

# Coping skills and quality of life in tongue cancer survivors:a cross-sectional study

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# Coping skills and quality of life in tongue cancer survivors: a cross-sectional study

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## Abstract

**Aim:** This study aimed to clarify the actual conditions of cancer survivor ability, ability in daily life, quality of life, and speech intelligibility in patients with tongue cancer who underwent tongue resection.

**Methods:** A questionnaire survey was conducted for this study. Descriptive statistics were used to elucidate the actual conditions of “cancer survivor ability,” “ability of patients with tongue cancer to lead their lives,” “quality of life (QoL),” and “speech intelligibility.” The Mann–Whitney U test was used to analyze the relationship between the actual conditions and survivor duration for “cancer survivor ability,” “ability of patients with tongue cancer to lead their lives,” and “quality of life (QoL).”

**Results:** The number (%) of valid responses was 72 (97.3%). The items that showed decreased ability in the group who had survived for  $\geq 28$  months were “Negotiating: I can ask my healthcare provider if I am concerned about the onset or recurrence of an illness (P = 0.044)” and “Standing up for your rights: Do you feel empowered to stand up for your rights regarding your cancer? (P = 0.044).” There were no significant differences among the other items. None of the six skills of Cancer Survivor Competence and Tongue Cancer Patient Livelihood Competence were sufficient, and “Information Seeking” was low in both. The overall QoL score was 62.2 for EORTC QLQ-C30. The lowest score on the functioning scale was 83.3 for emotion, and the highest score on the symptom scale was 20.0 for fatigue. In terms of speech intelligibility, 44 patients (61.1%) reported that their speech had changed from that before surgery.

**Conclusion:** The cancer survivor skills and life skills of patients with tongue cancer are insufficient and do not improve over time, suggesting a need for long-term support to help them acquire these skills.

## KEY WORDS

tongue cancer survivorship, ability of survivor, quality of life

## Introduction

Oral and pharyngeal cancers are considered to be rare<sup>1)</sup>. According to the Japanese Cancer Registry, in 2018, the number of patients with cancer accounted for 2.3% of the total number of morbidities in Japan<sup>2)</sup>, and the incidence of tongue cancer is even rarer. Recently,

medical interest in rare cancers has been increasing; however, efforts to address this issue have just begun. In the postoperative period, the pathophysiology of the patients revealed that at 1 year postoperatively, dysphagia and dysphonia persist, although recovery rates are better than those immediately after surgery<sup>3)4)</sup>.

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The existing literature only reports physical dysfunction in patients with tongue cancer<sup>5)</sup>, and there are no reports on the aspect of patients' lives. There are a few memoirs of such patients, but they are limited to personal experiences. Moreover, there are few reports on the establishment of patient associations<sup>6)</sup>, where patients and their families can obtain information, and because no such patient association exists close to the patients, it is believed that patients with rare cancers and their families lack access to information and resources useful for disease management in all periods (before to after treatment) because of the rarity of the disease. As a result, it is predicted that useful knowledge and support are difficult to obtain.

Furthermore, in 2020, the 5-year relative survival rate of patients with oral and pharyngeal cancers, including patients with tongue cancer, was 63.5%<sup>7)</sup>, and the 5-year relative survival rate for cases with a 5-year follow-up was 83.3%<sup>8)</sup>.

More than half of the patients with cancer attain long-term survival, and the 5-year survival rate is high. In this regard, we considered that patients with tongue cancer need lifelong care that goes beyond addressing functional impairment postoperatively.

This concept is consistent with Mullan's definition of a cancer survivor. The definition is that "the patient needs to be cared for as a cancer patient, focusing on life after diagnosis rather than only on whether or not he or she is cured"<sup>9)</sup>. Therefore, we explored care for patients diagnosed with tongue cancer considering them as "cancer survivors." However, the characteristics of patients with tongue cancer over a relatively long period were unclear.

Therefore, before conducting this study, a qualitative research method was used to determine the experiences of patients who had undergone tongue resection from before diagnosis to the present<sup>10)</sup>. Patients who underwent tongue resection 9 months to 10 years ago were included in this study. Patients' experiences included "having a hard time being a cancer patient" as they had to visit several medical institutions and needed time to start treatment before they were diagnosed with tongue cancer because it was a rare cancer, even after they noted abnormalities on their tongues and consulted a physician. Moreover, after returning to daily life with a stable condition after surgery, early detection of recurrence or

abnormality was more important than relying on medical personnel, and the patients were "determined to protect themselves from cancer" and engaged in recuperation. Moreover, they "experienced situations in which they were reminded on a daily basis that they were patients with tongue cancer" and "felt constrained in their relationships with others due to their lisp."

From these results, it was inferred that from the time of cancer diagnosis, patients had an underlying belief that they had no choice but to protect themselves from the threat of cancer and that they could not depend on medical personnel. Moreover, even after their condition stabilized, the impaired speech and pronunciation affected not only their communication but also their behavior and relationships with others. This result is consistent with our hypothesis that patients may have difficulty in obtaining support and knowledge regarding the way to continue life as a patient with cancer. Furthermore, we believe that this is an issue that will remain unresolved for a relatively long time and that there is a need to find a direction of care based on the survivor's perspective.

