Research Square

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Quantitative Evaluation of Healthcare Information Provided to Patients with Lung Cancer: Patient Satisfaction Survey of The Japan Lung Cancer Society

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Research Article

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Abstract

Background: Healthcare professionals are increasingly providing medical information to patients. However, few objective evaluations of the information's usefulness exist. This study posited that analyzing objective, quantified data facilitates future information provision. Our questionnaire survey on patient satisfaction with medical information using the European Organization for Research and Treatment of Cancer's (EORTC) Quality of Life 25-item information module (QLQ-INFO25) was unprecedented in Japan.

Methods: Lung cancer patients were enrolled in the trial in response to calls from patient support groups and the Japanese Lung Cancer Society. Patient satisfaction was based on information obtained from the 2019 Japanese Lung Cancer Society's patient guidebook and a web-based survey of patients with lung cancer. Satisfaction with the information was analyzed based on EORTC QLQ-INFO25 scores and stratified into user and nonusers of the guidebook.

Results: Of 332 participants (110 male, 222 female), 283 (85.2%) completed the questionnaire, among which, 170 (60.1%) respondents participated in the patient advocacy group and 82 (29.0%) read the guidebook. Participants found the research through online sources or by responding to an invitation from their primary physician or patient support group. Seventy-one users (91%) were satisfied with the guidebook content as shown by the individual scale score on the QLQ–INFO25. No statistically significant differences were observed based on the presence or absence of information in the guidebook. Subgroup analysis revealed a trend toward greater satisfaction among participants that joined the patient group and used the guidebook.

Conclusions: Guidebooks and patient advocacy groups are effective in providing information to patients. Our results provide an objective basis for discussing information provision for patients with lung cancer. Strategies should be developed to communicate information reflecting patients' diverse backgrounds.

Key Points

Question: What sources of information do lung cancer patients find most satisfactory for treatment?

Findings: Satisfaction with treatment information was assessed from 332 lung cancer patients using the EORTC QLQ-INFO25 questionnaire. An inclination towards higher satisfaction was noted when participation in patient groups was combined with guidebooks created by academic societies.

Meaning: Information from credible sources and patient associations can complement each other to boost patient satisfaction.

Introduction

Patients with lung cancer require accurate information about the disease [1–5] regarding topics such as diagnosis, treatment, palliative care, alternative medicine, diet, and COVID-19. To fulfill this need,

healthcare professionals worldwide are increasingly striving to provide such information to their patients [6, 7].

However, no guidelines for the provision of appropriate medical information to patients with lung cancer existed in Japan until the Japanese Lung Cancer Society (JLCS) published a guidebook for patients and began to conduct editorial meetings in 2018. The JLCS had been working with patients to develop treatment guidelines and provide employment assistance. For this guidebook, the JLCS editorial committee worked with specialists in lung cancer treatment, social workers, nurses, pharmacists, physical therapists, and representatives of patient advocacy groups to develop a lung cancer guidebook for patients and their families, titled *JLCS Lung Cancer Guidebook for Patients and Families* (the *Guidebook*) which was published in 2019. The *Guidebook* consisted of 97 QUESTIONS AND ANSWERS, which addressed questions that patients had, answered from the perspective of experts and patient advocates. The guidebook was printed and available at bookstores, conference centers, and hospitals for patient access. In this study, we reviewed the expressions used in the *Guidebook* based on the opinions of patient advocacy group representatives.

After publication of the *Guidebook*, the editorial board members wanted to ascertain its usefulness for information acquisition for patients, and to incorporate their feedback into future editions of the *Guidebook*.

This study was designed and conducted to objectively and quantitatively assess whether patients are satisfied with the information provided by the JLCS *Guidebook*.

Methods

Study design

Lung cancer patients were enrolled in the trial in response to calls from patient support groups and the JLCS. Participants were asked to access and respond to an online questionnaire using SurveyMonkey® (http://www.surveymonkey.com) between July and August 2020. Participants were stratified into two groups: those who had used the *Guidebook* and those who had not. Participants were asked to complete the European Organization for Research and Treatment of Cancer's (EORTC) Quality of Life of Cancer Patients 30-item questionnaire (QLQ-C30), Quality of Life 25-item information module (QLQ-INFO25), and an additional questionnaire designed by the JLCS.

