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ORIGINAL ARTICLE

Achievement of a good death among young adult patients with cancer: analyses of combined data from three nationwide surveys among bereaved family members

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Abstract

Purpose Although little improvement has been made in the survival rate among young cancer patients over recent decades, whether they have achieved a good death has never been systematically explored. We aimed to clarify whether young cancer patients (aged 20–39 years) have achieved a good death, and compare their achievement with that of middle-aged patients (aged 40–64 years).

Methods We analyzed combined data of three nationwide, cross-sectional surveys of families of cancer patients who died at inpatient hospices in Japan (2007–2014). We measured 10 core items of the Good Death Inventory (GDI) short-version on a 7-point scale, and calculated rates of "agree/absolutely agree" and the mean scores.

Results We analyzed 245 and 5140 responses of families of young and middle-aged patients, respectively. Less than 60% of families of young patients reported "agree/absolutely agree" regarding 9 items, which included "feeling that one's life was completed" in 44 (18%; 95% confidence interval (CI) = 14–23%), "being independent in daily life" in 48 (20%; 95% CI = 15–25%), and "being free from physical distress" in 103 (42%; 95% CI = 36–48%) young patients. Young patients were significantly less likely to feel "one's life was completed" (mean = 3.3 (standard deviation = 2.0) vs. 3.8 (1.9), respectively; effect size (ES) = 0.29; adjusted p value = 0.000) and "not being a burden to others" (3.1 (1.5) vs. 3.5 (1.6), respectively; ES = 0.24; adjusted p value = 0.010) than the middle-aged.

Conclusions Overall, young cancer patients did not achieve a good death. Future efforts are needed to improve the quality of palliative care for young patients, focusing on psychosocial/spiritual suffering.

Keywords Young adult · Cancer · Bereaved family · Good death

Introduction

Young adult cancer patients, broadly defined as those adult patients aged 39 or younger, have distinct physical and psychosocial features [1–3]. Young adults face considerable challenges when they are diagnosed with advanced cancer and their diseases progress; these include disruptions in work, increased dependence on parents and partners, financial

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difficulties, and premature confrontation with mortality [4, 5]. Despite the marked progress in cancer care, little improvement has been made in the survival rate among young adult cancer patients over the past few decades [6]. Thus, it is imperative not only to improve the effectiveness of anticancer treatments for young patients with advanced cancer, but also to develop quality end-of-life (EOL) care and help them achieve a good death.

Recent studies have explored the contents and quality of care young adult cancer patients receive at their EOL. Young adult patients often receive aggressive EOL care [7, 8], and experience numerous physical and psychosocial symptoms at their EOL [9]. Multidimensional roles of palliative care have been proposed to better relieve such suffering of young adult cancer patients [10]. Young adult patients who received palliative care tended to receive less aggressive EOL care [11]. Moreover, a recent population-based survey from the Swedish register of palliative care revealed that the quality of EOL care (e.g., systematic assessment of pain or other symptoms, EOL prescriptions of injectable drugs for symptom relief, and dying in the presence of a family member or caregiver) during the last week of life was higher in younger patients than that in older ones [12]. Yet, little is known about whether young patients with advanced cancer actually have achieved a good death. Given their distinct and considerable challenges, we hypothesized the following: (1) young cancer patients would have low achievement of a good death overall, as evaluated by a valid and reliable tool to measure the achievement of a good death from the perspective of the bereaved family; (2) some underlying patients' and families' factors would contribute to low achievement of a good death in young cancer patients; and (3) young patients would have lower achievement in some specific good death domains such as those related to premature confrontation with mortality and increased dependence, as compared with older patients. Bereaved family members of cancer patients may provide valuable perspectives on their loved one's achievement of a good death [13, 14].

Thus, the primary aim of our study was to clarify whether terminally-ill young patients with cancer achieved a good death as perceived by their bereaved family members. Our secondary aim was to explore factors contributing to the lower achievement of a good death among young cancer patients, and to compare their achievement of a good death with that of middle-aged cancer patients.

