and seven items for HADS-D in an intermingled manner. Each item measures anxiety or depressive symptoms on a 0–3 scale over the prior week, yielding a total score ranging from 0 to 21. Higher total scores indicate more anxiety or depressive symptoms. A score of eight or higher was used to indicate the presence of anxiety in HADS-A subscale and the presence of depression in HADS-D subscale.[16]

Preference Regarding End-of-Life Care. Participants were asked about preferences regarding EOL care (prognosis disclosure, palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity, use of narcotic drugs for palliation of pain, place to stay at EOL). For the preference of prognostic disclosure, we asked participants "How do you wish for an explanation of expectable prognosis?" Participants selected an answer from the following choices: 1) "I wish to be informed of detailed expectable prognosis with the concrete figure," 2) "I wish to be informed of expectable prognosis with range," and 3) "I do not wish to be informed of expectable prognosis." For analysis, answers were dichotomized into "want to know prognosis" for choices 1 and 2 and "want not to know prognosis" for choice 3. For the preference of palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity, we asked participants "Which attitude do you prefer if cancer is an incurable disease?" Participants selected an answer from the following choices: 1) "I want to receive chemotherapy if there is a little possibility of response even when strong adverse effects are expected," and 2) "I do not want to receive chemotherapy which has an uncertain response and has strong adverse effects." For the preference of use of narcotic drugs for palliation of pain, we asked participants "Narcotic drugs are commonly used for palliation of pain or suffering. Which attitude do you prefer?" Participants selected an answer from the following choices: 1) "I want to actively receive treatment for palliation of pain or suffering" and 2) "I do not want to receive drugs as much as possible if there is a pain." For the preference of place to stay at EOL, we asked participants "Where do you want to stay if you are unable to visit hospital due to disease progression?" Participants selected an answer from the following choices: 1) home, 2) hospital, 3) hospice/palliative care unit, 4) other places (e.g., nursing home), and 5) no particular wish. For analysis, answers were dichotomized into "want to stay home" for choice 1 and "want to stay at places other than home" for choices 2, 3, 4, and 5, or "want to stay hospice/palliative care unit" for choice 3 and "want to stay at places other than hospice/palliative care unit" for choices 1, 2, 4, and 5.

Statistical Analysis

We used descriptive statistics to summarize participants' sociodemographic data. Chi-squared tests were used to evaluate differences in proportion. Logistic univariate regression analyses were performed to explore the potential association between sociodemographic factors and preferences of EOL care. To identify independent factors contributing to preferences of EOL care, all factors with P value of <0.25 in univariate analysis were used in multivariate logistic regression analyses. A P value of <0.05 was considered statistically significant in multivariate analysis. Multiplicity was not adjusted because of the exploratory nature of the investigation.

All statistical analyses were performed using SPSS for Windows (version 25.0; IBM Japan Institute, Tokyo, Japan).

Results

Characteristics of Study Participants

A total of 349 respondents (213 AYA cancer patients and 136 AYA cancer survivors) were eligible for the present study. Characteristics of participants are summarized in Table 1. A majority of the participants were female, currently ages 30–39 years, were without child, and had nonhematological cancer. Twenty-five percent of participants had depression (≥8 in HADS-D score) and 34% had anxiety (≥8 in HADS-A score). Among 213 AYA cancer patients, 56 received treatment for systemic cancer, recurrent cancer, or secondary cancer.

Preferences Regarding End-of-Life Care

Over half of the participants preferred to know their prognosis (86%; 296/344), receive palliative chemotherapy with limited efficacy at expense of considerable toxicity (53%; 180/338), actively use treatment for palliation of pain or suffering (88%; 301/341), and stay home at EOL (61%; 207/342) (Table 2). Even when we focused on the preferences of 56 participants with systemic cancer, recurrent cancer, or secondary cancer, the results did not change; preferences regarding prognosis disclosure, palliative chemotherapy with limited efficacy at the expense of considerable toxicity, active use of treatment for palliation of pain or suffering, and staying home at EOL were observed in 86%, 53%, 84%, and 64% of participants, respectively.

