

Preference of Japanese cancer patients for being informed about their prognosis

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Background: Prognostic information, which consists of life expectancy, functional prognosis, and uncertainty, of cancer patients is essential. However, the evidence regarding the prognostic preferences of cancer patients is limited. To clarify the prognostic preferences of cancer patients and whether cancer patients want to be informed about their prognosis.

Methods: We conducted a cross-sectional web-based anonymous survey through a private survey company in January 2022. We assessed whether patients would prefer to be informed about their life expectancy and functional prognosis, and explored correlations between patients' backgrounds.

Results: A total of 132 patients responded to the survey. The mean age was 63.1 ± 9.3 , and 67 (50.8%) were male. The most frequent primary tumor was gastrointestinal/hepatobiliary and pancreatic (n=43, 32.6%). Among the patients, 26.6% answered "Strongly agree" or "Agree" to wanting to be informed about their life expectancy, and 33.6–46.9%. wanted to be informed of their functional prognosis. Experience of a family member that had died from cancer had a significant correlation with the preference to be informed about "Life expectancy" (r_s=0.344, P<0.001), "Moving freely" (r_s=0.210, P=0.016), and "Proper communication" (r_s=0.344, P=0.038).

Conclusions: More cancer patients wanted to be informed about their functional prognosis than their life expectancy. In addition, the experience of a family member that had died of cancer had a significant correlation with the preference for wanting to be informed about their life expectancy and functional prognosis.

Keywords: Life expectancy; functional prognosis; prognostic preference; cancer patients

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Introduction

Prognostic information of cancer patients is essential as complex decisions regarding treatment and care are affected by prognosis. In general, prognostic information consists of life expectancy, functional prognosis, and uncertainty (1,2). Previous studies reported that about 80%

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of advanced cancer patients wanted to be informed of their life expectancy, and this preference persists over time (3-5). Enzinger et al. reported that 71.0% of advanced cancer patients wanted to be told their life expectancy, though only 17.6% recalled receiving a prognostic disclosure by their physician (5). In general, patients desire to maintain their independence to continue essential personal activities and not to be a burden to others (6,7). In terms of the quality of death and dying, the Good Death Inventory (GDI) (8), which is a well-validated tool for assessing the quality of death and dving, consists of items including not being a burden to others and maintaining independence (8). Thus, functional prognosis is important for patients and family as well as life expectancy. A recent longitudinal study reported the personal last wishes of patients with a life-limiting illness, such as travel, activities, and being with family and friends, did not show significant intra-personal changes over time (9).

Although the evidence regarding patient behavior for being informed of prognostic information is limited, a previous study reported that many patients hesitated to ask about their prognosis directly and instead expected clinicians to initiate such a conversation (10). The major reasons patients seek clinical information are to better understand their disease and treatment options, and to aid in decision making when they are dissatisfied with the information provided to them by health professionals (11,12). Yun *et al.* reported that 56.2% of advanced cancer patients were told their prognosis by the doctor, and 28.5% guessed based on their worsening condition (13). In addition, Nguyen *et al.* reported that 71.0% of breast cancer patients used the Internet to search for breast cancer information, and 51.1% sought information on prognosis (14).

Previous research indicated that patient satisfaction and the quality of physician-patient communication were improved when physicians asked patients whether they wanted to obtain prognostic information and what that information meant to them (15). Therefore, it is worth exploring the kind of prognostic information that cancer patients want to be informed about, and whether they want to be informed about it. This evidence would help determine desirable prognostic information provision, prognosis communication, and future prognostic research directions. Based on several previous studies and discussion among the authors of this study, we proposed the following hypotheses: (I) more cancer patients want to be informed about their functional prognosis than life expectancy; (II) more cancer patients search for information about their prognosis themselves on the Internet than ask a doctor; and (III) many cancer patients want to be informed about their functional prognosis using the Internet under the assumption that a functional prognosis is available. Thus, we mainly aimed to clarify the prognostic preference of cancer patients and whether the cancer patients want to be informed about their prognosis. We also explored the correlation between the prognostic preference of cancer patients and patients' characteristics. We present the following article in accordance with the SURGE reporting checklist (available at https://apm.amegroups.com/article/ view/10.21037/apm-22-772/rc).