Methods

We conducted secondary analyses of combined data of three Japan Hospice and Palliative Care Evaluation studies (J-HOPE 1–3) which were nationwide, cross-sectional, anonymous, self-reported questionnaire surveys. The detailed methodology of these surveys was described elsewhere [15–17]. In brief, these were surveys of the bereaved family members of cancer patients to evaluate the quality of EOL care and the achievement of a good death in certified inpatient hospices/palliative care units (PCUs) in Japan. These were primarily quality improvement projects, regularly performed every 3 to 4 years. All of the 153, 195, and 296 PCUs certified by the Hospice Palliative Care Japan were invited to participate in J-HOPE 1 in 2007, J-HOPE 2 in 2010, and J-HOPE 3 in 2014, respectively; and 100, 103, and 133 PCUs, respectively, agreed to participate. All of the participating PCUs cared for young adult patients within an adult setting, and none of them had separate units for children or adolescent and young adult patients. We asked each institution to identify and consecutively list up to 80 bereaved family members of patients who had died prior to the study year. We did not offer specific support beyond the survey, but provided with the information sheet and the survey contact information of the principal investigator and secretariat office as well as when they could be available, so that bereaved families could contact us should the needs arise. The ethical and scientific validity of these surveys was verified by the institutional review boards of all participating institutions.

Participants

The main surveys included bereaved family members of cancer patients who had died in each of the participating institutions. The inclusion criteria of the three surveys (J-HOPE 1–3) included: (1) the patient had died of cancer, (2) the patient was aged 20 years or older, (3) the patient had been admitted to a PCU for more than 3 days, and (4) the bereaved family member was aged 20 years or older, as those aged 20 or older are legally regarded as adults in Japan. This study included a subpopulation of the three main studies: bereaved family members of cancer patients aged 20–39 years (defined as "young" patients in this report) primarily, and those aged 40–64 years (defined as "middle-aged" patients) for comparison, who had died in one of the participating PCUs. The rationale for introducing the upper age limit in this study was that a geriatric population was shown to have distinct EOL characteristics compared with a non-geriatric population, and thus we deemed them inappropriate as a control for a young adult population [12, 18].

The exclusion criteria were as follows: (1) the bereaved family member could not be identified; (2) the potential participant would have suffered serious psychological distress, as determined by the primary physician and a nurse; and (3) the potential participant was incapable of completing the self-reported questionnaire because of cognitive impairment or visual disability.

Procedure

The questionnaires were sent to the bereaved family members identified by each participating institution. The return of a completed questionnaire was considered consent to participate in the study. Participants were asked to return the completed questionnaires to the study secretariat office. A reminder was sent to non-responders 1 month after the questionnaire had been sent out. If they did not wish to participate, they were asked to check a "no participation" box and return the incomplete questionnaire.

Measurements

The good death inventory—short version

The Good Death Inventory (GDI) is a valid and reliable tool to measure the achievement of a good death from the perspective of the bereaved family [14]. The GDI was developed based on qualitative interviews and a quantitative study of bereaved family members of deceased cancer patients [19, 20]. The GDI consists of 18 domains, including 10 core and 8 optional domains. The 10 core domains evaluate attributes that most Japanese consistently rate as important, whereas the 8 optional domains evaluate attributes that are not as consistently rated as important. In this study, we used the short version of the GDI core domains, which consists of 10 representative items from each of the 10 core GDI domains: "being valued as a person," "trusting physician," "living in calm circumstances," "being free from physical distress," "spending enough time with one's family," "being a burden to others," "being able to stay at one's favorite place," "having some pleasure in daily life," "being independent in daily life," and "feeling that one's life was completed." The short version has also been shown to exhibit sufficient psychometric properties [14]. Each item was evaluated on a 7-point Likert scale (1 [absolutely disagree] to 7 [absolutely agree]). The total score possible ranged from 10 to 70, with higher scores indicating a higher achievement of a good death. The item "being a burden to others" was inversely rated. The GDI has been used in Western and Eastern countries [21, 22].

Participant characteristics

We also collected background data, such as patients' age, sex, primary cancer sites, and length of admission, as well as families' age, sex, health status during the caregiving periods, relationship with the patient, availability of another person who could stay with the patient, and medical expenses.

Statistical analyses

The primary endpoint was the percentages of the bereaved family members of the young patients who reported "agree" or "absolutely agree" with each of the 10 core items. The secondary endpoints included the mean score of each of the GDI short-version core items and the total score of the GDI short-version core items.