Next, we analyzed preferences regarding EOL care according to age groups (Table 3). Participants in their 30s more likely to prefer active use of treatment for palliation of pain or suffering ($P = 0.002$). Furthermore, that age group tended not to prefer home as a place at EOL compared with other age groups

Table 1
Characteristics of Participants ($N = 349$)

Characteristics	*n* (%)
Treatment status	
Under active cancer treatment[a]	213 (61)
Survivor	136 (39)
Gender[b]	
Male	99 (28)
Female	244 (70)
Cancer type[b]	
Hematological cancer	72 (21)
Nonhematological cancer	273 (78)
Age at diagnosis of cancer (yrs)	
15–19	63 (18)
20–24	41 (12)
25–29	62 (18)
30–39	183 (52)
Current age (yrs)	
15–19	28 (8)
20–24	34 (10)
25–29	58 (17)
30–39	229 (66)
Educational status[b]	
Less than university	177 (51)
University or more	160 (46)
Working status[b]	
Not working	159 (46)
Currently working	184 (53)
Marital status[b]	
Unmarried	177 (51)
Married	140 (40)
Child status[b]	
Having child	91 (26)
No child	233 (67)
Depression[b] (≥8 in HADS-D score)	
Yes	87 (25)
No	230 (66)
Anxiety[b] (≥8 in HADS-A score)	
Yes	118 (34)
No	199 (57)
History of chemotherapy	
Yes	254 (73)
No	95 (27)

HADS-A = Hospital Anxiety and Depression Scale—anxiety; HADS-D = Hospital Anxiety and Depression Scale—depression.

[a] Including 56 participants with systemic cancer, recurrent cancer, or secondary cancer.

[b] Total percentages do not equal 100% because of missing data.

Table 2
Preferences Regarding End-of-Life Care

Preference	*n* (%)[a]
Prognosis disclosure	
Question	
"How do wish for an explanation of expectable prognosis?"	
Answers	
1) "I wish to be informed of detailed expectable prognosis with the concrete figure."	165 (48)
2) "I wish to be informed of expectable prognosis with range."	131 (38)
3) "I do not wish to be informed of expectable prognosis."	48 (14)
"Want to know prognosis" (answers: 1, 2)	296 (86)
Receiving chemotherapy for incurable cancer	
Question	
"Which attitude do you prefer if cancer is an incurable disease?"	
Answers	
1) "I want to receive chemotherapy if there is a little possibility of response even when strong adverse effects are expected."	180 (53)
2) "I do not want to receive chemotherapy which has an uncertain response and has strong adverse effects."	158 (47)
"Want to receive chemotherapy" (answer: 1)	180 (53)
Use of narcotic drugs for palliation of pain	
Question	
"Narcotic drugs are commonly used for palliation of pain or suffering. Which attitude do you prefer?"	
Answers	
1) "I want to actively receive treatment for palliation of pain or suffering."	301 (88)
2) "I do not want to receive drugs as much as possible even if there is a pain."	40 (12)
"Want to use narcotic drug" (answer: 1)	301 (88)
Place to stay at EOL	
Question	
"Where do you want to stay if you are unable to visit hospital due to disease progression?"	
Answers	207 (61)
1) "Home."	
2) "Hospital."	34 (10)
3) "Hospice/palliative care unit."	72 (21)
4) "Other places."	1 (0.3)
5) "No particular wish."	28 (8)
"Want to stay home" (answer: 1)	207 (61)

EOL = end of life.

[a] In each answer, the proportion was computed by the number of items divided by the sum of valid response.

(P = 0.07), whereas the proportion that preferred hospice/palliative care unit as a place at EOL was significantly higher in participants aged 30–39 years compared to those in other age groups ($P = 0.000003$).

Factors Contributing to Preference Regarding End-of-Life Care

By using potential contributing factors selected in univariate analyses (Table 4), we identified several factors significantly associated with preference regarding EOL care in multivariate analyses (Table 5). Participants without children or without a history of chemotherapy were more likely to prefer prognostic disclosure. Preference regarding palliative chemotherapy for incurable cancer with limited efficacy at the expense of considerable toxicity was more likely associated with participants who were under active cancer treatment. No independent determinants of active use of narcotic drugs for palliation of pain or suffering were identified. Participants with anxiety (≥8 in HADS-A score) were correlated with a preference of "home" as place to stay at EOL.