Methods

Study design and setting

We conducted a cross-sectional web-based anonymous survey of cancer patients in January 2022.

Participants and procedure

Participants were recruited in January 2022 through a private web-based survey company (MACROMILL; Tokyo, Japan). The inclusion criteria were cancer patients aged 40 to 75 years old who consented to participate. The definition of cancer patients was patients that were being treated for cancer or those who had regular visits to the hospital for follow-up. Based on a response rate of 50%, sample error of 5%, and confidence level of 95%, our sample size calculation showed that the minimum required number of participants was 73. We planned to recruit 132 cancer patients across Japan, and we determined the number of recruits for each patient category based on age and sex (40-64 years old: 34 men, 32 women; 65-75 years old: 33 men, 33 women), and primary cancer site (breast cancer: 14, prostate cancer: 14, thyroid cancer: 8, others: 96). A survey company recruited potential participants across Japan by convenient sampling and sent questionnaires to them online. Responses to the questionnaire were voluntary, and response was considered consent to participate. Confidentiality and anonymity were maintained throughout all investigations and analyses. The participants received an incentive equivalent to 50 cents from the survey company for completing the questionnaire, and no followup was required after the survey completion. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The Institutional Review Board of Seirei Mikatahara General Hospital (Approval No. 21-37) approved the protocol of this study.

Questionnaires

In the absence of specific and validated instruments for evaluating patients' preference for receiving information about their prognosis and whether they want to be informed, we developed a draft questionnaire based on data from previous studies and discussion among the authors of this study (16-19). The face validity of the draft questionnaires was confirmed by five patients in October 2021, and the questionnaires were revised by researchers.

We asked about background characteristics; age, sex, primary site of cancer, period from cancer diagnosis, presence of recurrence or metastasis, experience of chemotherapy, performance status, maritage status, living with family, education, and experience of having a family member who died from cancer.

We asked the patients to respond with whether they wanted to be informed about their life expectancy and functional prognosis using a 6-point scale (1= Strongly agree, 2= Agree, 3= Agree somewhat, 4= Disagree somewhat, 5= Disagree, 6= Strongly disagree). This consisted of life expectancy, moving freely, complex thinking, eating well, and proper communication. We referred to our previous study, which developed prognostication of walking, talking, and eating to determine the items of functional prognosis (2). We also asked the patients to reply to questions about whether and how often they asked or searched about their prognosis with using a 4-point scale (1= Often, 2= Sometimes, 3= Occasionally, 4= Never). Subsequently, we asked whether the patient wanted to be informed about their prognosis directly from a doctor, and whether they wanted to be informed about their prognosis on the web by entering their information, such as the result of a blood test, using a 6-point scale (1= Strongly agree, 2= Agree, 3= Agree somewhat, 4= Disagree somewhat, 5= Disagree, 6= Strongly disagree) (Supplemental Questionnaire - Appendix 1).

Statistical analysis

We conducted descriptive analysis for the background characteristics of the patients, the prevalence of patients' preference to be informed about their prognosis, the frequency of asking or searching for information about their prognosis, and the prevalence of patients' preference of means to be informed about their prognosis.

We defined the answer of whether they wanted to be informed about their prognosis into two categories: Strongly agree/Agree, and others. Subsequently, we investigated the correlation between the prognostic preference and the patient's characteristics using Spearman's correlation coefficient. We defined the variables based on the previous research and discussion among the researchers (3-5,13). Probability values were two-sided and statistical significance was P<0.05. Adjustment for multiple comparisons, such as Bonferroni correction, was not performed due to the exploratory nature of this study. All analyses were conducted using SPSS-J (ver. 28.0; IBM, Tokyo, Japan).

Results

A total of 132 patients from all the eight regions of Japan responded to the survey. The mean age was 63.1 ± 9.3 , and 67 (50.8%) were men. The most frequent primary tumor was gastrointestinal/hepatobiliary and pancreatic (n=43, 32.6%), followed by urogenital (n=23, 17.4%) and gynecological (n=20, 15.2%). In total, 19 (14.4%) had recurrence or metastases, and 13 (9.8%) were currently undergoing chemotherapy (*Table 1*).