We used descriptive statistics to summarize the participants' responses. We also conducted *t* tests and chi-square analyses for continuous and categorical variables, respectively, to compare responses from the bereaved family members of the young and middle-aged patients. The original data set included 4–8% missing data in the GDI items of the three studies. The missing data were imputed using the mean score of the indicated variable for all other cases. When comparing GDI items, we made adjustments using demographic factors (patient's sex, cancer site, and length of admission; bereaved family member's age, sex, and relationship with the patient) [23].

As the total scores of the GDI short-version core items showed a normal distribution, we defined scores higher than the mean value as the higher achievement of a good death, and those lower than the mean as the lower achievement of a good death. To explore the determinants of the lower achievement of a good death, uni- and multivariate logistic univariate regression analyses were performed using demographics as independent variables and the lower achievement of a good death as a dependent variable.

We conducted all statistical analyses using SPSS version 24.0 (IBM Japan Institute, Tokyo, Japan). A value of $p < 0.05$ was considered significant in all analyses. Because of the exploratory nature of this study, we had decided not to use the Bonferroni correction for multiple comparisons.

Results

Questionnaires were sent to a total of 35,245 bereaved family members (8340 in J-HOPE 1; 13,194 in J-HOPE 2; and 13,711 in J-HOPE 3). Of them, 22,451 (64%) family members responded to the questionnaires (5563 in J-HOPE 1, 7797 in J-HOPE 2, and 9091 in J-HOPE 3). After excluding the responses of 17,066 family members of patients aged 65 or older, we included those of 5385 family members for analyses in the present study, which comprised 245 families of young patients and 5140 families of middle-aged patients. The characteristics of the deceased patients and bereaved family members are summarized in Table 1.

Table 1 Characteristics of participants

Variables	Young patients (aged 20–39 years, *n* = 245)		Middle-aged patients (aged 40–64 years, *n* = 5140)		*p* value
	n/mean	%/SD	*n*/mean	%/SD	
Patients					
Age	34	4.5	57	6.0	.000
Sex					0.01
Male	107	44	2712	53	
Female	138	56	2406	47	
Cancer sites					0.000
Esophagus, stomach, colon, and rectum	64	26	1494	29	
Uterus, ovary	36	15	431	8	
Breast	28	11	515	10	
Brain	24	10	89	2	
Lung	22	9	956	19	
Liver, gall bladder, and pancreas	16	7	788	15	
Soft tissue	13	5	53	1	
Kidney, prostate, and bladder	9	4	253	5	
Blood and lymph nodes (leukemia, myeloma, and lymphoma)	8	3	68	1	
Head and neck	3	1	192	4	
Other	20	8	291	6	
Length of admission	57	94	46	76	.051
Bereaved families					
Age	53	14	56	12	.000
Sex					
Male	94	38	1935	38	0.88
Female	144	59	3080	60	
Health status during the caregiving period					0.004
Good	33	13	1119	22	
Not bad	141	58	2720	53	
Bad	46	19	970	19	
Very bad	13	5	207	4	
Relationship with the patient					0.000
Parent	122	50	251	5	
Spouse	89	36	3321	65	
Sibling	11	4	554	11	
Child	0	0	650	13	
Child-in-law	0	0	137	3	
Other	16	7	128	2	
Availability of another person who could stay with the patient					0.073
Yes	187	76	3621	70	
No	50	20	1384	27	
Medical expenses					0.521
< 2000 dollars	92	38	1927	37	
≥ 2000 dollars	139	57	2903	56	

Values are mean ± standard deviation, or *n* (%)

Total percentages do not equal 100% because of missing values

Achievement of a good death in young cancer patients

Figure 1 presents percentages of bereaved family members of the younger patients who reported “somewhat agree,” “agree,” or “absolutely agree” with each of the GDI core 10 items. Less than 60% of families of the young patients agreed or absolutely agreed that their loved one had achieved a good death in 9 of the 10 core items. Specifically, 44 (18%; 95% CI, 14–23%), 48 (20%; 95% CI, 15–25%), 63 (26%; 95% CI, 21–32%), and 93 (38%; 95% CI, 32–44%) young patients were reported to have exhibited the following (“agree,” or “absolutely agree”): “feeling that one’s life was completed,” “being independent in daily life,” “having some pleasure in daily life,” and “being a burden to others,” respectively. In addition, 103 (42%; 95% CI, 36–48%) young patients were reportedly “free from physical distress.” On the other hand, 195 (80%; 95% CI, 74–84%) young patients were “valued as a person.”