Therefore, this study aimed to clarify "ability to survive cancer," "ability to lead daily life," and "quality of life (QOL)" of patients with tongue cancer after surgery to determine the direction of care of these patients as "cancer survivors," which remains unclear. Furthermore, it was determined whether these aspects are related to survival duration and ways by which care can be provided according to survival duration were explored.

## Methods

### 1. Research design

Since there were no previous studies on "tongue cancer survivors," it was necessary to examine the existing literature on the theme of cancer survivors and the literature in related fields to select or develop the survey content and items. Therefore, the design was a cross-sectional, fact-finding survey using a questionnaire.

### 2. Participants

Patients who had been diagnosed with tongue cancer, had undergone tongue resection, were outpatients at a cancer center hospital, and aged  $\geq 20$  years who

understood the purpose of this study and provided consent were included in the study. The exclusion criteria were cognitive impairment and difficulty in answering the questionnaire due to physical or mental fatigue.

We selected seven cancer treatment-based hospitals with a large number of patients with tongue cancer who underwent surgery and obtained their consent for participation in the study. First, a written request for research cooperation was sent to the director of the nursing department, and three facilities responded that they were willing to cooperate. Next, we explained the purpose and methods of the study in writing and orally to the attending physicians and nurses at the three facilities willing to cooperate and asked them to prepare a list of potential study participants. Then, the researcher explained the study purpose, research methods, and ethical considerations to the patients in writing and orally based on the list, and those who provided consent were selected as study participants.

### 3. Research method

The survey was conducted using a self-administered, unmarked questionnaire during the waiting time of the subjects' outpatient visits.

### 4. Questionnaire content

A questionnaire containing questions regarding "target attributes," "ability to survive cancer," "ability in daily life," and "QOL" was designed.

#### 1) Target attribute

General demographic questions included age, sex, smoking history, alcohol consumption history, last school attended, and source of income. Moreover, items on the survival period (the number of months from diagnosis to the date of survey response), treatment and speech intelligibility<sup>11)</sup> were created as information on tongue cancer. Age was self-reported, and data on sex, smoking history, alcohol consumption history, last school attended, source of income, and speech intelligibility were collected using the questionnaire. The date of diagnosis of tongue cancer, date of surgery, details of surgery, and presence of chemotherapy and radiation therapy were obtained from clinical records with the permission of the participants and their attending physicians.

The method of mapping clinical records to anonymous questionnaire data is described below.

The doctor at the research collaborating facility serially listed the subjects and confirmed from their clinical records the date of tongue cancer diagnosis, date of surgery, details of surgery, and administration of chemotherapy/radiation therapy.

On the day of the survey, the researcher confirmed with the nurse at the collaborating facility the number of the subject, and entered the corresponding number in the questionnaire.

After the researcher was introduced to the subject by the nurse at the cooperating facility, the study was explained to the subject by the researcher.

The names of the subjects on the forms where they were listed were removed to ensure privacy, and the form included only the number and clinical record information of the subject, which was matched with the number on the questionnaire.

#### 2) Ability to survive cancer

The participants' ability to survive cancer was measured using the "Cancer Survivor Ability Measurement Questionnaire" developed by Davis et al.<sup>12)</sup> This questionnaire was developed based on the philosophy that learning self-advocacy skills improves the ability to survive cancer (not only tongue cancer but also other cancers). The self-advocacy skills were communication, information seeking, decision making, problem solving, negotiation, and assertion of rights, and the questionnaire consisted of 31 items with sub-items for each. The reliability and validity of this questionnaire were confirmed by Davis et al. in 2013 in patients with breast cancer. Recently, self-advocacy skills have been widely published as a training program [Cancer Survival Toolbox (NCCS)]. All cancer survivors are recommended to master it as a competency<sup>13)</sup>. Therefore, it was also adopted in this study.

Each item in the questionnaire is scored on a six-point Likert scale (0, not at all; 1, very rarely; 2, rarely; 3, sometimes; 4, often; 5, much); the higher the score, the higher the ability. Inverted items were tabulated after reversal processing, and as with other items, the higher the score, the higher the ability. As there is no Japanese version of this questionnaire, it was translated into Japanese following the forward/backward translation procedure with the permission of the

developer. In particular, the first author performed the forward translation, which was then discussed among the authors and modified until consensus was achieved. Next, a bilingual native-English speaker was asked to back-translate the translated version to ensure that the translation adequately reflected the original text, and corrections were made until the problematic parts were finally eliminated.

### 3 ) Ability in daily life of patients with tongue cancer

This ability was established by the researcher because no existing questionnaire was available. This questionnaire is needed because the ability to survive cancer is not specific to patients with tongue cancer and to a previous study by Hatta et al. and Takagaki. Hatta et al. reported that “It was inferred that impaired speech and pronunciation affected not only the sense of difficulty in speaking but also one’s overall life, such as one’s behavior and the way one conducts relationships with others”<sup>10)</sup>. Takagaki revealed that the direction of cancer survivor care is to determine one’s way of life and enhance self-control to maintain a social life<sup>14)</sup>.