Table 2 shows the prevalence of whether patients wanted to be informed about their life expectancy and functional prognosis. Among the patients, 26.6% answered "Strongly agree" or "Agree" to wanting to be informed about their life expectancy, and 33.6–46.9% wanted to be informed of their functional prognosis. There was no significant difference in the prevalence of preference of being informed about their prognosis between the patients who had recurrence/ metastases and those that did not (data not shown).

The experience of having family member who had died from cancer had a significant positive correlation with the preference to be informed about their prognosis of "Life expectancy" (r_s =0.344, P<0.001), "Moving freely" (r_s =0.210, P=0.016), and "Proper communication" (r_s =0.18, P=0.038) (*Table 3*).

Table 4 shows the means and frequency of the patients that ask or search for information about their prognosis. Most patients did not actively seek information about their prognosis; however, more patients actively wanted to be informed about their life expectancy prognosis than their functional prognosis.

Table 5 shows the answers to questions about whether the patients wanted to be informed about their prognosis directly from a doctor, or whether they wanted to be

Table 1 Patients' background

Age, years 63.1±9.3 ≥65 66 50.0 Sex 67 50.8 Male 67 50.8 Female 65 49.2 Site of primary cancer 100 5.3 Gastrointestinal/hepatobiliary and pancreatic 43 32.6 Gynecological 20 15.2 Urogenital 23 17.4 Breast 14 10.6 Thyroid 8 6.1 Others 17 12.9 Have recurrence or metastases 14 10.6 PS_0 97 73.5 PS_1 29 22.0 PS_2 5 3.8 PS_3 1 0.8 PS_4 0 0.0 Purentreated 88 66.7 Qurently undergoing 13 9.8 Had finished 31 23.5 Duration from the diagnosis of cancer 15 More than 1 month to less than 2 years 16 12.1	Variables	n=132	%
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More than 1 month to less than 6 months21.5More than 6 months to less than 2 years1612.1More than 2 years to less than 5 years6045.5More than 5 years5440.9Marital status10176.5Unmarried1712.9Bereavement53.8	Duration from the diagnosis of cancer		
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More than 2 years to less than 5 years6045.5More than 5 years5440.9Marital status10176.5Unmarried1712.9Bereavement53.8	More than 6 months to less than 2 years	16	12.1
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Unmarried1712.9Bereavement53.8	Married	101	76.5
Bereavement 5 3.8	Unmarried	17	12.9
	Bereavement	5	3.8
Divorce 9 6.8	Divorce	9	6.8

 Table 1 (continued)

Variables	n=132	%
Living with family		
Yes	108	81.8
No	24	18.2
Education		
Less than high school	2	1.5
High school graduate	35	26.5
Post-high school education	95	72.0
Family member has died of cancer		
No	68	51.5
Yes (within 10 years)	11	8.3
Yes (more than 10 years ago)	53	40.2

informed about their prognosis on the Internet by entering their information. About a third of patients answered "Strongly agree" or "Agree" to wanting to be informed about their prognosis directly from a doctor, and about a fifth of patients wanted to be informed about their prognosis on the Internet by entering their information.

Discussion

Table 1 (continued)

To the best of our knowledge, this is the first survey to explore the prognostic preferences of cancer patients and whether cancer patients wanted to be informed about their prognosis.

The first important finding of our study was that the cancer patients were more likely to want to be informed about their functional prognosis than their life expectancy. Our result is valuable as our findings suggest that a certain number of cancer patients wanted to know their functional prognosis as well as time left to be physically and mentally independent, which is a novel finding. Ullrich et al. revealed that the major personal last wishes of people with a lifelimiting illness were travel, activities, and being with family and friends (9). Thus, the concept of unfinished business may provide a clue to the interpretation of this result. As cancer patients may have unfinished business, such as engaging in meaningful activities, they may prefer to know their functional prognosis as a guidepost for completing their unfinished business (20). Furthermore, cancer patients may think that their life expectancy does not have the biggest effect on them completing their unfinished business.