Factors contributing to the lower achievement of a good death in young cancer patients

The mean total score of the GDI core 10 items was 46.8 (SD, 8.8) in young patients. Table 2 shows factors contributing to the lower achievement of a good death in young patients based on uni- and multivariate analyses. The univariate analyses revealed that the lower achievement of a good death was significantly correlated only with younger age of the bereaved families (odds ratio (OR), 1.02; 95% CI, 1.00–1.04; $p = 0.03$). The multivariate analyses revealed that no factor was an independent determinant of a lower achievement of a good death.

Achievement of a good death between young and middle-aged cancer patients

Table 3 shows differences in the achievement of a good death between younger and middle-aged cancer patients. Bereaved family members of the young patients, as compared with those of the middle-aged, were significantly less likely to report that the patients felt “one’s life was completed” (mean, 3.3 (SD, 2.0) vs. 3.8 (1.9), respectively; effect size (ES), 0.29; p value = 0.000; adjusted p value = 0.000) and “not being a burden to others” (mean, 3.1 (SD, 1.5) vs. 3.5 (1.6), respectively; ES, 0.24; p value = 0.000; adjusted p value = 0.010).

Discussion

This is, to the best of our knowledge, the first empirical report from nationwide surveys to clarify the achievement of a good death of young adult patients with advanced cancer. The first and most important finding is that young cancer patients had a low achievement of a good death overall. Less than 60% of their families agreed or absolutely agreed that they had achieved a good death in 9 of the 10 core items, even at certified PCUs where marked resources were available on multiple levels to provide comprehensive, multidisciplinary palliative care [24, 25]. Potential interpretation is that the young cancer patients might not necessarily have considered the PCU environment appropriate for their age. According to a recent systematic review, young adult cancer patients who received care in settings with much older patients tended to feel that they were isolated and did not receive sufficient empathy by clinicians, and to consider the environment

Fig. 1 Percentages of young cancer patients who had achieved a good death (aged 20–39 years, $n = 245$). Figures indicate percentages of bereaved family members of the young patients who reported “somewhat agree,” “agree,” or “absolutely agree” in response to each of the 10 core items of the Good Death Inventory

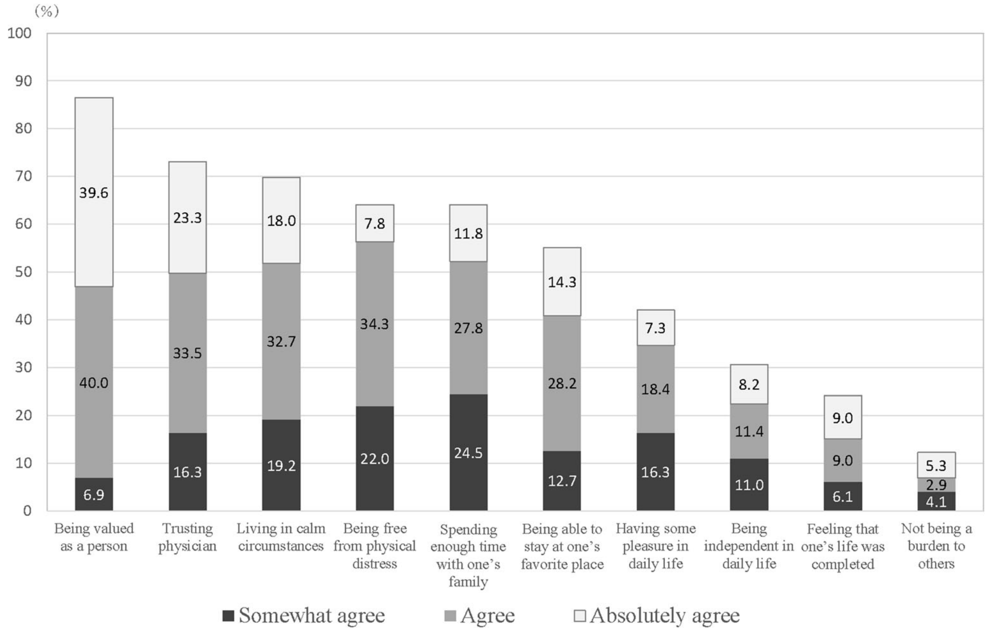

Table 2 Factors contributing to the lower achievement of a good death in young patients (aged 20–39 years, *n* = 245)

