

# Factors Involved in Shared Decision-making Regarding Treatment Selection by Patients With Cancer

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**Abstract.** *Background/Aim:* Patients diagnosed with cancer are expected to choose one or more treatment modalities after receiving corresponding explanations of the options. When making these choices, patients consider the effects of treatment and aspects related to their quality of life. These concerns can cause confusion and conflict owing to the complicated information provided by medical caregivers. The objective of the study was to identify perceptions of cancer treatment in patients with cancer and the decision-making factors affecting their treatment choices. *Patients and Methods:* In this observational (cross-sectional) study, an online questionnaire survey was administered to 194 Japanese cancer patients with treatment experience. Patient information, perceptions of explanations provided by healthcare professionals, treatment views, and reasons for treatment decisions were subjected to a simple tabulation. Content and factor analysis was conducted to determine important treatment selection elements. *Results:* Regarding treatment perception, 60.3% of respondents ( $n=117$ ) considered treatment a financial and family burden, 47.4% ( $n=92$ ) had concerns about physical pain, and 40.2% ( $n=78$ ) were worried about increased stress.

*Regarding decision-making quality, 95.9% determined their preferred treatment within one week, 49.0% reported difficulties in making their decisions, and 83.0% chose their treatment themselves. Major decisive factors were prolonging life, opinions of medical staff, and accepting treatment risks (68.0%, 68.6%, and 60.3% of patients, respectively). The main attitudes toward treatment were anxiety, expectations of benefit, and expectations of support and care. Conclusion:* SDM should enable patients to visualize the changes that their bodies will experience and include discussions on prognosis. Psychological care should be prioritized to alleviate anxiety and improve readiness for decision-making; attention should be paid to the extent and timing of information provision.

Patients diagnosed with cancer are expected to choose one or more treatment methods after receiving explanations of the treatment options. Cancer treatment involves multiple phases, depending on the type and stage of the cancer, disease progression, and the patient's condition. A patient is, thus, faced with the decision-making process at each phase. When making these choices, patients consider not only treatment effects but also aspects of quality of life; these concerns can cause confusion and conflict with the often-complicated information provided by medical caregivers.

Shared decision-making (SDM) occurs when healthcare professionals provide support in this decision-making process. The concept of SDM has been used frequently since the 1990s and is considered among the main methodologies for supporting active decision-making, backed by advanced communication skills. SDM has been found to maximize patient health outcomes (1), strengthen patient empowerment and responsibility by ensuring that the chosen treatment plan is based on patient preferences (2-4), and increase patients' understanding of any acquired knowledge (5). In addition, SDM allows patients to experience a sense of control and confidence (6, 7) and helps maintain and strengthen their

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independence and empowerment, resulting in improved psychosocial adaptive capacity (3, 7, 8) and improved adherence to medical care (1, 3, 4, 6, 8). In a Dutch study on SDM, it was found that physicians and patients did not discuss the short- and long-term effects of treatment in 22% and 26% of the cases, respectively (9). Furthermore, a significant financial burden is associated with inadequate SDM among adolescent and young adult cancer survivors (10). In a previous study, it was found that when SDM was practiced, older patients were more active in decision-making and more satisfied with their treatment than younger patients (11). Moreover, both patients and clinicians prefer adopting a collaborative role in treatment decisions. In previous studies of patients with early-stage cancer, most patients stated that they did not remember having to choose a treatment modality and experienced little or no decision-making conflict (12), preferred playing an active or cooperative role with their caregivers in treatment decision-making, and found it important to discuss and share their opinions/decisions with their caregivers (13). Thus, to provide effective decision support, it is necessary to understand the factors that influence the patient's decision-making process. This study aimed to identify the cancer treatment perceptions of patients with cancer and the decision-making factors that affect their treatment choices.

## Patients and Methods

*Study design.* This was an observational (cross-sectional) study. The selection criteria were as follows: diagnosis with cancer (any type) in the past 10 years and age of 18-69 years. Patients were excluded if they had never received any formal cancer treatment. The study was conducted in October 2019.

