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ORIGINAL ARTICLE

What determines the timing of discussions on forgoing anticancer treatment? A national survey of medical oncologists

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Abstract

Purpose End-of-life discussions (EOLd) including the option of forgoing anticancer treatment infrequently occur until treatment options have been exhausted for advanced cancer patients. We aimed to identify oncologist-related factors contributing to the timing of discussing the option of forgoing anticancer treatment.

Methods In this nationwide survey of 864 medical oncologists, we asked about physicians' attitudes toward the timing of discussing the option of forgoing anticancer treatment for a simulated patient with newly diagnosed metastatic cancer, physicians' experience of EOLd, perceptions of a good death, and beliefs. Multivariate analyses identified determinants of early discussions.

Results Among 490 physicians (response rate = 57%), 167 (35%) would discuss the option of forgoing anticancer treatment "now (at the diagnosis)." Physicians' attitudes toward discussing the option "now" were significantly correlated with a greater physician-perceived importance of life completion (odds ratio (OR) = 1.30, 95%CI = 1.00–1.69, $p = 0.048$) and dying in a preferred place (OR = 1.29, 95%CI = 1.01–1.65, $p = 0.045$) for a good death, and not perceiving EOLd as being severely distressing for patients/families (OR = 0.70, 95%CI = 0.54–0.95, $p = 0.021$). In multivariate analyses, independent determinants of the attitude toward discussing the option now included a greater physician-perceived importance of life completion for a good death (OR = 1.38, 95%CI = 1.05–1.81, $p = 0.019$), and not perceiving EOLd as being severely distressing for patients/families (OR = 0.70, 95%CI = 0.52–0.94, $p = 0.017$).

Conclusions Reflection by oncologists on their own perception regarding a good death and beliefs about EOLd may help oncologists individualize the timing of discussing the option of forgoing anticancer treatment.

Keywords Oncologists · Communication · Chemotherapy · Attitude

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Introduction

The last several decades have seen unprecedented progress in the efficacy of anticancer treatment [1]. At the same time, however, there has been an increasing trend toward more aggressive cancer care near the end of life (EOL) [2, 3]. Approximately 20 to 50% of patients with advanced cancer reportedly receive anticancer treatment during the month before death [4–6]. The use of anticancer treatment in the last months of life has been shown to be associated with a poorer quality of life (QOL) as well as an increased risk of undergoing cardiopulmonary resuscitation, mechanical ventilation, and dying in an intensive care unit [7, 8]. The American Society of Clinical Oncology recommends avoiding the use of anticancer treatment near the EOL because of the lack of evidence supporting its clinical value and encourages realistic conversations about treatment options and alternatives to maximize the QOL of advanced cancer patients [9, 10].

Having timely EOL discussions (EOLd) including the option of forgoing anticancer treatment is thus essential to maximize the QOL through the provision of individualized care for patients with advanced cancer [10]. Multiple studies have demonstrated that EOLd reduced unnecessary aggressive care near death, provided EOL care consistent with patients' preferences, and increased early hospice referrals [11–15]. Oncologists play major roles in discussing EOL options; however, many of them perceive a high-level burden of such discussions, do not actually have EOLd until advanced cancer patients are in the terminal phase of life, and tend to treat patients with chemotherapy toward the EOL with varying degrees [3, 16–18].

To obtain insights into how we can further improve EOLd, it is important to understand physician-related factors associated with the timing of discussing the option of forgoing anticancer treatment. Existing literature has identified various physician-related factors associated with their attitudes toward overall EOLd topics [11, 16]. We recently reported our findings from a nationwide survey study of Japanese oncologists to explore factors contributing to the timing of EOLd, such as the prognosis, hospice, place of death, and do-not-resuscitate status [19]. Unlike these themes, discussing the option of forgoing anticancer treatment is more relevant to most oncologists earlier in the disease trajectory, as the default care plan in its absence is often further treatment [10]. Thus, there is a need for oncologists to regularly and specifically address the question of whether further treatment is consistent with the patient's wishes and the current clinical picture [10]. However, little is known about when oncologists specifically discuss the option of forgoing anticancer treatment, and what factors, especially oncologists' in-depth ones such as their own experiences, perception, and beliefs about EOL, influence the timing of discussion.

In this study, we aimed to systemically explore oncologists' factors contributing to the timing of discussing the option of forgoing anticancer treatment with advanced cancer patients. We also explored when they would discuss the option.