	Univariate analysis			Multivariate analysis		
	OR	95% CI	*p* value	OR	95% CI	*p* value
Patients						
Sex (ref. male)						
Female	1.09	0.66, 1.82	0.74	1.08	0.55, 2.13	0.82
Cancer sites (ref. esophagus, stomach, colon, and rectum)						
Lung	0.35	0.12, 1.08	0.07	0.39	0.12, 1.21	0.10
Liver, gall bladder, and pancreas	1.21	0.40, 3.61	0.74	0.90	0.28, 2.97	0.87
Head and neck	2.41	0.21, 28.0	0.48	1.73	0.13, 22.5	0.67
Kidney, prostate, and bladders	0.60	0.14, 2.63	0.50	0.84	0.18, 3.99	0.83
Uterus and ovary	1.35	0.59, 3.06	0.47	1.05	0.41, 2.66	0.92
Blood and lymph nodes	0.40	0.08, 2.15	0.29	0.34	0.06, 1.94	0.23
Brain	0.60	0.23, 1.61	0.31	0.51	0.18, 1.48	0.22
Breast	0.67	0.27, 1.68	0.39	0.68	0.25, 1.80	0.44
Soft tissue	1.41	0.43, 4.66	0.58	1.25	0.35, 4.53	0.73
Other	1.81	0.65, 5.03	0.25	1.72	0.59, 5.07	0.32
Length of admission	1.00	1.00, 1.00	0.74	1.00	1.00, 1.00	0.73
Bereaved families						
Age	1.02	1.00, 1.04	0.03	1.02	0.99, 1.05	0.29
Sex (ref. male)						
Female	1.07	0.63, 1.81	0.81	0.91	0.48, 1.72	0.76
Relationship to the patient (ref. spouse)						
Parent	1.64	0.93, 2.88	0.08	1.21	0.45, 3.24	0.71
Sibling	1.56	0.44, 5.52	0.49	1.90	0.49, 7.41	0.36
Other	1.87	0.64, 5.47	0.25	1.48	0.45, 4.86	0.52

Nagelkerke $R^2 = 0.08$. A lower achievement of a good death was defined as the total scores of the Good Death Inventory short-version core items lower than the mean

OR, odds ratio; *CI*, confidence intervals

unsuitable for them [26]. The overall suboptimal achievement of a good death indicates that future efforts are needed to improve the quality of EOL care for young cancer patients.

The second important finding is that none of the baseline factors was found to be an independent determinant of the lower achievement of a good death among young cancer patients. In this study, we measured only limited demographic data of the patients and their families, though other factors such as marital, employment, and financial status might have been associated with their psychological status [4]. However, demographic data are not sufficient to explain the levels of achievement of a good death, as a good death may be associated with multiple baseline factors such as patients' and families' psychological features, coping styles, and EOL discussions with their physician [23]. To our knowledge, no prior studies systematically explored the effect of patient-, family-, clinician-, and system-related factors on the achievement of a good death in young patients with cancer. Future studies should systematically identify factors contributing to the achievement of a good death in order to better individualize EOL care in young cancer patients.

Of note, is the finding that the young patients were significantly less likely to feel a sense of life completion and more likely to suffer a self-perceived burden than the middle-aged patients, although the effect sizes of these items were relatively small. Their lack of life completion and self-perceived burden are fully understandable because of their premature confrontation of mortality and physical deterioration, which may cause fundamental psychosocial and spiritual distress in young patients [4, 5, 10]. Self-perceived burden may be overwhelming among young patients, as they have lost only recently gained independence and have to depend on their parents or partner for physical, financial, and emotional needs [27]. The previously proposed care strategies for reducing a self-perceived burden that could be applicable to younger patients included the following: assisting patients with their daily life activities in a natural manner, strengthening the sense that the patient's value is intact, avoiding a condescending attitude, supporting patients' efforts to care for themselves, and minimizing patient disability [28]. Future multifaceted support programs for young cancer patients and education programs for caregivers and health care professionals should include

Table 3 Differences in the lower achievement of a good death between young and middle-aged cancer patients