*Recruitment of participants.* Patients with cancer and treatment experience were recruited from an existing online research company panel. There were no geographic or ethnic restrictions, but participants had to be able to respond in Japanese. A request to participate in the self-administered, online survey was sent to patients with cancer registered with Rakuten Insight Inc. (<https://insight.rakuten.co.jp/en/>, accessed September 9, 2023) and who met the selection criteria. Sampling continued until 200 patients were enrolled.

*Questionnaire survey.* The survey was designed to clarify factors involved in determining treatment options for patients with cancer. The survey items included basic patient information (age, sex, treatment details, quality of life, length of time until treatment decision, etc.), perceptions of the explanations patients had received from healthcare professionals, views of their cancer treatment, and reasons for deciding on certain treatment methods.

*Data analysis.* All analyses were conducted using the IBM SPSS Statistics for Windows, version 26 (IBM Corp., Armonk, NY, USA). Means, ratios, frequencies, and percentages were calculated for patient demographics, characteristics of the cancers, and patients' perceptions of their disease and their treatment options. Content analysis was conducted to determine the important considerations

in treatment selection. Factor and cluster analyses were conducted to determine attitudes toward the actual treatments. The principal factor method was used to extract factors, while factor rotation was conducted using the varimax method with Kaiser's normalization. Lastly, the k-means (no update option) procedure, a component of the cluster analysis method, was conducted with the following criteria: cluster (3), mixture (10), and converge (0).

*Ethical considerations.* Potential participants were sent a written request for participation, an explanation of the purpose and methods of the study; information about the confidentiality of their data, the stringent protocols of data storage and disposal of personal information, and the voluntary nature of participation; and an agreement form to obtain consent for publishing their information. Data were collected anonymously using serial IDs. The study was approved by the Osaka University Graduate School of Human Sciences Research Ethics Committee (approval number: 19037). The planning, conduct, and reporting of human research were in accordance with the Helsinki Declaration as revised in 2013.

## Results

*Sample characteristics.* Valid responses were obtained from 194 patients [97%; 109 men (56.2%) and 85 women (43.8%)]. Twenty patients (10.3%) were currently undergoing treatment, and 158 (81.4%) had maintained an acceptable quality of life. Thirty-six patients (18.6%) had experienced cancer recurrence, 29 (14.9%) had metastasized disease, and 112 (57.7%) were not currently undergoing treatment for cancer but were receiving regular follow-up. Lastly, 158 (81.4%) were currently symptom-free and reported no limitations in social activities, such as professional work or housework (Table I).

*Perceptions of patients with cancer.* Perceptions regarding explanations provided by healthcare professionals. Among the respondents, 77.8% (n=151) were aware of the explanations given by their doctor and other healthcare professionals regarding their disease status. However, few patients were aware that treatment was intended to prolong their life rather than actually cure the disease [33.5% (n=65)], understood the concept of palliative care [20.1% (n=39)], or had a clear perspective on their prognosis [39.2% (n=76)] (Figure 1).

*Perceptions regarding cancer treatment.* The patients expressed the following concerns about undergoing treatment: major financial and family burdens [60.3% (n=117)], physical pain [47.4% (n=92)], and increased stress [40.2% (n=78)] (Figure 2).

*Quality of decision-making related to cancer treatment.* Among the patients, 95.9% (n=186) made their treatment choice within 1 week of receiving an explanation of their treatment options from their doctors. Nearly half of the patients (49.0%; n=95) reported difficulty in making a decision, although 83.0% (n=161) reported that they were able to make the treatment choices themselves.

Table I. Cancer patient medical condition and treatment status (n=194).