Material and methods

This study was a planned secondary analysis of the nationwide, anonymous, cross-sectional survey study. The methods were reported in detail previously [19].

Subjects and procedure

All medical oncologists certified by the Japanese Society of Medical Oncology who worked at designated cancer hospitals in Japan were recruited. We distributed questionnaires to the potential participants by mail in January 2014 with a reminder 1 month later. Responses were considered consent to participate. The study was exempt from review by the Institutional Review Board (IRB) of the National Cancer Center Hospital.

Measurements

Endpoint

The primary endpoint of the present study was oncologists' attitudes toward the timing of discussing the option of forgoing anticancer treatment (best supportive care: BSC). We used the same questions as those in the previous study [16]. We asked participants: "Assume you are caring for a patient who has been newly diagnosed with metastatic cancer, but is currently feeling well. When, in the course of the typical patient's illness, are you most likely, for the first time, to discuss the option of forgoing anticancer treatment (BSC)?" Response options were "now (at the diagnosis of a metastatic cancer)," "when the patient first has symptoms," "when there are no more nonpalliative treatments," "only if the patient is hospitalized," "only if the patient and/or family brings it up," and "never explain." As an example case of non-elderly patients where discussion about the option of forgoing anticancer treatment could pose particular challenges in the midst of multiple life events such as job and child-bearing, we specified the patient as 40 years old and with an estimated survival of 2–3 years for clarification.

We acknowledged that discussing the option of forgoing anticancer treatment at the time of diagnosis was not always appropriate for all patients and that the response options were not mutually exclusive. We considered that the distribution of the timing would demonstrate the overall tendency of oncologists toward discussing the option of anticancer treatment and thus decided to use the timing of the first discussion as the primary endpoint, consistent with the previous study [16].

Variables

We investigated demographic data (e.g., age, sex, specialty, institution, clinical experience, number of cancer patients seen in past year, and responsibility as treating physician at EOL), as well as oncologists' experience of EOLd, physician-perceived good death, and beliefs regarding EOLd, as these could potentially contribute to oncologists' attitudes toward the timing of EOLd. These measurements were developed based on a systematic literature review [11, 16, 17, 20–28], preliminary in-depth interviews with oncologists, and discussions among research groups. Face validity was confirmed by pilot testing.

Experience of EOLd

We presented participants with the following four statements to rate the frequency of their clinical experience on a 5-point Likert-type scale from 1 (never) to 5 (very frequently): marked anxiety of patients caused by EOLd, marked anxiety of families caused by EOLd, patients spend terminal phase as desired due to EOLd, and experience of patients attempting/committing suicide just after EOLd. We included the last statement, as the prior literature both from western and eastern countries has shown that the cancer diagnosis can be risks for suicide and suicide attempt [29, 30]. Because of their high internal consistency, we combined the first two statements into "marked anxiety of patients/families caused by EOLd" (alpha = 0.76) and calculated subscale scores by averaging individual item scores. Each score therefore ranged from 1 to 5, with higher scores indicating higher levels of agreement for each subscale or item. Based on the actual distributions of the responses, we divided responses to the last statement (experience of patients attempting/committing suicide just after EOLd) into "never" and others.

Physician-perceived good death

Based on a conceptual framework utilized in a validated Good Death Inventory [31–33], we asked participants about how important they perceived each element for terminally ill patients on a 6-point Likert-type scale from 1 (not important at all) to 6 (essential). We determined four concepts to be investigated: autonomy (three items, alpha = 0.73), life completion (three items, alpha = 0.83), physical comfort, and dying in one's preferred place (one item for each). In particular, "life completion" was evaluated by responses to the following three statements: "patient feels that his or her life is completed," "patient is able to say what he or she wants to dear people," and "patient has arranged everything according to his or her own will." For domains with multiple items, the score was defined as the mean of item scores, and thus higher scores indicate a higher physician-perceived importance of the domain. The actual questions are shown in Table A.1.