	Young patients (aged 20–39 years, $n = 245$)		Middle-aged patients (aged 40–64 years, $n = 5140$)		Effect size	p value	Adjusted p value[a]
	Mean	SD	Mean	SD			
Being valued as a person	6.1	1.1	6.0	1.0	0.09	0.154	0.072
Trusting physician	5.5	1.3	5.5	1.3	0.04	0.556	0.996
Living in calm circumstances	5.3	1.4	5.4	1.3	0.11	0.116	0.228
Being free from physical distress	4.9	1.4	5.0	1.5	0.05	0.458	0.954
Spending enough time with one's family	5.0	1.4	5.0	1.5	0.01	0.819	0.534
Not being a burden to others[b]	3.1	1.5	3.5	1.6	0.24	0.000	0.010
Being able to stay at one's favorite place	4.8	1.7	5.0	1.6	0.15	0.022	0.117
Having some pleasure in daily life	4.3	1.6	4.3	1.6	0.03	0.697	0.696
Being independent in daily life	3.3	2.0	3.4	1.9	0.03	0.681	0.749
Feeling that one's life was completed	3.3	2.0	3.8	1.9	0.29	0.000	0.000

[a] Adjusted for baseline characteristics (patient: sex, cancer site, and length of admission; bereaved family: age, sex, relationship with the patient)

[b] Inverse item

Missing data were imputed

SD, standard deviation

care specific for their lack of life completion and self-perceived burden.

On the contrary, no significant differences were found in the 8 other items of the GDI short-version. For example, the scores of "being valued as a person" were equally very high in both groups, which may potentially reflect a ceiling effect in the hospice setting. In contrast, the item "being independent in daily life" was quite low in both groups. Potential interpretation of the similarities in most domains, in addition to the small effect sizes of domains with statistically significant differences, is that both young adult and middle-aged patients may share similar experiences at their EOL, as both are supposed to be physically and socially independent, unlike much older population. Future studies are needed to investigate the achievement of a good death across all the age groups. Another interpretation is that age-specific good death domains might exist (e.g., young adult patients might put higher priority on job, child-bearing, and sexuality as well as playing and learning than older patients might do) in addition to the domains of the GDI that was developed primarily based on the perceptions of cancer patients in a general age group [4, 14, 19, 29]. Future studies should characterize the age-specific needs and constituents of a good death among terminally ill young cancer patients, and explore whether an age-specific good death is achieved in various clinical settings.

Overall, a "good death" is a complex concept with multiple different domains [14, 19, 30, 31]. The unique characteristics of young adult cancer patients may add more complexity in end-of-life care to achieve a good death [10, 27]. Although the development of a holistic palliative care approach with the help of a multidisciplinary team has been recommended, such approach specifically for this distinct population remains to be standardized [9, 10, 27]. Our surveys in bereaved family members indicate that young cancer patients have low achievement of a good death overall even with specialist-level palliative care. This finding underlines the importance of conducting future studies with qualitative, quantitative, and/or mixed-method designs that will help (1) identify common as well as age-specific domains of a good death, (2) develop a conceptual framework of how various factors contribute to the achievement of a good death in young adult cancer patients, and (3) establish complex-intervention programs with individualized care to help them achieve a good death.

Despite the strengths of the combined large dataset based on three nationwide surveys and utilization of well-validated outcomes, our study has several limitations. First, we included bereaved families of cancer patients who had died in PCUs only. These patients had received quality EOL care provided by a multidisciplinary care team. They might have accepted their status of an impending death through the transition to hospice care, which was reported to be particularly difficult for young cancer patients [27]. Thus, our findings may not be generalized to young patients in non-hospice settings. Second, we conducted surveys among bereaved family members, not patients. Third, J-HOPE 1–3 were after-death surveys with a moderate response rate (64%), which may have introduced both recall and selection biases. However, a previous national survey from the USA involving bereaved family members also reported similar response rates [30]. Fourth, as the GDI was developed from families of patients in a general-age group, it does not measure age-specific good death domains for young cancer patients that could potentially include issues of job, child-bearing, and sexuality at their EOL. Fifth, because of the exploratory nature of this study, we did not perform correction for multiple comparisons. In addition, the unequal sample sizes, especially the much larger number of the middle-aged group, might have led to overly significant, potentially false positive findings. However, we calculated effect sizes to ensure clinically meaningful interpretation. Lastly, only limited demographic data were available as factors that potentially contributed to the lower achievement of a good death. Thus, we would strongly encourage future studies to elucidate what constitutes and contributes to a good death in young patients with terminal cancer in both hospice and non-hospice settings. As part of the next J-HOPE study, we are planning to integrate data from a prospective, observational study with a survey among bereaved families, and collect more detailed patient-, treatment-, family-, and clinician-related factors, to better understand the complex nature of the EOL experiences.