Discussion

We elucidated preferences regarding EOL care among the AYA cancer population and observed several important findings in the present study as a part of a comprehensive nationwide survey aiming to

Table 3
Preferences Regarding End-of-Life Care According to Current Age Group

Preference	Current Age 15–19, %[a]	20–24, %[a]	25–29, %[a]	30–39, %[a]	*P*-value[b]
Prognosis					
“Want to know prognosis”	82	82	93	85	0.39
Chemotherapy					
“Want to receive chemotherapy”	61	61	52	52	0.65
Narcotic drug					
“Want to use narcotic drug”	81	75	81	93	0.002
Place to stay at EOL					
“Want to stay home”	69	68	72	56	0.07
“Hospice/palliative care unit”	0	12	4	29	0.000003

EOL = end of life.
[a] In each answer, the proportion was computed by the number of items divided by the sum of valid response.
[b] *P*-value was based on the chi-square test.

investigate the experience and needs of AYA with cancer.

A majority of AYA with cancer (86%) had the preference of prognostic disclosure with similar tendency across the age range. This tendency is consistent with the recent report uncovering that 83% of AYA (ages 15–29 years) with cancer considered prognostic information of great importance.[17] Of note, our study included a relatively older population, presenting the preference of prognostic disclosure among the population in their 30s. Furthermore, the preference regarding prognostic disclosure among AYA cancer population was similar to that in adult cancer patients described in another study; 79% of adult patients with terminal cancer preferred to be informed their terminal condition.[18] In multivariate analysis, the presence of children was negatively associated with preference of prognostic disclosure, potentially reflecting the hope for long-term survival and potential cure in parents with cancer, as observed in a previous study.[19] Although prognostic disclosure may help patients to delineate future plans and preferences of EOL care in a realistic time scale, it is a challenging task for health care providers.[20] According to a national survey, only 43% of physicians always or usually had discussions regarding prognostic disclosure with their patients and 53% reported a lack of formal education regarding prognosis communication.[21] Development of guidance and educational system for supporting communication about prognostic disclosure may help health care practitioners to improve their ability in this area.

Half of AYA participants (53%) preferred to receive palliative chemotherapy with limited efficacy at the expense of considerable toxicity. This finding is similar to a previous report which demonstrated 65.4% of young adult patients (ages 20–44 years) preferred to receive chemotherapy that would only extend life for one week.[22] Furthermore, our finding implies palliative chemotherapy with limited efficacy is preferred in AYA cancer population as well as adult cancer patients.[23] We observed that treatment status affected this preference significantly; patients under treatment showed a more aggressive attitude toward palliative chemotherapy compared to cancer survivors. Misperception of treatment purpose for incurable cancer may partially explain the high proportion of participants who preferred to receive palliative chemotherapy. Cancer patients are likely to overestimate their prognosis; 55% of patients treated with palliative chemotherapy reported that their cancer was curable.[24] Weeks et al. reported that patients who overestimated their prognosis tended to have the preference for life-extending therapy over comfort care.[25] Sharing accurate information of disease status, potential risks and benefits of palliative chemotherapy may be crucial for AYA cancer patients to decide whether a receipt of chemotherapy is congruence in their preferences in EOL care.

In our study, the AYA cancer population positively recognized the importance of palliative care. Notably, this preference was more likely to be observed in population in their 30s. Often, both pediatric and medical oncologists hesitate to make formal referrals to palliative care teams for psychological concerns (e.g., the referral to palliative care may decrease hope or increase patient or caregiver distress).[20] However, our finding supports the active integration of palliative care in AYA cancer population.

As for a place to stay at EOL, 61% of AYA cancer population preferred home. The proportion of preference regarding the place of EOL care as home among AYA cancer population seems to be higher compared with the adult population in Japan (44%).[26] Although Japan has a public long-term care insurance system that provides in-home, community-based, and facility services, patients aged 39 years or less are currently ineligible for these services, resulting in the financial burden on AYA cancer patients. Our finding illuminates the need for reform in health care to support

Table 4

Association Between Sociodemographic Factors and Preferences Regarding End-of-Life Care (Univariate Analysis)