		N	%
Sex	Male	109	56.2
	Female	85	43.8
By site	Breast cancer	25	12.9
	Colorectal cancer	34	17.5
	Gastric/esophageal cancer	24	12.4
	Lung cancer	16	8.2
	Liver cancer	7	3.6
	Prostate cancer	15	7.7
	Uterine (cervical and body) and ovarian cancer	26	13.4
	Pancreatic cancer, bile duct, and gall bladder cancer	2	1.0
	Oral, pharyngeal, and laryngeal cancer	6	3.1
	Thyroid cancer	18	9.3
	Malignant lymphoma, leukemia, myeloma	19	9.8
	Brain tumor	5	2.6
	Bladder cancer, kidney, and renal cancer	12	6.2
	Primary cancer unknown	1	0.5
	Other	13	6.7
Recurrence	Not diagnosed as ill	0	0
	Yes	36	18.6
Metastasis	No	158	81.4
	Yes	29	14.9
Treatment	No	165	85.1
	Currently undergoing treatment for cancer (anticancer drugs, surgery, radiation therapy)	20	10.3
QOL	Currently not receiving treatment for cancer, but visiting the hospital/clinic regularly (under observation)	112	57.7
	No current treatment for cancer and no regular visits to the hospital	62	32.0
	No symptoms and no restrictions on social activities, such as work or housework	158	81.4
	Mild symptoms, limited physical exertion, but able to walk and do sedentary work	28	14.4
	Cannot perform light work but can walk and look after him/herself.	4	2.1
	He/she is awake for more than half of the day.	4	2.1
Time taken to choose treatment	Lying down for more than half of the day	0	0.0
	Lying down all day.	147	75.8
	Chosen on the spot	39	20.1
	Chosen after thinking for around one week	7	3.6
Difficulty to choose treatment	Took around one month	1	0.5
	Took more than one month	99	51.0
	Not difficult at all	95	49.0

QOL: Quality of life.

When deciding on a treatment method, 1) prolonging life [68.0% (n=132)], 2) opinion of the medical staff [68.6% (n=133)], and 3) risks associated with treatment [60.3% (n=117)] were the most important selection criteria (Figure 3). The patients prioritized minimizing the impact on family, living for as long as possible, maintaining time spent with family, and avoiding pain. From the patients' perspectives, their families valued prolonging the patient's life, respecting the patient's wishes, minimizing suffering, and supporting the patient to the extent that the family could maintain their own lives (Table II).

*Stratification based on perceptions of cancer treatment.* Based on the responses concerning perceptions of current (10

items, Figure 2) and future treatment (10 items), four main themes were detected on factor analysis: Factor 1, "maintenance of the quality of life through cancer treatment-related systems"; factor 2, "expectations regarding cancer treatment itself"; factor 3, "adverse effects of cancer treatment on daily life" and factor 4, "psychological anxiety about cancer treatment" (Table III). Based on the similarity of their benefits, factors 1 and 2 were summarized as positive expectations regarding cancer treatment and care, while factors 3 and 4 were summarized as anxiety-provoking aspects related to the burden and side effects of treatment. Patients who experienced difficulty in selecting their treatment tended to have low awareness of factor 1 and high awareness of factor 4.