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	-	-		-	-						
	Life expectancy		Moving	Moving freely		Complex thinking		Eating well		Proper communication	
variables	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%	
Strongly agree	15	11.4	25	18.9	18	13.6	25	18.9	25	18.9	
Agree	20	15.2	31	23.5	29	22.0	32	24.2	37	28.0	
Agree somewhat	41	31.1	37	28.0	37	28.0	29	22.0	27	20.5	
Disagree somewhat	27	20.5	18	13.6	23	17.4	24	18.2	24	18.2	
Disagree	24	18.2	15	11.4	19	14.4	13	9.8	10	7.6	
Strongly disagree	5	3.8	6	4.5	6	4.5	9	6.8	9	6.8	

Table 2 The prevalence of preference of being informed about their prognosis

Table 3 Correlation analysis between the preference of being informed of their prognosis and patients' characteristic

Variables	Life expectancy		Moving freely		Complex thinking		Eating well		Proper communication	
vanables	r _s	Р	r _s	Р	r _s	Р	r _s	Р	r _s	Р
Female	-0.008	0.927	-0.018	0.841	0.027	0.758	-0.002	0.981	0.014	0.871
Age ≥65 years	-0.12	0.17	-0.153	0.079	-0.142	0.103	-0.107	0.222	-0.121	0.165
Colorectal cancer	-0.11	0.208	-0.149	0.088	-0.049	0.573	-0.112	0.199	-0.144	0.1
Prostate cancer	0.128	0.145	0.103	0.242	-0.51	0.564	0.047	0.589	0.12	0.172
Breast cancer	0.016	0.855	0.053	0.548	0.052	0.553	0.047	0.589	0.07	0.424
Metastatic site: yes	0.145	0.098	0.041	0.64	0.011	0.904	-0.052	0.55	0.047	0.596
Less than 2 years since cancer diagnosis	0.061	0.484	0.106	0.228	0.166	0.058	0.144	0.1	0.113	0.199
Performance status ≥2	0.028	0.75	0.005	0.952	0.019	0.826	-0.004	0.964	-0.015	0.863
Chemotherapy: currently undergoing or had finished	0.049	0.58	0.011	0.902	0.078	0.372	0	1	-0.021	0.807
Married	0.13	0.136	0.078	0.375	0.001	0.987	0.05	0.569	0.056	0.524
Living with family	0.105	0.23	0.087	0.323	0.022	0.799	0.054	0.538	0.129	0.141
Post-high school education	0.031	0.724	0.024	0.787	0.077	0.383	0.033	0.705	0.047	0.596
Experience of family member who died from cancer	0.344	<0.001	0.21	0.016	0.165	0.059	0.103	0.24	0.18	0.038

To clarify this hypothesis, a qualitative study is needed to explore the reasons why cancer patients wanted to know their functional prognosis.

The second important finding was that the majority of patients did not strongly prefer to know their prognosis. This result was inconsistent with a previous study in Japan that indicated that 72.8% of cancer patients would like their physician to explain how their life expectancy will influence their future plans (20). One possible explanation of this discrepancy was the difference in the treatment stages of the participants. A previous study by Umezawa *et al.* targeted cancer patients deemed by their physician to have received bad news about anticancer treatment cessation at least one week earlier (21). However, most of the participants in the present study were before or after completion of chemotherapy and were in relatively good general health.

The third important finding was that fewer patients actively seek their prognosis compared to the number of patients that want to know their prognosis. Previous studies reported that there were cultural differences regarding

95

84.1

111

Never

TADIC + WITC	able 4 whether and now often patients ask for or search for miorination about then prognosis																	
	Life expectancy					Moving freely					Proper communication							
Variables	Ask doct	to or	Search we	on the b	Ask a f	riend	Ask doc	to tor	Searc the v	h on veb	Ask a fi	riend	Ask to c	loctor	Searc the w	h on veb	Ask a f	riend
	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%	n=132	%
Often	2	1.5	4	3.0	2	1.5	1	0.8	1	0.8	0	0.0	3	2.3	0	0.0	1	0.8
Sometimes	4	3.0	6	4.5	1	0.8	3	2.3	5	3.8	2	1.5	0	0.0	1	0.8	0	0.0
Occasionally	15	11.4	27	20.5	7	5.3	8	6.1	11	8.3	6	4.5	3	2.3	5	3.8	3	2.3

87.1

115

124

93.9

126

95.5

126

95.5

128

97.0

and how often natients ask for or search for information about their prognosis

Table 5 The preference of means for patients to be informed about their prognosis