Beliefs regarding EOLd

We asked participants to rate 17 statements on a 5-point Likert-type scale from 1 (strongly disagree) to 5 (strongly agree). We performed exploratory factor analysis to identify the underlying structure of beliefs regarding EOLd, and we calculated Cronbach's alpha coefficients for each factor. The subscales of the underlying structure included "difficulty estimating prognosis" (one item), "discomfort talking about death" (one item), "severely distressing for patients and families" (four items, alpha = 0.77), "lack of sufficient time" (one item), "lack of education on EOLd" (two items, alpha = 0.64), "negative general image of hospices and palliative care" (one item), "availability of other health care professionals" (five items, alpha = 0.83), "perception of EOLd as failure of medicine" (one item), and "perception of physician's role as sustaining patient's life" (one item). For a subscale with multiple items, we defined the score as the mean of item scores. Each subscale score therefore ranged from 1 to 5, with higher scores indicating higher levels of agreement for each subscale factor. The actual questions are listed in Table A.2.

Statistical analysis

For comparisons, responses regarding the attitude toward the timing of discussing the option of forgoing anticancer treatment were divided into two categories ("now" vs. other responses). To explore the potential association between oncologists' factors and the timing of the discussion, logistic univariate regression analyses were performed to screen using demographics, experience of EOLd, physician-perceived good death, and beliefs regarding EOLd as independent variables and the timing of discussing the option of forgoing anticancer treatment as a dependent variable. Lastly, to identify independent determinants of discussing the option at the diagnosis, all factors with $p < 0.1$ identified in univariate analyses were entered into multivariate logistic regression analysis, using a forward selection method.

In all statistical evaluations, p values of 0.05 or lower were considered significant due to the exploratory nature of the study. All analyses were performed using the Statistical Package for the Social Sciences, version 22.0 (SPSS Inc., IBM, Japan).

Results

Participants' characteristics

Among the 864 participants who were provided with the questionnaire, 490 responded (response rate 57%). We further excluded 11 physicians who were neither medical oncologists nor hematologists. The characteristics of the 479 remaining physicians (effective response rate 55%) are summarized in Table 1.

Attitudes toward timing of discussing the option of forgoing anticancer treatment

The most frequent timing of discussing the option of forgoing anticancer treatment was “when there are no more nonpalliative treatments” (*n* = 252, 53%), followed by “now (at the diagnosis of a metastatic cancer)” (*n* = 167, 35%), “only if the patient is hospitalized” (*n* = 22, 4.6%), “only if the patient and/or family brings it up” (*n* = 16, 3.3%), and “when the patient first has symptoms” (*n* = 13, 2.7%). Five (1.0%) of the participants reported that they would “never explain.”

Table 1 Baseline characteristics of participating physicians (*N* = 479)

Characteristics	Data[a]
Demographics	
Age, years	48 (7.4)
Male physician, *n* (%)	437 (91%)
Specialty, *n* (%)	
Medical oncology	341 (71%)
Hematology	135 (28%)
Institutions, *n* (%)	
General/cancer hospitals	256 (53%)
University hospitals	223 (47%)
Clinical experience, years	22 (SD 7.5)
Number of cancer patients seen in past year	
< 49	168 (35%)
≥ 50	304 (64%)
Responsibility as treating physician at EOL	186 (39%)
Experiences of EOLd	
Marked anxiety of patients/families caused by EOLd[b,e]	2.2 (0.6)
Patients spend terminal phase as desired due to EOLd[b]	3.5 (0.7)
Experience of patients attempting/committing suicide just after EOLd, *n* (%)	94 (20%)
Physician-perceived good death[c]	
Autonomy[e]	4.0 (0.8)
Life completion[e]	4.8 (0.7)
Physical comfort	5.5 (0.7)
Dying in preferred place	4.9 (0.8)
Beliefs regarding EOLd[d]	
Difficulty estimating prognosis	3.6 (1.0)
Discomfort talking about death	3.1 (1.1)
Severely distressing for patients and families[e]	2.7 (0.7)
Lack of sufficient time	2.3 (1.0)
Lack of education on EOLd[e]	3.1 (0.9)
Negative general image of hospices and palliative care	3.1 (1.0)
Availability of other health care professionals[e]	3.0 (0.9)
Perception of EOLd as failure of medicine	1.5 (0.7)
Perception of physician’s role as sustaining patient’s life	1.7 (0.8)

Data given as mean (standard deviation; SD) or number (percentage)

EOL end-of-life, *EOLd* end-of-life discussion

[a] Because of missing data, some percentages do not add up to 100%

[b] Ranging from 1 = never to 5 = very frequently, with higher values indicating more frequently encountered experiences

[c] Ranging from 1 = not important at all to 6 = essential, with higher values indicating higher levels of importance for each item