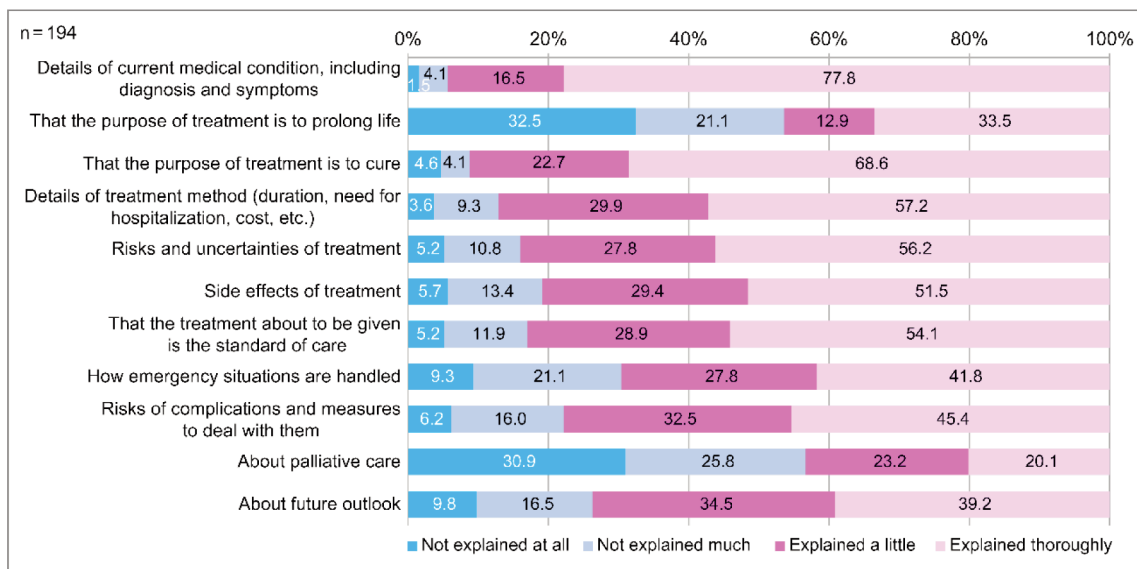


Figure 1. Degree of explanation provided by the healthcare personnel.

Non-hierarchical clustering analysis was conducted with the factors arranged in three clusters: Cluster 1, “those anxious about cancer treatment”; cluster 2, “those who expect a therapeutic effect” and cluster 3, “those who expect support and care”. Patients in cluster 1 had higher rates of recurrence and difficulty in selecting treatment methods. Patients in cluster 2 experienced symptoms at higher rates, and those in cluster 3 actively collected information and handled the situation independently at higher rates than those in the other clusters (Table IV).

### Discussion

Our survey results showed that the respondents tended to have low awareness of the following aspects of cancer treatment: the intent of prolonging life rather than curing the disease, the role of palliative care, and treatment prognosis. This finding is in line with the results reported by Shay *et al.* (14), namely that “in open-ended responses, the most commonly reported concerns related to medical decision-making are feelings of uncertainty and fear of receiving bad news”. Therefore, the patients may not have attempted to gain awareness of their treatment plans as a psychological response to the fear of uncertainty and bad news. Furthermore, many patients receiving palliative treatment expect the treatment to cure their disease, and explanations from medical personnel are not always easy to understand (15). These observations suggest that prognosis should be thoroughly discussed with patients receiving palliative treatment.

Regarding physical pain, when it became difficult to continue standard treatment, 56% (1st line), 64% (2nd line),

and 59% (3rd line) of respondents were willing to try another treatment despite the risk of severe side effects (16). Thus, the inability of patients to accurately assess the likelihood of side effects can result in the treatment choices being misunderstood by them. Therefore, in decision-making support, it is necessary to assist patients in visualizing the side effects. Physicians involved in cancer treatment consider minor surgical complications of grade 1-2 as acceptable (17), and a survey on patient satisfaction with surgical treatment in patients with musculoskeletal sarcoma showed that priority 1 was tumor removal, followed by functional preservation as a factor that increased satisfaction (18). Therefore, healthcare professionals and patients must discuss the physical pain associated with treatment and its impact on quality of life well in advance. Furthermore, if perceptions of cancer treatment among patients with cancer differ from those predicted by healthcare professionals, their decision-making in treatment selection may be distorted. Therefore, it is important to confirm the perception of treatment and correct the course of treatment before its initiation.

The aspect of increased stress can be attributed to feelings of dependence on the physician for treatment. In their study of prostate cancer survivors, Shen *et al.* (19) found that “compared to the initial diagnosis, survivors with rising levels of prostate-specific antigen (PSA) reported increased negative affect following their diagnosis, concern about the treatability of their disease, increased planning and health behavior change, heightened levels of worry preceding doctor’s appointments (especially prior to the discussion of PSA testing results), and a strong reliance on physicians’