	Prognosis “Want to Know Prognosis”		Chemotherapy “Want to Receive Chemotherapy”		Narcotic Drug “Want to Use Narcotic Drug”		Place to Stay at EOL “Want to Stay Home”	
Factor	OR (95% CI)	*P*-value[a]	OR (95% CI)	*P*-value[a]	OR (95% CI)	*P*-value[a]	OR (95% CI)	*P*-value[a]
Treatment status								
Under active cancer treatment	1.56 (0.84–2.87)	0.16	1.44 (0.93–2.23)	0.11	0.85 (0.43–1.69)	0.64	1.14 (0.73–1.77)	0.57
Survivor (reference)								
Gender								
Male	0.84 (0.43–1.63)	0.60	1.45 (0.90–2.34)	0.13	0.57 (0.29–1.12)	0.10	1.37 (0.84–2.24)	0.21
Female (reference)								
Cancer type								
Hematological cancer	0.85 (0.41–1.77)	0.67	1.15 (0.68–1.95)	0.61	0.48 (0.23–1.00)	0.05	1.38 (0.80–2.39)	0.249
Nonhematological cancer (reference)								
Age at diagnosis of cancer								
Young adult	1.60 (0.78–3.29)	0.20	0.57 (0.32–1.00)	0.05	1.67 (0.77–3.64)	0.19	0.70 (0.39–1.26)	0.24
Adolescent (reference)								
Current age								
Young adult	1.38 (0.50–3.82)	0.54	0.72 (0.33–1.58)	0.41	1.81 (0.65–5.09)	0.26	0.66 (0.28–1.57)	0.35
Adolescent (reference)								
Educational status								
Less than university	0.94 (0.49–1.78)	0.85	0.95 (0.61–1.46)	0.80	1.09 (0.56–2.10)	0.81	0.92 (0.59–1.44)	0.72
University or more (reference)								
Working status								
Not working	0.58 (0.31–1.08)	0.09	1.59 (1.03–2.46)	0.04	0.99 (0.51–1.94)	0.98	1.24 (0.80–1.92)	0.35
Currently working (reference)								
Marital status								
Unmarried	1.35 (0.70–2.59)	0.37	0.99 (0.63–1.56)	0.97	0.49 (0.23–1.06)	0.07	0.85 (0.54–1.34)	0.48
Married (reference)								
Presence of children								
No child	2.39 (1.25–4.57)	0.01	0.93 (0.57–1.53)	0.78	0.64 (0.28–1.46)	0.29	0.72 (0.43–1.20)	0.21
Having child (reference)								
Depression								
Yes	0.99 (0.47–2.07)	0.97	0.73 (0.44–1.20)	0.21	0.95 (0.43–2.06)	0.89	0.95 (0.57–1.57)	0.83
No (reference)								
Anxiety								
Yes	1.00 (0.50–1.99)	1.00	0.77 (0.49–1.22)	0.27	1.02 (0.49–2.11)	0.96	1.51 (0.94–2.44)	0.09
No (reference)								
History of chemotherapy								
Yes	0.21 (0.07–0.60)	0.003	1.72 (1.06–2.80)	0.03	0.54 (0.23–1.27)	0.16	1.38 (0.85–2.24)	0.19
No (reference)								

EOL = end of life; OR = odds ratio.

[a] *P* value was based on the logistic regression analysis.

Table 5

Association Between Sociodemographic Factors and Preferences Regarding End-of-Life Care (Multivariate Analysis)[a]