Therefore, in this study, we named this ability as “ability in daily life” and created the items, considering that it is the ability in daily life, while evaluating the ability of the patient with tongue cancer to survive cancer. The 31 items were created by utilizing the results of a previous study by Hatta et al. on the 6 aforementioned “Cancer Survivor Abilities,” which have been verified for reliability and validity.

The questionnaire consisted of 31 items for 6 competencies, and each item was scored on a 5-point Likert scale (1, not so; 2, somewhat so; 3, not so sure; 4, somewhat so; 5, yes); the higher the score, the higher the ability. The ability was determined to be high. Inverted items were tabulated after reversal processing, and as with other items, the higher the score, the higher the evaluation of that ability. The content validity of the questionnaire items was confirmed by six nurses with  $\geq 5$  years of clinical experience in providing care to patients with head and neck cancer.

### 4 ) QOL

The Japanese version of the EORTC Core Quality of Life questionnaire (EORTC QLQ-C30) was used to assess QOL. The EORTC QLQ-C30 is a self-administered questionnaire consisting of 30 questions specific to patients with cancer. The Japanese version of

the EORTC QLQ-C30 has been confirmed to have high reliability and validity in a QOL survey conducted by Kobayashi et al.<sup>15)</sup> The questionnaire consisted of three components: overall QOL, functional, and symptom scales. The overall QOL scale consisted of one item, the functional scale consisted of five items, and the symptom scale consisted of nine items. The results of 15 items were scored according to the manual. Each score ranged from 0 to 100 for the overall QOL and functional scales, with a higher score indicating a better condition. The symptom scale score ranged from 0 to 100, with a lower score indicating a better condition. The questionnaire was registered for use on the EORTC Quality of Life Group website<sup>16)</sup>, and permission was obtained for its use.

### 5. Study period

The study period was from September 1, 2020 to August 9, 2021.

### 6. Data analysis

#### 1 ) Facts

For each survey item, descriptive statistics were initially conducted for the total number of respondents. The real number (%) was calculated for the nominal scale, and the mean (standard deviation) was calculated for the proportional scale. Means and standard deviations were calculated for the ability to survive cancer and the ability in daily life of patients with tongue cancer for each subcategory.

#### 2 ) Relationship between facts and survival period

The number of months from the date of tongue cancer diagnosis to the date of obtaining survey response was calculated as the survival period.

Then, we used inferential statistics to analyze whether the actual “ability to survive cancer,” “ability in daily life,” and “QOL” are related to the survival period.

For inferential statistics, after testing the normality of the distribution, we classified the samples into two groups according to the median because a normal distribution was not confirmed; then, the Mann–Whitney U test was performed. Tests were considered significantly different when the significance level was  $< 5\%$ . IBM SPSS Statistics<sup>®</sup> version 24 was used in the statistical analysis.

### 7. Ethical considerations

The purpose of the study, method of analysis,

fact that responses were voluntary, and method of publication were clearly explained to the potential participants in writing and orally via a request letter and instructions. It was also explained that the responses obtained would be converted into numerical values for statistical analysis and that individuals would not be identified. Consent to participate in the study was deemed to have been obtained when the questionnaires were answered and collected.

This study was approved by the Ethical Review Committee of the institution where the researcher belongs and the institution where the study was conducted (approval number: 969-2).

## Results

### 1. Status of collection

All 75 survey participants who visited the clinic as outpatients during the study period were asked to complete the survey, and 74 of them provided a response (response rate: 98.7%). No one met the exclusion criteria. Of the 74 respondents, 72 had valid responses (excluding 2 participants who were frequently missing) and were included in the analysis (valid response rate: 97.3%).

### 2. Target attribute (Table 1)

The subject attributes are shown in Table 1. The mean age was  $60.2 \pm 14.7$  years; 52 (72.2%) participants were men and 20 (27.8%) were women. The median duration of survivorship was 28 months. Moreover, 61 (84.7%) patients underwent partial tongue resection with or without combined chemotherapy and radiotherapy, and 11 (15.3%) underwent resection of more than half of the tongue. Forty-four respondents mentioned that "some words are difficult to pronounce" or "some words are difficult to hear and the other person hears them back," which indicated that they experienced changes related to pronunciation.

### 3. Relationship between facts and survival period

#### 1) Ability to survive cancer (Table 2)

##### (1) Facts

There were a total of 31 sub-items of the 6 skills, and 2 items had a mean score of  $\geq 4$ : "Negotiating: Do you feel intimidated negotiating with insurance agents or employers regarding your cancer?" and "Standing

up for your rights: Do you feel hopeful rather than hopeless?" Thirteen items had a mean score of  $< 3$ , and one item with a mean score of  $< 3$  for all sub-items was the skill for "solving problems." The lowest skill was identified using the following question: "Communication: Do you know the five most important communication skills?"