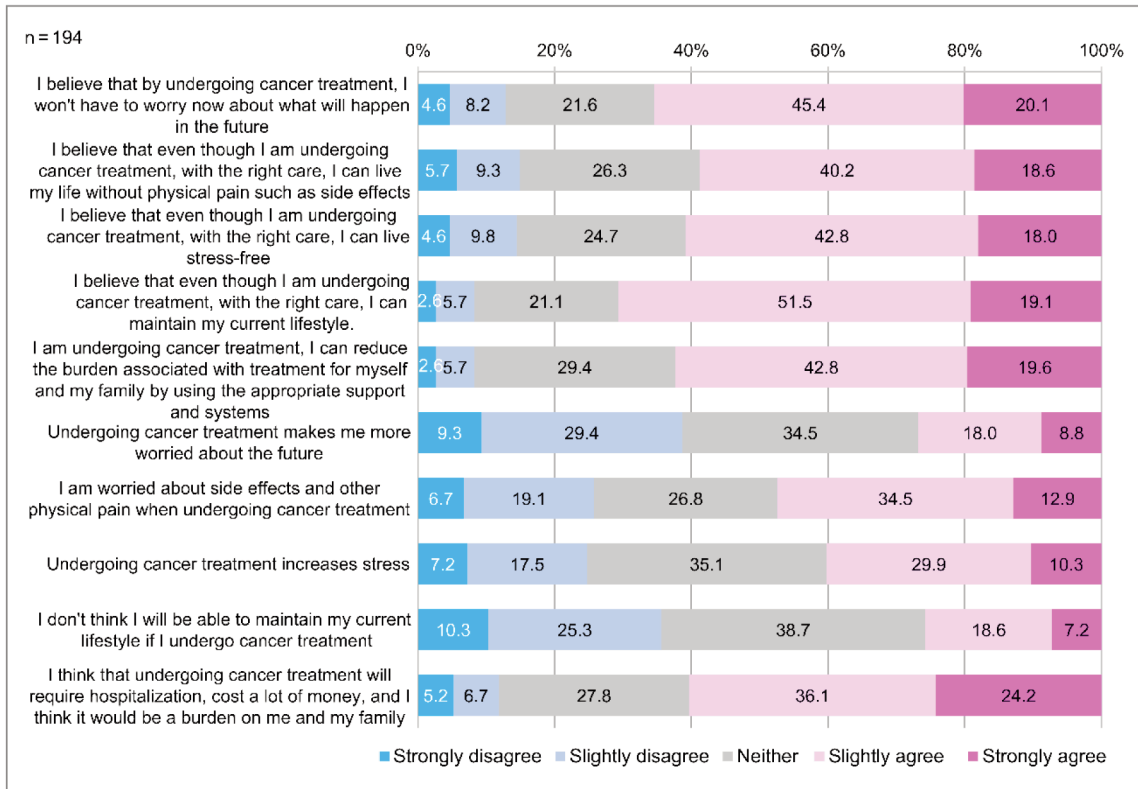


Figure 2. Perceptions of cancer treatments of which patients.