In conclusion, these nationwide surveys of bereaved family members revealed that young cancer patients had a low achievement of a good death in many of the good death domains and they specifically suffer from the lack of life completion and self-perceived burden to others. Future efforts are urgently needed to elucidate constituents of a good death in young patients with terminal cancer, and to improve quality palliative care for young patients in both hospice and non-hospice settings, focusing on age-specific components of a good death.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

References

1. Institute NC Adolescent and young adults with Cancer https://www.cancer.gov/types/aya. Accessed 16 Oct 2017
2. Ke Y, Ng T, Chan A (2018) Survivorship care models for breast cancer, colorectal cancer, and adolescent and young adult (AYA) cancer survivors: a systematic review. Support Care Cancer 26(7): 2125–2141. https://doi.org/10.1007/s00520-018-4197-y
3. Shimizu C (2017) Current status of adolescent and young adult cancer patients. https://www.mhlw.go.jp/file/05-Shingikai-10901000-Kenkoukyoku-Soumuka/0000186548.pdf. Accessed 10 July 2018
4. Zebrack B, Isaacson S (2012) Psychosocial care of adolescent and young adult patients with cancer and survivors. J Clin Oncol 30(11):1221–1226. https://doi.org/10.1200/JCO.2011.39.5467
5. Zebrack BJ, Block R, Hayes-Lattin B, Embry L, Aguilar C, Meeske KA, Li Y, Butler M, Cole S (2013) Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. Cancer 119(1):201–214. https://doi.org/10.1002/cncr.27713
6. Ferrari A, Montello M, Budd T, Bleyer A (2008) The challenges of clinical trials for adolescents and young adults with cancer. Pediatr Blood Cancer 50(5 Suppl):1101–1104. https://doi.org/10.1002/pbc.21459
7. Mack JW, Chen K, Boscoe FP, Gesten FC, Roohan PJ, Schymura MJ, Schrag D (2015) High intensity of end-of-life care among adolescent and young adult cancer patients in the New York state Medicaid program. Med Care 53(12):1018–1026. https://doi.org/10.1097/MLR.0000000000000437
8. Mack JW, Chen LH, Cannavale K, Sattayapiwat O, Cooper RM, Chao CR (2015) End-of-life care intensity among adolescent and young adult patients with cancer in Kaiser Permanente Southern California. JAMA Oncol 1(5):592–600. https://doi.org/10.1001/jamaoncol.2015.1953
9. Cohen-Gogo S, Marioni G, Laurent S, Gaspar N, Semeraro M, Gabolde M, Dufour C, Valteau-Couanet D, Brugieres L (2011) End of life care in adolescents and young adults with cancer: experience of the adolescent unit of the Institut Gustave Roussy. Eur J Cancer 47(18):2735–2741. https://doi.org/10.1016/j.ejca.2011.09.008
10. Wein S, Pery S, Zer A (2010) Role of palliative care in adolescent and young adult oncology. J Clin Oncol 28(32):4819–4824. https://doi.org/10.1200/JCO.2009.22.4543
11. Snaman JM, Kaye EC, Lu JJ, Sykes A, Baker JN (2017) Palliative care involvement is associated with less intensive end-of-life care in adolescent and young adult oncology patients. J Palliat Med 20(5): 509–516. https://doi.org/10.1089/jpm.2016.0451
12. Lindskog M, Tavelin B, Lundstrom S (2015) Old age as risk indicator for poor end-of-life care quality - a population-based study of cancer deaths from the Swedish register of palliative care. Eur J Cancer 51(10):1331–1339. https://doi.org/10.1016/j.ejca.2015.04.001
13. Miyashita M, Morita T, Hirai K (2008) Evaluation of end-of-life cancer care from the perspective of bereaved family members: the Japanese experience. J Clin Oncol 26(23):3845–3852. https://doi.org/10.1200/JCO.2007.15.8287
14. Miyashita M, Morita T, Sato K, Hirai K, Shima Y, Uchitomi Y (2008) Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. J Pain Symptom Manag 35(5):486–498. https://doi.org/10.1016/j.jpainsymman.2007.07.009
15. Miyashita M, Morita T, Sato K, Tsuneto S, Shima Y (2015) A nationwide survey of quality of end-of-life cancer care in designated cancer centers, inpatient palliative care units, and home hospices in Japan: the J-HOPE study. J Pain Symptom Manag 50(1):38–47 e33. https://doi.org/10.1016/j.jpainsymman.2015.01.007
16. Shimizu M, Aoyama M, Morita T, Tsuneto S, Shima Y, Miyashita M (2016) A second time nationwide survey of quality of end-of-life cancer care in general hospitals, inpatient palliative care units, and clinics in Japan: the J-HOPE 2 study. Palliat Care Res 11(4):254–264
17. Aoyama M, Morita T, Kizawa Y, Tsuneto S, Shima Y, Miyashita M (2016) The Japan HOspice and palliative care evaluation study 3: study design, characteristics of participants and participating institutions, and response rates. Am J Hosp Palliat Care 34:654–664. https://doi.org/10.1177/1049909116646336