##### (2) Relationship to survival period

We evaluated the differences in the 6 skills and 31 sub-item scores between survivors who had been diagnosed with tongue cancer within  $\geq 28$  months from the date of diagnosis and survivors who had been diagnosed within a shorter period. There were no differences between the two groups in terms of age, sex, smoking history, drinking history, educational qualification, source of income, treatment, or speech intelligibility. Scores for "Standing up for my rights: Do you feel empowered to stand up for your rights regarding your cancer?" were significantly less among survivors diagnosed within  $> 28$  months ( $P = 0.044$ ). The other 30 sub-items were not significantly different.

#### 2) Ability in daily life of patients with tongue cancer (Table 3)

##### (1) Facts

There were 31 sub-items of the 6 skills, with 14 items having a mean score of  $\geq 4$ . The skills with a mean score of  $< 4$  points were "Finding information" and "Making decisions." Three items had a mean score of  $< 3$ : "Communicating: I have consulted with others about pronunciation and other ways of speaking," "Communicating: I choose words that are easy to pronounce," and "Standing up for your rights: I would like to participate in discussions and e-mails with other people with the same disease if there is an opportunity."

##### (2) Relationship to survival period

We evaluated the differences in 6 skills and 31 sub-item scores between survivors who had been diagnosed with tongue cancer  $\geq 28$  months from the date of diagnosis and survivors who had been diagnosed within a shorter period. Scores for "Negotiate: I can ask my healthcare provider if I am concerned about the onset or recurrence of an illness." were significantly less among survivors diagnosed within  $> 28$  months ( $P = 0.044$ ). The other 30 sub-items were not significantly different.

Table 1. Target attribute

		n	Mean $\pm$ SD
1. Age (years)		72	60.2 $\pm$ 14.7
2. Survivor period (month)		72	Median (min-max) 28 (2-193)
3. Sex		n	%
	Male	52	72.2
	Female	20	27.8
4. Smoking history			
	None	26	36.1
	Ex-smoker	40	55.6
	Sometimes	1	1.4
	Daily	5	6.9
5. Drinking history			
	None	19	26.4
	Previous	7	9.7
	Sometimes	23	31.9
	Daily	22	30.6
	Unknown	1	1.4
6. Educational attainment			
	Junior high school	9	12.5
	High school	21	29.2
	Vocational school /junior college	14	19.4
	College and above	28	38.9
7. Source of income			
	Salary	35	48.6
	Pension	29	40.3
	Others	8	11.1
8. Treatment			
	Partial glossectomy	39	54.2
	Partial glossectomy, chemotherapy	10	13.8
	Partial glossectomy, radiation therapy	1	1.4
	Partial glossectomy, chemotherapy, radiation therapy	11	15.2
	Hemiglossectomy	2	2.8
	Hemiglossectomy, skin graft reconstruction	5	6.9
	Subtotal glossectomy , skin graft reconstruction	1	1.4
	Subtotal glossectomy, skin graft reconstruction, chemotherapy	2	2.8
	Subtotal glossectomy, skin graft reconstruction, chemotherapy, radiation therapy	1	1.4
9. Speech intelligibility			
	No change	27	37.5
	Some words are difficult to pronounce	29	40.3
	Some words are difficult to hear, and the other party hears them back	15	20.8
	Unknown	1	1.4