72.0

122

92.4

120

90.9

Variables	Want to be infor prognosis direct	rmed about their ctly from doctor	Want to be informed about their prognosis on the Internet by entering their information such as the result of a blood test			
	n=132	%	n=132	%		
Strongly agree	19	14.4	7	5.3		
Agree	29	22.0	23	17.4		
Agree somewhat	34	25.8	50	37.9		
Disagree somewhat	21	15.9	29	22.0		
Disagree	17	12.9	13	9.8		
Strongly disagree	12	9.1	10	7.6		

preferences for prognostic information (22-24); thus, this result could be interpreted in terms of cultural differences. A previous qualitative study that was conducted in western countries reported that the reason patients did not discuss their prognosis were: concern that discussing prognosis is too emotionally difficult, that the information would not be useful, or that they may not believe that doctors can estimate prognosis accurately (22). Previous research that compared the preference of prognostic disclosure among Japanese Americans and Japanese living in the U.S. revealed that there were group differences regarding the detailed process of initiating prognostic disclosure in cases where the patient had developed an incurable cancer. Japanese living in Japan (J/J) were much more reluctant to ask their physician to initiate prognostic discussion and to inform them about their prognosis in detail compared to Japanese Americans living in America (JA/A) and Japanese living in America (J/A) (23). (J/J: 42%, JA/A: 62%, J/A: 63%)

The fourth important finding was that the experience of family members that had died of cancer had a significant positive correlation with the preference for being informed

about life expectancy and functional prognosis. Several previous studies explored associated factors, such as sex, age, marital status, education, and performance status, with the patient's preference for being informed about their life expectancy (25-27); however, there was no consistent evidence. Thus, our result is novel in terms of identifying a correlation between the preference of prognostic information and having the experience of family bereavement from cancer. We did not evaluate GDI in this study; however, one possible explanation was that the experience of family bereavement from cancer may evoke patients to ask questions such as "Would I burden others?" and "Could I maintain my own independence?", which are components in GDI (8). Another possible explanation was as health care providers discuss prognostic information with the family rather than the patient in Japan (24), the family may have been more accustomed to such conversations. Therefore, the family may be more likely to consider the pros and cons of telling or not informing the patient of their prognosis in discussions with health care providers (28). Thus, the experience of family members who have died of

cancer may facilitate the patient to consider whether to be informed about their prognostic information. Furthermore, many families of cancer patients have received explanations of prognosis and how long they can expect to be able to talk to the patient and have had the experience of acting on the assumption of death (24,29). In addition, a previous study reported that a fourth of the families of terminally ill patients felt distressed because of unfinished business (30). Therefore, patients who had the experience of family members who had died of cancer may understand the importance of prognostic information. In terms of associated factors with the preference for being informed about their life expectancy and functional prognosis, our study did not show a significant correlation between cancer type (colorectal, prostate, and breast cancer) and education level. This result was inconsistent with previous research that found that cancer type and education level were correlated (27). A possible explanation was the difference of the duration from the diagnosis of cancer. Nagler et al. enrolled patients who were diagnosed with cancer within 1 year prior to their survey (15); however, the majority of the participants in the present study were analyzed more than 2 years after diagnosis.

The fifth important finding was that about a third of patients wanted to be informed about their prognosis directly from a doctor. This result was consistent with previous studies in Japan and Australia (31,32). Moreover, another national survey in Japan reported that 34% of physicians would discuss prognosis with a hypothetical patient with newly diagnosed metastatic cancer (33). Although further research is warranted, one possible reason why only a third of patients wanted be informed about their prognosis directly from a doctor was that patients felt that they would be dissatisfied with the prognostic information provided by the doctor (14). Another possible reason was that elderly adults in Japan prefer to leave decisions to a medical expert, and considered it an important component of good death (23,34). As several previous randomized controlled trials suggested it is important not only to "tell and know the life expectancy" but also to "have a dialogue about the prognosis" (35-37), further research is warranted to facilitate the dialogue about prognosis.