[d] Ranging from 1 = strongly disagree to 5 = strongly agree, with higher values indicating higher levels of agreement for each item

[e] Combination of several items

Factors contributing to attitudes toward EOLd

The results of univariate analyses are summarized in Table 2. Participants' attitudes toward discussing the option of forgoing anticancer treatment now were significantly correlated with a greater physician-perceived importance of life completion (OR 1.30, 95%CI 1.00–1.69, $p = 0.048$) and dying in one's preferred place (OR 1.29, 95%CI 1.01–1.65, $p = 0.045$) for a good death, and not perceiving EOLd as being severely distressing for patients and families (OR 0.70, 95%CI 0.54–0.95, $p = 0.021$).

Multivariate analyses

The results of multivariate analyses are summarized in Table 3. Independent determinants of the attitude toward discussing the option of forgoing anticancer treatment now included a greater physician-perceived importance of life completion for a good death (OR 1.38, 95%CI 1.05–1.81, $p = 0.019$), and not perceiving EOLd as being severely distressing for patients and families (OR 0.70, 95%CI 0.52–0.94, $p = 0.017$).

Table 2 Factors predicting physicians discussing the option of forgoing anticancer treatment "now" (at the diagnosis of a metastatic cancer): univariate analyses

	Discussing the option of forgoing anticancer treatment "now" (at the diagnosis)		
Factors	OR	95%CI	*P*
Demographics			
Age	0.98	0.96, 1.01	0.20
Sex: female (vs. male[a])	1.33	0.68, 2.59	0.41
Specialty: hematology (vs. medical oncology[a])	0.71	0.46, 1.10	0.13
Institutions: university hospitals (vs. cancer center and general hospital[a])	0.75	0.51, 1.10	0.14
Clinical experience (years)	0.98	0.96, 1.01	0.15
Number of cancer patients seen in the past year: ≥ 50 (vs. < 49[a])	1.13	0.76, 1.68	0.56
Responsibility as treating physician at EOL: no (vs. yes[a])	1.10	0.75, 1.62	0.63
Experiences of EOLd			
Marked anxiety of patients/families caused by EOLd[b]	0.74	0.53, 1.03	0.073
Patients spend terminal phase as desired due to EOLd[b]	1.05	0.81, 1.37	0.71
Experience of patients attempting/committing suicide just after EOLd: yes (vs. no[a])	0.92	0.57, 1.49	0.74
Physician-perceived good death[c]			
Autonomy	1.12	0.89, 1.41	0.33
Life completion	1.30	1.00, 1.69	0.048
Physical comfort	1.08	0.81, 1.44	0.61
Dying in preferred place	1.29	1.01, 1.65	0.045
Beliefs regarding EOLd[d]			
Difficulty estimating prognosis	1.04	0.86, 1.27	0.66
Discomfort talking about death	0.96	0.81, 1.13	0.61
Severely distressing for patients and families	0.71	0.54, 0.95	0.021
Lack of sufficient time	0.99	0.83, 1.19	0.92
Lack of education on EOLd	0.93	0.76, 1.13	0.45
Negative general image of hospices and palliative care	0.99	0.81, 1.20	0.91
Availability of other health care professionals	0.89	0.72, 1.11	0.30
Perception of EOLd as failure of medicine	0.95	0.72, 1.26	0.72
Perception of physician's role as sustaining patient's life	0.81	0.64, 1.04	0.097

Age, clinical experience, and scale items (marked with b, c, and d) were modeled as continuous variables

EOL end-of-life, *EOLd* end-of-life discussion, *OR* odds ratio, *CI* confidence interval

[a] Reference

[b] Ranging from 1 = never to 5 = very frequently, with higher values indicating more frequently encountered experiences

[c] Ranging from 1 = not important at all to 6 = essential, with higher values indicating higher levels of importance for each item

[d] Ranging from 1 = strongly disagree to 5 = strongly agree, with higher values indicating higher levels of agreement for each item

Table 3 Factors predicting physicians discussing the option of forgoing anticancer treatment "now" (at the diagnosis of a metastatic cancer): multivariate analyses

Factors	Discussing the option of forgoing anticancer treatment "now" (at the diagnosis)		
	OR	95%CI	*P*
Physician-perceived good death[a]			
Life completion	1.38	1.05, 1.81	0.019
Beliefs regarding EOLd[b]			
Severely distressing for patients and families	0.70	0.52, 0.94	0.017