SD: standard deviation



Table 2. Ability as cancer survivor

	Survival period			P-value
	All (n = 72) Mean ± SD	Less than 28 months (n = 37) Median	More than 28 months (n = 35) Median	
<b>Communicating</b>				
1) Are you assertive in telling your medical team about your needs?	3.5 ± 1.5	4.0	3.0	.469
2) Do you feel you can express your feelings appropriately?	3.6 ± 1.4	4.0	4.0	.664
3) Do you know the five most important communication skills? <sup>§</sup>	1.8 ± 1.8	2.0	2.0	.305
4) <sup>a</sup> Do you feel the need to improve your communication skills? <sup>†</sup>	2.8 ± 1.6	3.0	3.0	.582
5) Do you feel you have the skills to communicate effectively? <sup>‡</sup>	3.1 ± 1.5	3.0	3.0	.593
<b>Finding information</b>				
6) Do you consider yourself to be resourceful in obtaining cancer information? <sup>‡</sup>	2.9 ± 1.5	3.0	3.0	.787
7) When given cancer information, do you read and understand it?	3.5 ± 1.4	4.0	3.0	.313
8) Do you use the Internet to find information about your cancer?	2.8 ± 2.0	3.0	4.0	.501
9) Are you confident in your ability to find needed cancer information?	2.6 ± 1.6	3.0	3.0	.845
10) <sup>a</sup> Do you need new skills to locate, judge, and understand cancer information?	2.4 ± 1.6	2.0	3.0	.262
11) <sup>a</sup> How often do you feel overwhelmed with too much cancer information?	2.6 ± 1.4	2.0	3.0	.902
<b>Making decisions</b>				
12) Do you feel in control of your cancer decisions?	3.1 ± 1.6	3.0	3.0	.986
13) <sup>a</sup> Do you find that you second guess your cancer decisions?	3.3 ± 1.7	4.0	4.0	.239
14) <sup>a</sup> How often do you feel rushed to make decisions about your cancer?	3.8 ± 1.2	4.0	4.0	.140
15) Do you have the necessary skills to make important health decisions?	3.3 ± 1.5	3.5	3.0	.518
16) Are you confident in your decision-making skills?	3.4 ± 1.5	3.0	4.0	.125
17) Are you confident in asking for a second opinion about your treatment?	2.5 ± 1.7	2.0	3.0	.363
<b>Solving problems</b>				
18) Do you know the necessary steps to follow for effective problem-solving? <sup>†</sup>	2.1 ± 1.5	2.0	2.0	.724
19) Are you able to approach problem-solving from different viewpoints? <sup>‡</sup>	2.9 ± 1.4	3.0	3.0	.251
20) Do you feel you are effective in solving problems brought on by your cancer?	2.7 ± 1.4	3.0	3.0	.315
21) Do you have the skills to solve problems when you feel depressed or sad?	2.9 ± 1.4	3.0	3.0	.696
<b>Negotiating</b>				
22) Do you feel empowered to negotiate your needs and wishes related to your cancer?	3.6 ± 1.3	4.0	3.5	.662
23) Do you feel you have the necessary skills to negotiate on your own behalf?	3.4 ± 1.4	3.0	3.5	.479
24) <sup>a</sup> Do you feel intimidated negotiating with insurance agents or employers regarding your cancer?	4.0 ± 1.3	4.0	5.0	.774
25) Are you able to separate your emotions when negotiating issues related to your cancer? <sup>†</sup>	2.7 ± 1.7	3.0	3.0	.497
<b>Standing up for your rights</b>				
26) Do you feel empowered to stand up for your rights regarding your cancer? <sup>†</sup>	3.8 ± 1.3	3.5	3.0	.044*
27) Are you good at standing up for your rights regarding your cancer? <sup>‡</sup>	3.4 ± 1.3	4.0	3.0	.837
28) Are you confident in facing challenges brought on by your cancer? <sup>†</sup>	3.3 ± 1.5	3.0	3.0	.620
29) Do you feel you can reach out to others to negotiate what you need?	3.3 ± 1.5	3.0	3.0	.611
30) Are you aware of who can help you advocate for your cancer rights?	3.1 ± 1.8	3.0	4.0	.229
31) Do you feel hopeful rather than hopeless?	4.1 ± 1.0	4.0	4.0	.931

0, not at all; 1, very rarely; 2, seldom; 3, sometimes; 4, often; 5, a great deal

Mann–Whitney U test, p &lt; 0.05

SD: standard deviation

Translated and used in Japanese

<sup>a</sup> Items reversed scored: The numbers in the table are after the inversion process. Therefore, the higher the score, the higher the ability.<sup>†</sup> 1 missing value; <sup>‡</sup> 2 missing values; <sup>§</sup> 3 missing values



Table 3. Ability in the daily life of patients with tongue cancer

	Survival period			P-value
	All (n = 72)	Less than 28 months (n = 37)	More than 28 months (n = 35)	
	Mean ± SD	Median	Median	
<b>Communicating</b>				
1) I can express my thoughts and feelings in concrete terms.	4.7 ± 0.7	5.0	5.0	.744
2) I have consulted with others about pronunciation and other ways of speaking.	1.9 ± 1.6	1.0	1.0	.205
3) I choose words that are easy to pronounce.	1.8 ± 1.2	1.0	1.0	.527
4) I listen carefully to what my family and friends say, and when I don't understand, I listen until I do.	3.1 ± 1.5	4.0	3.0	.364
5) <sup>a</sup> I use fewer words when I talk to people than before the surgery.	3.8 ± 1.5	5.0	4.0	.364
6) I feel that my feelings are fully heard by those close to me, including my family.	4.1 ± 1.2	5.0	4.0	.188
<b>Finding information</b>				
7) I am able to find a medical professional or specialist I can trust.	3.8 ± 1.4	4.5	4.0	.176
8) I know how to obtain a second opinion. <sup>‡</sup>	3.5 ± 1.6	4.0	4.0	.912
9) I know how to find the latest treatment for my disease.	3.0 ± 1.3	3.0	3.0	.660
10) I choose reliable sources for information about treatment.	3.2 ± 1.3	3.0	3.0	.867
<b>Making decisions</b>				
11) When I make treatment decisions, I know how much I want to be involved in those decisions. <sup>†</sup>	3.7 ± 1.2	4.0	4.0	.504
12) I know the benefits of not deciding on only one treatment plan. <sup>†</sup>	3.6 ± 1.2	4.0	4.0	.275
13) I feel that I have allowed enough time to decide on a treatment option.	3.5 ± 1.4	4.0	4.0	.991
14) I am able to compare the advantages and disadvantages of the treatment options presented to me before deciding on a treatment option.	3.7 ± 1.2	4.0	4.0	.177
15) I do not base my treatment decisions solely on figures such as disease survival rates.	3.6 ± 1.2	4.0	4.0	.981
<b>Solving problems</b>				
16) When I feel discomfort in my tongue, I immediately seek medical attention.	4.3 ± 1.1	5.0	5.0	.990
17) I know how to tell my healthcare provider if I have a problem.	4.3 ± 1.0	4.5	5.0	.916
18) I have a way to calm my mind about problems that are not immediately resolved.	3.7 ± 1.1	3.5	4.0	.889
19) If the problem is solved, I can use that next time. <sup>‡</sup>	4.1 ± 0.9	4.0	4.0	.088
<b>Negotiating</b>				
20) I can ask my healthcare provider if I am concerned about the onset or recurrence of an illness.	4.3 ± 0.9	5.0	4.0	.044*
21) If I want to know more about my life, I can ask my healthcare provider to help me.	4.2 ± 1.0	4.5	4.0	.241
22) I can accept that I may not be 100% satisfied with my treatment.	4.2 ± 1.0	4.0	4.0	.713
23) I can persevere in discussing with my healthcare provider even if his or her words and attitude toward me are not what I want.	3.7 ± 1.1	4.0	4.0	.258
24) I am able to have my own solutions by discussing with medical professionals.	4.2 ± 1.0	4.0	4.0	.315
<b>Standing up for your rights</b>				
25) I am more confident in speaking than I was shortly after my discharge from the hospital after surgery.	4.1 ± 1.2	5.0	4.0	.101
26) My physical strength is better than it was shortly after my discharge from the hospital after surgery.	4.2 ± 1.0	5.0	5.0	.282
27) I would like to participate in discussions and e-mails with other people with the same disease if there is an opportunity.	2.9 ± 1.3	3.0	3.0	.635
28) I tell my friends/workers that I have (had) a tongue disorder.	4.1 ± 1.4	5.0	5.0	.295
29) I am able to find enjoyment in life even if speaking is slightly inconvenient.	4.3 ± 0.8	4.0	5.0	.766
30) <sup>a</sup> I am always worried about people's stares when I try to do something in a crowded place.	3.8 ± 1.3	4.0	4.0	.905
31) <sup>a</sup> I feel that the range of activities that express my personality, such as hobbies and connections with others, has become smaller than that before the surgery.	4.0 ± 1.3	5.0	5.0	.332