Of note, about a fifth of patients wanted to be informed about their prognosis on the Internet by entering their information such as the result of a blood test. This result would suggest new clinical questions such as "What is the most desirable way for cancer patients to be informed about their own prognostic information?". As a previous cohort study revealed that cancer patients who were informed of their terminal diagnosis had a significantly better quality of life and a lower rate of emotional distress than patients who guessed it from their worsening condition (13), it is important to explore the most desirable way for patients to be informed about their prognostic information. This may require a variety of options to meet individual needs.

The strengths of our study were that is included patients with various cancer types, age categories, an almost equal male/female ratio, respondents from all eight regions of Japan, and no missing data regarding variables and outcomes. However, our study had some limitations. First, the number of participants who were wanted to be informed about their prognostic information was small. Most participants had relatively good performance status and did not receive aggressive chemotherapy; therefore, they may not be representative of incurable cancer patients that need prognostic information. Second, as we applied convenient sampling via the Internet using a private webbased company and analyzed the first 132 responders, we could not extract a response rate or the characteristics of non-responders. Although this sampling method may introduce selection bias, we recruited the patients based on several categories, such as age, sex, and primary cancer site; therefore, we believe that we could minimize the influence of selection bias. In addition, our study mostly targeted patients that were more active online, future studies using a different methodology are needed to assess the preferences of elderly cancer patients. Third, we used questionnaires that had not been clearly validated; thus, we could not strictly compare the patients' various preferences with clinical and statistical significance. It is necessary to develop reliable and valid survey items to analyze the preference of cancer patients for being informed about their prognosis. Fourth, as 66.7% of the participants had never had chemotherapy and only 14.4% had recurrence or metastases, the majority of the participants could be interpreted as a group with a high probability of cure. Our findings may suggest that the preference of these populations may be closer to the general population. Thus, caution is needed when adapting the results of the present study to all patients undergoing cancer treatment.

Conclusions

Our study found that cancer patients were more likely to want to be informed about their functional prognosis than

their life expectancy. In addition, the experience of having a family member that had died of cancer had a significant correlation with the preference for the patient wanting to be informed about their life expectancy and functional prognosis.

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Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at https://apm. amegroups.com/article/view/10.21037/apm-22-772/rc

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://apm. amegroups.com/article/view/10.21037/apm-22-772/coif). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The Institutional Review Board of Seirei Mikatahara General Hospital (Approval No. 21-37) approved the protocol of this study. All the participants consented to participate.

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Appendix 1

Supplemental Questionnaire

I. What is your current situation?

1. What disease(s) are you currently receiving treatment for? If you have more than one disease, please indicate the disease that seems to affect your health the most.

Cancer 2: Heart failure 3: Cardiomyopathy 4: Emphysema 5: Interstitial pneumonia
 Chronic renal failure with dialysis treatment 7: Chronic renal failure without dialysis treatment

2. Which organ(s) of the body were you diagnosed with cancer?

1: Lungs 2: Stomach 3: Esophagus 4: Small intestine, large intestine and rectum 5: Peritoneum 5: Liver 6: Gall bladder and bile duct 7: Pancreas 8: mammary gland 9: uterus 10: ovary 11: kidney 12: renal and ureter 13: bladder 14: prostate 15 16: Testis 16: Lymph glands (lymphoma) 17: Blood (leukemia) 18: Myeloma 19: Thyroid gland 20: Throat and larynx (head and neck except thyroid gland) 21: Brain 22: Bone 23: Soft tissue (muscle, etc.) 23: Thymus 24: Mesothelioma 25: Skin 26: Primary unknown 27: Other (28: Do not know

3. How long has it been since your cancer was diagnosed? Please circle the number that best describes your experience.

1. less than 1 month	2. more than 1 month Less than 6 months	3. more than 6 months Less than 2 years
4. more than 2 years to less than 5 years	5. more than 5 years	

4. Please choose the one that applies to your current cancer status.

1. no recurrence or metastasis	2. recurrence or metastasis
--------------------------------	-----------------------------

5. Please select the most applicable items regarding your experience with anti-cancer drug treatment.

1. no experience	2. experience	3. experience
(Never treated with anticancer drugs)	(Currently undergoing anti-cancer treatment)	(Completed anticancer drug treatment)

6. Please tell us about your situation. Please select the most appropriate one.

0. Asymptomatic, able to engage in social activities and behave in the same way as before the illness	1. mildly symptomatic, limited physical exertion, but able to walk, perform light or sedentary work.	2. able to walk and take care of him/herself, but sometimes needs a little assistance	3. able to do some personal activities, but often needs assistance and is bedridden more than 50% of the time	4. unable to take care of himself/herself, needs constant assistance, and stays
way as before the illness	light or sedentary work.	little assistance	more than 50% of the time	assistance, and stays
without any restrictions.			during the day	in bed all day.