	Prognosis "Want to Know Prognosis"		Chemotherapy "Want to Receive Chemotherapy"		Narcotic Drug "Want to Use Narcotic Drug"		Place to Stay at EOL "Want to Stay Home"	
Factor	OR (95% CI)	*P*-value[b]	OR (95% CI)	*P*-value[b]	OR (95% CI)	*P*-value[b]	OR (95% CI)	*P*-value[b]
Treatment status								
Under active cancer treatment	1.59 (0.78–3.24)	0.20	1.74 (1.05–2.88)	0.03				
Survivor (reference)								
Gender								
Male			1.49 (0.87–2.56)	0.14	0.87 (0.39–1.94)	0.73	1.34 (0.75–2.38)	0.32
Female (reference)								
Cancer type								
Hematological cancer					0.51 (0.22–1.19)	0.12	1.02 (0.53–2.00)	0.94
Nonhematological cancer (reference)								
Age at diagnosis of cancer								
Young adult	1.64 (0.67–4.01)	0.28	0.75 (0.37–1.49)	0.41	0.78 (0.28–2.17)	0.63	0.47 (0.21–1.05)	0.07
Adolescent (reference)								
Current age								
Young adult								
Adolescent (reference)								
Educational status								
Less than university								
University or more (reference)								
Working status								
Not working	0.77 (0.37–1.61)	0.49	1.57 (0.93–2.67)	0.09				
Currently working (reference)								
Marital status								
Unmarried					0.54 (0.24–1.22)	0.14		
Married (reference)								
Presence of children								
No child	3.05 (1.45–6.44)	0.003					0.64 (0.37–1.13)	0.12
Having child (reference)								
Depression								
Yes			0.60 (0.35–1.05)	0.07				
No (reference)								
Anxiety								
Yes							1.72 (1.03–2.87)	0.04
No (reference)								
History of chemotherapy								
Yes	0.23 (0.08–0.69)	0.009	1.57 (0.89–2.76)	0.12	0.56 (0.20–1.56)	0.27	1.13 (0.65–1.97)	0.67
No (reference)								

EOL = end of- life; OR = odds ratio.

[a] Variables with *P*-value < 0.25 in univariate analysis were used in multivariate analysis.

[b] *P*-value was based on the logistic regression analysis.

AYA cancer patients who prefer to live home at EOL. Furthermore, the preference regarding place at EOL care was different according to age groups. In our study, approximately 30% of the AYA cancer population aged 30–39 years were more likely to prefer a hospice/palliative care unit as a place of EOL care compared with those among other age groups. This difference may be partially explained by the uniqueness of family structure in the AYA cancer population in 30s such as living with dependents (e.g., presence of young children or elderly parents).

Despite a part of the comprehensive multicenter survey, the present study had several limitations. First, the response rate was relatively low (AYA cancer patients: 37.9%, AYA cancer survivors: 34.7%) in the main study, potentially resulting in hidden selection biases. In addition, all participants were Japanese who lived in Japan, limiting the generalizability of the findings to other race groups and acculturated Japanese population. Second, owing to the design of a cross-sectional study, the present study was not intended to investigate the change in preferences over time. Third, although we identified some predictive factors contributing preferences, validation of these predictive factors is needed in different cohorts.

Conclusion

This study elucidated the preferences regarding EOL care among the Japanese AYA cancer population. The key findings may help health care professionals to understand general preferences regarding EOL care among the AYA cancer population and to discuss the plan for EOL care with their patients effectively. In addition, our findings underscore development of guidelines, educational system for supporting health care professionals, and health policy for fine-tuning of health care service to provide more effective EOL care for AYA cancer patients.

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Appendix

1) 「予測される生命予後（あとどれくらい生きられるか）」について、医師は「平均的な数値」を把握していますが、これらは個々の患者さんに必ずしも当てはまるものではありません。あなたは「**予測される生命予後（あとどれくらい生きられるか）**」についてどのような説明をしてほしいとお考えですか
    1. 具体的な数値を含め、詳しく教えてほしい
    2. ある程度のことが知りたいので、幅を持たせて（「○ヵ月から○ヵ月程度」など）教えてほしい
    3. 知りたくないので説明してほしくない
2) もし、がんが治らない場合、**ご自身が希望される治療により近いもの**はどちらですか。あてはまる番号一つに○をおつけください。
    1. 副作用が強い治療であっても、わずかでも効く可能性がある抗がん剤は受けたい
    2. 副作用が強い治療であれば、効くか分からない抗がん治療は希望しない
3) **痛みや苦痛を和らげるために医療用麻薬を使うことがあります。ご自身が希望される治療により近いもの**はどちらですか。あてはまる番号一つに○をおつけください。
    1. 痛みや苦痛を和らげる治療を積極的に受けたい
    2. 痛みがあってもなるべく薬を使わずに過ごしたい
4) もしも病状が進んで通院することが難しくなったときに、**どこで過ごしたい**と思われますか。
    1. 自宅
    2. 病院
    3. ホスピス･ 緩和ケア病棟
    4. その他の場所（施設など）
    5. 特に希望はない