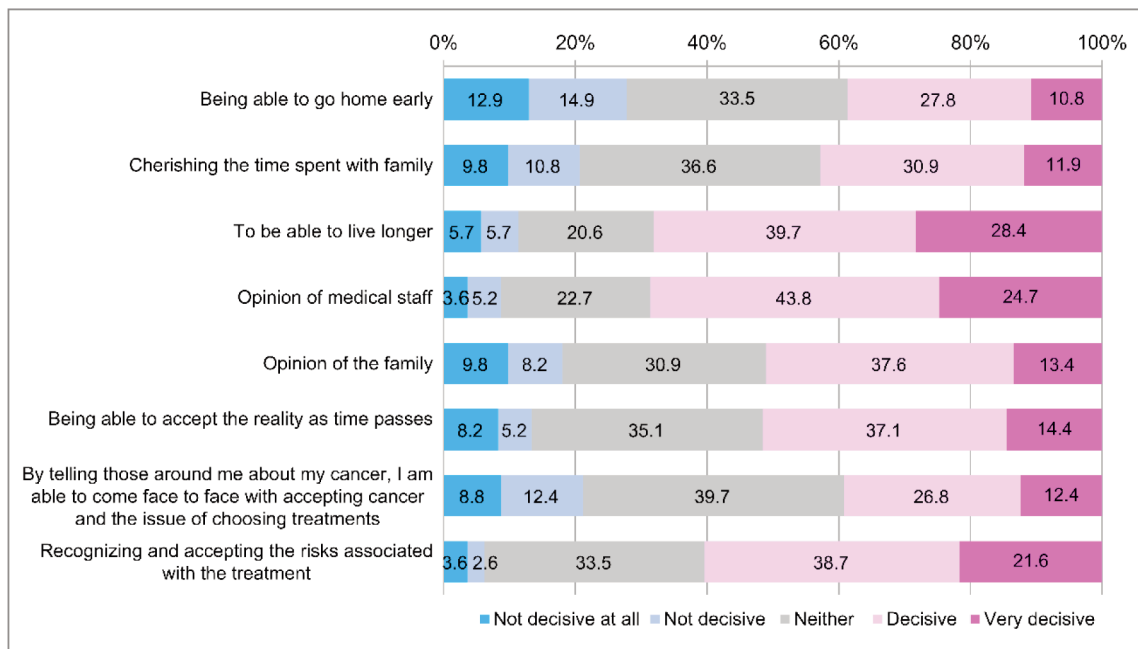


Figure 3. Factors involved in selecting cancer treatment of which patients.

Table II. Values influencing treatment choice.

	Categories	Subcategories
Patient	Want to minimize the patient’s suffering	I want to make sure that those who I leave behind won’t have to worry I don’t want to inconvenience my partner I want to spend my last days in the hospital
	Want to live as long as possible	I want to maintain my current appearance as much as possible I’d like to see a brighter future
	Want to maintain the amount of time to spend with family	I want to live as long as possible I want to try all the treatments that are available I would like treatments that slow disease progression
	Want to avoid difficult experiences	I want to avoid tough things and leave them to my family I expect too much from treatment I want to alleviate the fear of physical pain I want to alleviate the physical pain I want to avoid stress
Family	Wish to prolong the patient’s life	I want to alleviate the burden associated with treatment I have hopes for the treatment I want him/her to live as long as possible I want him/her to actively receive treatment
	Respect the patient	I want to do for him/her as much as I can I don’t want him/her to lose hope I respect the patient’s decision I will prioritize the patient’s wishes
	Want to minimize the patient’s suffering I want to support the patient to the extent that I can maintain my own life	I don’t want him/her to have a difficult time I don’t want to change my living environment

treatment recommendations” (19). This is an important point for clinicians when providing support for SDM – when autonomous decision-making is inhibited by temporary anxiety or concern, it is necessary to prioritize psychological care to improve readiness for decision-making.

We found that 1) the desire to prolong life (68.0%), 2) the opinion of the medical staff (68.6%), and 3) acceptance of risks associated with treatment (60.3%) were the main decisive factors involved in treatment selection. While it is important to prioritize survival in the decision to undergo a given treatment, as illustrated by the results of a previous study – “Priority for survival substantially motivated BA/BC men to take up radical treatment for prostate cancer” (20) – adverse events and risks associated with treatment and their impact on life need to be properly recognized and discussed prior to the commencement of the treatment.

Regarding attitudes toward cancer treatment, 1) “patients who were anxious about cancer treatment” had higher rates of recurrence and difficulty in choosing treatment, 2) “patients who expected to benefit from treatment” had higher rates of “any symptoms”, and 3) “patients who expected support and care” showed higher rates of “active information gathering” and “proactive responses.” This may be an important clue to guide support based on the patient’s condition. For example, in case 1), it may be necessary to alleviate anxiety about treatment, symptom management can

be prioritized for case 2), and the need for support and care can be identified and addressed in case 3).

Regarding information gathering in this context, we found that self-initiated information seekers tended to be female, had high levels of education and good information retrieval skills, and engaged in communication with their healthcare providers (21). Therefore, even if healthcare professionals actively provide information to patients who seek it on their own, it is less likely to cause information overload and confusion. However, when providing information to patients who do not seek it on their own, healthcare providers must carefully consider the amount of information provided and the timing of information provision. The limitation of this study was that the diversity of cancer types prevented a detailed analysis of type-specific differences in treatment decision-making methods.