7. Please choose the one that applies to your life.

marital status	1. married 2. unmarried 3. bereaved 4. bereavement
Those who live with you	1. no 2. yes

8. Please select the last school you graduated from (if you left school before graduation, please select the school before that).

1. Elementary and junior high schools	2. High school and former junior high school	3. Junior college/Vocational school	4. University
5. Graduate School			

9. Did any of your family members or close friends die from cancer? Please choose the one that applies.

1. no

2. yes (within 10 years)

3. present (prior to 10 years)

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II. If some degree of prediction were technically possible, would you "want to know" about the following regarding "how long we can do XXX "?

- 1. I would like to know "how long I can live".
- 1. strongly disagree
- 2. disagree
- 3. disagree somewhat
- 4. agree somewhat
- 5. agree
- 6. strongly agree
- 2. I would like to know "how long I am free to move (travel, etc.)"
- 1. strongly disagree
- 2. disagree
- 3. disagree somewhat
- 4. agree somewhat
- 5. agree
- 6. strongly agree

3. I would like to know "how long can I read a book or do other complex thinking"

- 1. strongly disagree
- 2. disagree
- 3. disagree somewhat
- 4. agree somewhat
- 5. agree
- 6. strongly agree
- 4. I want to know "how long I can eat well".
- 1. strongly disagree
- 2. disagree
- 3. disagree somewhat
- 4. agree somewhat
- 5. agree
- 6. strongly agree
- 5. I would like to know "how long can we have a proper conversation".
- 1. strongly disagree
- 2. disagree
- 3. somewhat disagree
- 4. agree somewhat
- 5. agree
- 6. strongly agree

III. Have you ever asked your doctor or done any research on your own about how long you will live, how long you will be able to move freely, or how long you will be able to talk?

- 1. How long can I live? (1) Asked by the doctor in charge Never Sometimes Sometimes Often (2) I have never researched by myself on the Internet or in books Sometimes Sometimes Often (3) Asked by acquaintances or acquaintances Never Sometimes Sometimes Often (4) Others () Were you satisfied with it? If not, please explain why. 1. very satisfied 2. satisfied 3. somewhat satisfied 4. somewhat unsatisfied 5. unsatisfied 6. very unsatisfied 2. How long can I move freely? (1) Asked by the doctor in charge Never Sometimes Sometimes Often (2) I have never researched by myself on the Internet or in books Sometimes Sometimes Often (3) Asked by acquaintances or acquaintances Never Sometimes Sometimes Often (4) Others () Were you satisfied with it? If not, please explain why. 1. very satisfied 2. satisfied 3. somewhat satisfied 4. somewhat unsatisfied 5. unsatisfied 6. very unsatisfied 3. How long can I talk to you? (1) Asked by the doctor in charge Never Sometimes Sometimes Often (2) I have never researched by myself on the Internet or in books Sometimes Sometimes Often (3) Asked by acquaintances or acquaintances Never Sometimes Sometimes Often (4) Others () Were you satisfied with it? If not, please explain why. 1. very satisfied 2. satisfied 3. somewhat satisfied 4. somewhat unsatisfied
- 5. unsatisfied
- 6. very unsatisfied

IV. If it were technically possible to predict "how long I can do XXX" like "how long I can move freely (e.g. travel)", how would you like to know about it?

1. I would like to hear an explanation directly from the doctor in charge.

- 1. strongly disagree
- 2. disagree
- 3. somewhat disagree
- 4. agree somewhat
- 5. agree
- 6. strongly agree

2. I would like to use the Internet if there is a way to enter simple information such as blood test data and have the predictions shown on a graph.

- 1. strongly disagree
- 2. disagree
- 3. disagree somewhat
- 4. agree somewhat
- 5. agree
- 6. strongly agree