1, not really ; 2, somewhat less so; 3, cannot say either way ; 4, if anything, yes; 5, that is right  
SD:standard deviation

Mann-Whitney U test p < 0.05

a-Items reversed scored: The numbers in the table are after the inversion process. Therefore, the higher the score, the higher the ability.

† 1 missing value; ‡ 2 missing values

3) Average scores of the six skills

(1) Ability to survive cancer (Table 4.1)

Of the six skills related to the ability to survive cancer, the mean values of “Standing up for your rights” and “Negotiating” (3.5 and 3.4, respectively) were higher and those of “Finding information” and “Solving problems” (2.8 and 2.7, respectively) were lower.

Table 4.1. Average of six skills (Ability as cancer survivor)

(n = 72)	
	Mean ± SD
Communicating	3.0 ± 1.6
Finding information	2.8 ± 1.6
Making decisions	3.2 ± 1.5
Solving problems	2.7 ± 1.4
Negotiating	3.4 ± 1.4
Standing up for your rights	3.5 ± 1.4

score:0, not at all; 1, very rarely; 2, seldom; 3, sometimes; 4, often; 5, a great deal

SD:standard deviation

(2) Ability in daily life of patients with tongue cancer (Table 4.2)

Of the six skills related to the ability in the daily life of patients with tongue cancer, the mean values of “Solving problems” and “Negotiating” (4.1 and 4.1, respectively) were higher and those of “Finding information” and “Communicating” (3.4 and 3.2, respectively) were lower.

Table 4.2. Average of six skills (Ability in the daily life of patients with tongue cancer)

(n = 72)	
	Mean ± SD
Communicating	3.2 ± 1.3
Finding information	3.4 ± 1.4
Making decisions	3.6 ± 1.2
Solving problems	4.1 ± 1.0
Negotiating	4.1 ± 1.0
Standing up for your rights	3.9 ± 1.2

score:1, not really; 2, somewhat less so;

3, cannot say either way; 4, if anything, yes; 5, that is right

SD:standard deviation

4) QOL (Table 5)

(1) Facts

The mean overall QOL score was 62.2 of 100. With regard to the functional scale, the lowest score (83.3) was for emotion. In the symptom scale, fatigue had the highest score (20.0).

(2) Relationship to survival period

We evaluated differences between survivors who had been diagnosed with tongue cancer  $\geq 28$  months from the date of diagnosis and survivors who had been diagnosed within a shorter period in terms of the scores of five items of the functional scale and nine items of the symptom scale. The results showed that pain symptom scores were significantly ( $p = 0.032$ ) higher in the group with shorter survival duration. There were no significant differences with respect to the other items.

**Discussion**

This study included patients with tongue cancer who were living as cancer survivors after tongue resection and showed their actual ability to survive cancer, ability in daily life as a survivor, QOL, and speech intelligibility. Furthermore, we were able to clarify whether the length of time spent as a survivor makes a difference. In the discussion, the clinical applications are discussed.