Patients with advanced cancer may have less awareness and understanding of treatment and palliative care than those with early-stage cancer, so healthcare providers need to design explanations that are appropriate for their level of understanding. The “inability to visualize the physical condition after treatment” and “anxiety about life” are factors that influence these patients’ ability to actively make autonomous decisions. Therefore, when providing information on treatment, nurses and doctors should support patients in resolving their concerns by encouraging them to visualize their lives after treatment.

Table III. *Factor structure of attitudes toward cancer treatment.*

	Factor				Commonality	$\alpha$ -coefficient
	1	2	3	4		
Factor 1: Maintenance of quality of life through systems around cancer treatment						0.88
I believe that by undergoing cancer treatment, with the right care, I can live stress-free	0.891	0.165	-0.051	-0.118	0.838	
I believe that even though I am undergoing cancer treatment, with the right care, I can maintain my current lifestyle	0.778	0.280	0.013	-0.048	0.687	
I believe that even though I am undergoing cancer treatment, with the right care, I can live my life without physical pain such as side effects	0.765	0.178	-0.077	-0.052	0.626	
I believe that even though I am undergoing cancer treatment, I can reduce the burden associated with treatment for myself and my family by using the appropriate support and systems	0.669	0.281	0.006	0.063	0.531	
I believe that by undergoing cancer treatment, I won't have to worry now about what will happen in the future	0.592	0.250	-0.122	-0.089	0.435	
Factor 2: Expectations for cancer treatment itself						0.87
I believe that by undergoing cancer treatment, I can maintain my current lifestyle in the future	0.311	0.893	-0.144	-0.020	0.915	
I believe that undergoing cancer treatment will help me meet my family's expectations	0.249	0.735	-0.104	-0.050	0.615	
I believe that getting cancer treatment will help me live longer	0.168	0.704	-0.027	0.012	0.525	
I believe that undergoing cancer treatment can slow the progression of the disease	0.201	0.660	-0.011	0.044	0.478	
I believe that undergoing cancer treatment can cure the disease completely	0.190	0.660	-0.172	-0.093	0.510	
Factor 3: Negative impact of cancer treatment on daily life						0.82
I believe that the burden of cancer treatment will make it impossible to maintain my current lifestyle	-0.109	-0.055	0.762	0.273	0.671	
I believe the burden of cancer treatment may quicken the progression of the disease	0.009	-0.092	0.717	0.176	0.554	
I believe the burden of cancer treatment can shorten life expectancy	-0.103	-0.035	0.646	0.146	0.450	
I don't think cancer treatment would completely cure the disease	-0.041	-0.158	0.611	0.137	0.419	
I believe that undergoing cancer treatment will increase the burden on my family in the future	0.027	-0.034	0.596	0.261	0.426	
Factor 4: Psychological anxiety about cancer treatment						0.86
Undergoing cancer treatment increases stress	-0.142	-0.055	0.179	0.826	0.737	
I am worried about side effects and other physical pain when undergoing cancer treatment	-0.101	0.020	0.188	0.819	0.717	
I don't think I will be able to maintain my current lifestyle if I undergo cancer treatment	-0.123	-0.137	0.465	0.622	0.638	
Undergoing cancer treatment makes me more worried about the future	0.011	-0.043	0.379	0.607	0.513	
I think that undergoing cancer treatment will require hospitalization, cost a lot of money, and I think it would be a burden on me and my family	0.049	0.045	0.174	0.553	0.341	
Factor score covariance matrix						
1	0.895					
2	0.044	0.928				
3	0.003	-0.025	0.810			
4	-0.019	0.011	0.087	0.846		

Factor extraction method: Principal factor method; Rotation method: Varimax method with Kaiser's normalization<sup>a</sup>; <sup>a</sup>Rotation converged after 7 iterations; After factor analysis of Q16-17, the 20 items of attitudes toward cancer treatment were grouped into the following four factors; Factors 1 and 2 summarized positive expectancy attitudes toward cancer treatment and care, while Factors 3 and 4 summarized attitudes of anxiety toward the burden and side effects of cancer treatment.