18. Akechi T, Miyashita M, Morita T, Okuyama T, Sakamoto M, Sagawa R, Uchitomi Y (2012) Good death in elderly adults with cancer in Japan based on perspectives of the general population. J Am Geriatr Soc 60(2):271–276. https://doi.org/10.1111/j.1532-5415.2012.03895.x
19. Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y (2007) Good death in cancer care: a nationwide quantitative study. Ann Oncol 18(6):1090–1097. https://doi.org/10.1093/annonc/mdm068
20. Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y (2006) Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manag 31(2):140–147. https://doi.org/10.1016/j.jpainsymman.2005.06.012
21. Shin DW, Choi J, Miyashita M, Choi JY, Kang J, Baik YJ, Mo HN, Choi JS, Son YS, Lee HS (2011) Measuring comprehensive outcomes in palliative care: validation of the Korean version of the good death inventory. J Pain Symptom Manag 42(4):632–642. https://doi.org/10.1016/j.jpainsymman.2010.12.012
22. Mori M, Kuwama Y, Ashikaga T, Parsons HA, Miyashita M (2017) Acculturation and perceptions of a good death among Japanese Americans and Japanese living in the United States. J Pain Symptom Manag 55:31–38. https://doi.org/10.1016/j.jpainsymman.2017.08.010
23. Yamaguchi T, Maeda I, Hatano Y, Mori M, Shima Y, Tsuneto S, Kizawa Y, Morita T, Yamaguchi T, Aoyama M, Miyashita M (2017) Effects of end-of-life discussions on the mental health of bereaved family members and quality of patient death and care. J Pain Symptom Manag 54:17–26.e1. https://doi.org/10.1016/j.jpainsymman.2017.03.008
24. Mori M, Morita T (2016) Advances in hospice and palliative care in Japan: a review paper. Korean J Hosp Palliat Care 19(4):283–291
25. Morita T, Kizawa Y (2013) Palliative care in Japan: a review focusing on care delivery system. Curr Opin Supportive Palliat Ccare 7(2):207–215. https://doi.org/10.1097/SPC.0b013e3283612241
26. Marshall S, Grinyer A, Limmer M (2018) The experience of adolescents and young adults treated for cancer in an adult setting: a review of the literature. J Adolesc Young Adult Oncol 7:283–291. https://doi.org/10.1089/jayao.2017.0123
27. Pritchard S, Cuvelier G, Harlos M, Barr R (2011) Palliative care in adolescents and young adults with cancer. Cancer 117(10 Suppl): 2323–2328. https://doi.org/10.1002/cncr.26044
28. Akazawa T, Akechi T, Morita T, Miyashita M, Sato K, Tsuneto S, Shima Y, Furukawa TA (2010) Self-perceived burden in terminally ill cancer patients: a categorization of care strategies based on bereaved family members' perspectives. J Pain Symptom Manag 40(2):224–234. https://doi.org/10.1016/j.jpainsymman.2009.12.015
29. Nagoya Y, Miyashita M, Shiwaku H (2017) Pediatric cancer patients' important end-of-life issues, including quality of life: a survey of pediatric oncologists and nurses in Japan. J Palliat Med 20(5):487–493. https://doi.org/10.1089/jpm.2016.0242
30. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA (2000) Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 284(19):2476–2482
31. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA (2000) In search of a good death: observations of patients, families, and providers. Ann Intern Med 132(10):825–832