1. Ability to survive cancer

We believe that patients with tongue cancer need the ability to survive as a cancer patient and as a person living with a tongue disorder, which directly affects communication, food intake, and other aspects of daily life. Therefore, we consider “ability to survive cancer” as a combination of “ability as a cancer survivor” and “ability in daily life of patients with tongue cancer” and discuss each of the six skills.

1) Communicating

With respect to their daily life skills, patients with tongue cancer were less likely to “have consulted with others about pronunciation and other conversational skills” and “choose easy-to-pronounce words to talk about.” Stelzle et al. analyzed the speech of patients with oral cancer >5 years after surgery using an automatic speech recognition system and reported that their speech was significantly reduced compared to healthy subjects<sup>17)</sup>. In the self-assessment of speech intelligibility in this study, 44 (61.1%) patients felt that their speech was different from that before surgery; however, it was clear that they survived without consulting others regarding their conversation ability. Rehabilitation for functional improvement is intensive during hospitalization, but significant improvement afterward is unlikely. Despite the changes in speech,

Table 5. EORTC QLQ-C30

	Survival period			
	All (n = 72)	Less than 28 months (n = 37)	More than 28 months (n = 35)	P-value
	Mean ± SD	Median	Median	
Global health status	62.2 ± 20.7	50.0	54.2	.740
Function scales				
Physical†	91.9 ± 11.8	100.0	93.3	.364
Role	88.4 ± 19.9	100.0	100.0	.213
Emotional	83.3 ± 18.4	91.7	83.3	.593
Cognitive	85.9 ± 17.2	83.3	83.3	.632
Social†	91.1 ± 15.1	100.0	100.0	.440
Symptom scales				
Fatigue†	20.0 ± 16.9	16.7	22.2	.498
Nausea and vomiting	2.8 ± 8.4	0.0	0.0	.934
Pain	13.4 ± 20.7	16.7	0.0	.032*
Dyspnea	9.3 ± 15.0	0.0	0.0	.202
Insomnia	14.4 ± 20.0	0.0	0.0	.079
Appetite loss	13.0 ± 20.6	0.0	0.0	.940
Constipation	14.4 ± 23.6	0.0	0.0	.201
Diarrhea†	10.3 ± 17.4	0.0	0.0	.082
Financial difficulties	12.0 ± 20.4	0.0	0.0	.290

† 1 missing value

Mann–Whitney U test P &lt; 0.05

Higher scores indicate better overall quality of life and functional scale scores, and lower scores indicate better symptom scale scores.

SD:standard deviation

the ability in daily life of patients with tongue cancer, which was reflected by the following: “I have fewer words when talking to others than before surgery,” is high. Conversely, the scores were low (approximately 3 points) for both ability to survive cancer and ability in daily life. These results suggest that patients feel that their individual efforts to communicate with others have produced positive results but to develop survivor skills, healthcare providers need to be aware that patients are survivors and make deliberate efforts.

## 2 ) Finding information

Lifestyle skill scores of both cancer survivors and patients with tongue cancer tended to be lower than other skill scores. Among them, respondents were less confident of their ability to find the information they need regarding cancer; learn new skills to find, judge, and understand cancer-related information; and feel less often overwhelmed by excessive cancer-related information. The recent development of social networking services and the environment in which information can be easily disseminated may have had

an impact on the results. While access to cancer-related information has become easier, it is presumed that this has led to confusion.

A study that revealed cancer survivors’ information-seeking behavior reported that “the Internet was the most frequently accessed source of information; however, about half of the studies reported concerns regarding the quality of the information”<sup>18)</sup>. We believe that even if people find information, they do not feel confident of their information-handling ability. These findings suggest that it is necessary for healthcare providers to understand how patients with tongue cancer search for information, provide knowledge to the patients regarding sites that disseminate accurate information, and disseminate highly reliable information themselves.

## 3 ) Making decisions

The sub-item “confidently seek a second opinion about my disease” of the ability to survive cancer had a low score. This may be due to the limited number of hospitals that can provide medical care to patients

with tongue cancer and low information-seeking ability of the patients. Second opinions are highly valuable for patients with cancer. It is important to understand the environment in which patients want to seek treatment but find it difficult and assure them using a more courteous and convincing method and time.

#### 4) Solving problems

The problem-solving skills tended to be lower among the cancer survivors but higher among the ability in daily life of patients with tongue cancer. This may partially be attributed to the fact that the sub-items of the ability to lead a life were questions regarding the relationship that patients with tongue cancers have with medical care providers, whereas the sub-item on the ability to survive cancer was a question that assumed problems that were not limited to medical care. It was inferred that the problems of patients with tongue cancer are complex and difficult to be solved by medical institutions alone, although this result is partly due to the questions asked. It was thought that there was a need to examine the problems of cancer survivors and provide care to increase their ability to survive.

#### 5) Negotiating

The patients with tongue cancer tended to have higher scores for both the competence to survive cancer and life skills compared with other skill scores. This ability could be inferred from the ability to negotiate when the other party and content are clear. However, the scores for the ability to survive cancer were in the 3-point range, suggesting that there is a need to provide support for the development of negotiation skills.