All factors with $p < 0.1$ in univariate analyses (Table 2) were entered into multivariate logistic regression analysis, using a forward selection method. $R^2 = 0.053$

EOLd end-of-life discussion, *OR* odds ratio, *CI* confidence interval

[a] Ranging from 1 = not important at all to 6 = essential, with higher values indicating higher levels of importance for each item

[b] Ranging from 1 = strongly disagree to 5 = strongly agree, with higher values indicating higher levels of agreement for each item

Discussion

This is one of the largest surveys exploring oncologists' attitudes, perceptions, and beliefs regarding discussions on the option of forgoing anticancer treatment. Our results suggest several promising strategies to help oncologists discuss the option of forgoing anticancer treatment in the earlier phase of a metastatic cancer.

The first and most important finding was that oncologists who perceived life completion as important for a good death were more likely to discuss the option of forgoing anticancer treatment at the diagnosis of a metastatic cancer. This is in line with our previous report showing that such physicians were more likely to discuss a hospice and the preferred site of death at the time of the diagnosis [19]. Prior studies also demonstrated that early palliative care including timely EOL discussions and shared decision-making prevented the administration of intravenous chemotherapy near death, and resulted in a higher patient QOL [34, 35]; and that the earlier the EOLd occurred, the higher the patient's QOL became at their EOL, including life completion [36]. These findings may indicate that earlier discussions of future treatment options including both anticancer treatments and best supportive care could facilitate advance care planning (ACP), promote the timely cessation of anticancer treatment, and thus help patients and their families achieve a good death. When considering discussions about future treatment options with advanced cancer patients, oncologists may be encouraged to clarify patients' values, goals, and preferences, as well as to reflect on their own perception regarding life completion as part of a good death.

The second important finding is that physicians who believed that EOLd could be severely distressing to patients and families were more likely to report that they would defer discussion about the option of forgoing anticancer treatment to a later time. This was supported by a previous nationwide survey showing that oncologists were more likely to perceive a high-level burden when discussing the cessation of anticancer treatment, if they felt that the patient would lose hope and self-control and that the family would blame the oncologist because of such discussions [17]. Contrary to the oncologist-perceived burden, however, the majority of advanced cancer patients preferred their physicians to be realistic about their likely future [37]. Communication about forgoing anticancer treatment is a difficult but unavoidable task of oncologists who care for advanced cancer patients [38]. Having realistic conversations while maintaining optimism may show compassion on such an occasion [39]. Potential strategies to alleviate the oncologist-perceived burden may include clarification of patients' values, goals, and preferences earlier in the illness trajectory; the development of communication skills training focusing on communication about forgoing anticancer treatment; utilization of a question-prompt list for patients and families; and multidisciplinary support not only for patients and their families but also for physicians before, during, and after the communication.

Despite the strengths of the nationwide survey, this study had several limitations. First, the response rate was moderate (57%) and baseline characteristics of non-responders were not available. However, previous national surveys involving US and Japanese physicians also reported similar response rates [16, 32, 33]. Second, we performed no formal testing of the validity or reliability of some items of our questionnaire. We believe that this limitation does not severely limit the quality of our study, because established tools to measure physicians' experiences of and beliefs regarding EOLd are not available, and we performed exploratory analyses and calculated Cronbach's alpha. Third, our findings were based on self-reporting instead of actual occurrences of EOLd. Fourth, our model explained less than 10% of the variation, and thus there must have been unmeasured factors. Future studies should include other variables, such as participants' mental health, religious background, availability of specialized palliative care services, and previous training in communication skills. Finally, cultural differences might limit the generalizability of the findings. However, we believe that the findings of this study could be applied to other ethnic populations because the factors identified in the literature are universally consistent [11].

Conclusions

This large survey demonstrated that a greater physician-perceived importance of life completion for a good death and not perceiving EOLd as being severely distressing for patients and families may contribute to physicians' attitudes toward discussing the option of forgoing anticancer treatment at the diagnosis of a metastatic cancer. Reflection by oncologists on their own perception regarding a good death and beliefs about EOLd may help oncologists individualize the timing of discussing the option of forgoing anticancer treatment.

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Compliance with ethical standards

Disclaimers The funding bodies were not involved in the conducting of this study or its submission. We have no financial or personal relationships with individuals, organizations, or companies that might be perceived as a bias to this work.

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

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