Table IV. Characteristics of attitude towards cancer treatment.

	Cluster		
	1 86 pts.	2 16 pts.	3 92 pts.
Factor 1: Maintenance of QOL through cancer treatment-related systems	-0.44196*	-1.40956	0.65828 <sup>§</sup>
Factor 2: Expectations regarding cancer treatment itself	-0.26715 <sup>^</sup>	0.43147 <sup>§</sup>	0.17469
Factor 3: Adverse effects of cancer treatment on daily life	-0.23375 <sup>^</sup>	-0.25846 <sup>^</sup>	0.26346 <sup>&amp;</sup>
Factor 4: Psychological anxiety about cancer treatment	0.49524 <sup>§</sup>	-1.23505	-0.24815 <sup>^</sup>
Characteristics of each cluster	Expectations regarding support and care are low, and anxiety exceeds the expectations regarding therapeutic effects.	Despite anxiety about adverse effects of cancer treatment, expectations regarding therapeutic effects exceed the anxiety.	It is believed that QOL can be maintained with support and care for cancer patients, and there is less anxiety.
Name of cluster	Those anxious about cancer treatment.	Those who expect therapeutic effects.	Those who expect support and care.
Degree of difficulty in selecting treatment			
I experienced difficulty in selecting treatment.	57%	50%	41%
I decided immediately after the treating physician's explanation.	74%	69%	78%
Disease status			
I have recurrent cancer.	24%	13%	14%
I have cancer metastasis.	19%	13%	12%
I currently have symptoms.	21%	38%	13%
Behaviors after diagnosis			
I gathered knowledge and information from various sources.	56%	56%	70%
I was able to understand the knowledge and information that I gathered.	60%	50%	70%
I conveyed my opinion or thoughts to the doctor or person close to me.	53%	44%	64%
I asked myself if the information was applicable to me.	55%	63%	71%
I asked someone or checked if the information was correct.	55%	38%	61%
I gathered information regarding hospitals and treatment methods to make my own decision.	44%	44%	63%

QOL: Quality of life. <sup>§</sup>+40% or more; <sup>&</sup>+20% or more; <sup>^</sup>-20% or less; <sup>\*</sup>-40% or less; For factors 1 and 2, higher values indicate positive perceptions; For factors 3 and 4, higher values indicate negative perceptions.

Finally, patients who reported anxiety about cancer treatment were more likely to have experienced cancer recurrence or metastasis and were more anxious about recurrence than about the effectiveness of treatment. This finding is characteristic of patients with advanced cancer; in such cases, the anxiety must be addressed rather than focusing on providing information for SDM.

**Conclusion**

The results of this study suggest that factors involved in cancer treatment decision-making are better understood when classified according to cancer stage, type, and treatment

method. Decision support should also include helping patients to visualize the changes that will occur in their bodies both from the disease and from side effects of treatment and to fully discuss possible gaps between expectations and reality based on prognosis and the progression of disease. Further, our results suggest that care to alleviate anxiety to improve readiness for decision-making should be a priority and that attention should be given to the amount and timing of information provided to patients who do not ask for it on their own, in addition for their reasons for not doing so. Further exploration is needed on factors involved in decision-making, and how these factors may differ across populations, cancer stages, types, and treatment methods.



## Conflicts of Interest

The Authors declare no conflicts of interest.

## Authors' Contributions

Y.K., K.H., A.U., M.N., and Y.K.: Conceptualization; data curation; formal analysis; funding acquisition; project administration; Y.K., K.H.: investigation; methodology; resources; software; A.U., Y.K.: supervision; validation; visualization; Y.K.: roles/writing – original draft; Y.K., K.H., A.U., M.N., and Y.K.: writing – review & editing.

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