#### 6) Standing up for your rights

The Third Basic Plan for the Promotion of Cancer Control of the Ministry of Health, Labour and Welfare aims to realize patient-oriented medical care<sup>19)</sup>. In the results of this study, the item "I would like to participate if there is an opportunity to talk or e-mail people who have the same disease," which is a sub-item of the "ability to lead a life as a patient with tongue cancer," was low, but the scores for both the ability to survive cancer and ability in daily life of a patient with tongue cancer tended to be higher than those for other skills. Further research is needed to determine why the parties are not looking for a connection. Although the scores for the ability to survive cancer tended to be

higher than those for other skills, it was in the 3-point range, suggesting the need to provide support for the development of the ability to assert rights.

#### 2. Association between the ability to survive tongue cancer and survival period

There were significant differences in ability to survive cancer and ability in daily life of patients with cancer to lead their lives in only two subcategories in terms of survival period. Thus, the ability of tongue cancer survivors did not improve over the years. Regarding the ability to survive cancer, the group who had been cancer survivors for >28 months had significantly lower scores for the item "Assertion of rights: Feeling empowered to protect one's own rights regarding one's illness." Moreover, the scores for the item "Negotiating: I can ask my healthcare provider regarding my concerns about the disease onset or recurrence" was significantly low among survivors who had been cancer survivors for >28 months, indicating their decreased ability to manage their lives. This is consistent with a previous study (Hatta et al., 2021), which reported the results of the experience of "protecting the body from cancer."

In their study on patients with tongue cancer who were followed up within 6 months to 3 years after surgery, Ogama et al. stated that "multifaceted assistance is needed to promote reemployment"<sup>20)</sup>. In the present study, the ability to survive tongue cancer did not differ even if the survival period was high but decreased in two items. This suggests that long-term survivors need the same level of attentive care as short-term survivors. Future studies are needed to examine the care provided to improve patients' ability to survive cancer because this is a cross-sectional study and there are no studies that have examined differences in the survival durations among patients with tongue cancer.

#### 3. QOL

Overall mean score for QOL was 62.2 of 100. This score was comparable to the mean overall QOL score of 62.6 obtained in a large study on breast, colon, and prostate cancer survivors who had undergone surgery<sup>21)</sup>. The highest scoring symptom was fatigue, with 20.0 points. The high scores for "My physical fitness has improved compared to the time soon after discharge from the hospital after surgery" and low scores for

emotion in the functional aspect of QOL suggest that patients with tongue cancer included in this study may experience mental fatigue.

#### 4. Clinical applications

It is clear that tongue cancer survivors do not have sufficient skills to survive cancer and those related to daily life and that they need support to develop their skills. The results of this study can be used as a basis for increasing the dissemination of reliable information on tongue cancer and supporting tongue cancer survivors to negotiate with their doctors and assert their rights.

#### Conclusions

1. The ability to survive cancer and ability in daily life of patients with tongue cancer were insufficient and did not differ over time.
2. Among the six coping skills, information-seeking

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3. The QOL of patients who underwent tongue resection was similar to that of other cancer patients; however, they tended to have lower emotional functioning and experience higher fatigue.

#### Limitations

The Japanese version of the Cancer Survivor Ability Measurement Questionnaire employed by the present survey was used without pretesting the subjects; hence, it is necessary to increase the study sample size and ensure the validity of this questionnaire in future studies.

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## 舌癌サバイバーの対処能力と QOL：横断的研究

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### 要 旨

**目的：**本研究は、舌切除術を受けた舌癌患者のがんサバイバー能力、生活営み能力、生活の質、発話明瞭度の実態を明らかにする。

**方法：**本調査は質問紙調査を実施した。「がんサバイバー能力」「舌癌患者の生活営み能力」「生活の質 (QOL)」「発話明瞭度」の実態を記述統計により明らかにし、「がんサバイバー能力」「舌癌患者の生活営み能力」「生活の質 (QOL)」は実態とサバイバー期間との関連を分析するため、マンホイットニーの U 検定を行った。

**結果：**有効回答数 (%) は 72 名 (97.3%) であった。サバイバー期間が 28 か月以上の群で能力が低下していた項目は「病気の発症や再発の心配を医療者に聞くことができる (P = 0.044)」, 「自身の病気に関して、自分の権利を守る権限があると感じる (P = 0.044)」であった。これら以外の項目に有意差は無かった。がんサバイバー能力と舌癌患者の生活営み能力の 6 つのスキルのうち十分なスキルはなく, 「情報探索」は両方で低かった。全体 QOL 得点は 62.2 点, 機能スケールは情緒が最も得点が低く 83.3 点, 症状スケールは疲労が最も得点が高く 20.0 点であった。発話明瞭度は, 44 名 (61.1%) が手術前との発話に変化を感じていていた。

**結論：**舌癌患者のがんサバイバー能力と生活営み能力は, 十分ではなく月日を経ても向上しないため, これらを身につけるための長期的な支援の必要性が示唆された。