We quantified participants' degree of satisfaction with the medical information obtained to objectively evaluate whether the level of satisfaction differs depending on participants' backgrounds and source of information. We aimed to understand how the guidelines for patients formulated by the JLCS can be improved to provide beneficial medical information for patients. We also aimed to obtain primary data, as no existing study has investigated satisfaction with medical information for patients with lung cancer.

Participants and methods

Participants diagnosed with lung cancer, thymic carcinoma, or malignant mesothelioma were included in the study. All patients gave their informed consent to participate in the study by completing this questionnaire. The study protocol was in accordance with the Declaration of Helsinki and approved by the institutional review board. This study has been registered with the University Medical Hospital Information Network Clinical Trials Registry under the identifier 000040984.

Statistical analysis

The primary endpoint was to compare the level of satisfaction with the medical information obtained between the *Guidebook* user group and the nonuser group.

The EORTC questionnaire was scored according to established EORTC guidelines. The *t*-test was used to compare specific ranks (scores). A multiple regression analysis was performed to adjust for confounding factors, including personal attributes such as sex, age, cancer type, stage or treatment history, and source of medical information. A sensitivity analysis with different adjustment factors was also performed as a reference. The total INFO25 and QLQ-C30 subscale scores were analyzed as secondary endpoints. Additionally, the scores on the questionnaire set by the researchers were explored.

As exploratory evaluation items, free descriptions were analyzed using listing, after-coding, and text-mining methods.

Results

Participants

We received 332 responses from the online survey conducted. Among these, 283 were valid responses, defined as those with a response on every questionnaire item. The response rate was 85.2% (Fig. 1).

The age of the respondents ranged from 30 to 84 years, involved in a wide range of patient advocacy groups; the most common age group was between 55 and 59 years. Male and female participants accounted for 34% and 66% of the valid responses, respectively.

In this survey, we asked about the *Guidebook* readers about the timing of reading the healthcare information. The number of participants who read the Guidebook between within six months of diagnosis was slightly higher. We also asked collected information regarding the treatments they were receiving at the time of the survey. Participants were undergoing chemotherapy, molecular targeted therapy, and immune checkpoint inhibitors, as shown in Table 1. Approximately 20% of patients in both groups were under follow-up for disease recurrence. Very few participant questionnaire responses indicated receiving palliative treatment.

Table 1

	User, n = 82		nonUser, n = 201	
	n	%	n	%
Age				
30–39	3	3.7	4	2.0
40–49	13	15.9	35	17.4
50–59	33	40.2	73	36.3
60–69	20	24.4	56	27.9
70–79	12	14.6	29	14.4
80+	1	1.2	4	2.0
Gender				
Male	24	29.3	72	35.8
Female	58	70.7	129	64.2
Length of time since diagnosis (year)				
-0.5	9	11.0	12	6.0
0.5-1	8	9.8	20	10.0
1–2	12	14.6	31	15.4
2–3	13	15.9	36	17.9
3–4	9	11.0	26	12.9
4–5	12	14.6	29	14.4
5–10	13	15.9	35	17.4
10+	6	7.3	12	6.0
Current treatment				
Observation	20	24.4	41	20.4
Chemo	5	6.1	53	26.4
Chemo + ICI	3	3.7	8	4.0
Chemo + TT	2	2.4	5	2.5
Chemo + RT	1	1.2	2	1.0
Chemo + Ope	1	1.2	0	0.0

	User, n = 82		nonUser, n = 201	
Chemo + ICI + RT	1	1.2	0	0.0
CHEMO + TT + PC	0	0	1	0.5
CHEMO + PC	1	1.2	0	0
TT	37	45.1	66	32.8
TT + ICI	0	0.0	2	1.0
TT + RT	1	1.2	2	1.0
TT + AM	0	0.0	1	0.5
TT + PC	1	1.2	1	0.5
ICI	8	9.8	17	8.5
PC	0	0.0	1	0.5
Undetermined	1	1.2	1	0.5

Satisfaction with the guidebook among users

Of the 283 valid responses, 82 (29.0%) participants indicated that they had read the *Guidebook*. No significant differences were found between the backgrounds of users and nonusers (Table 1). Readers were surveyed regarding their satisfaction with the *Guidebook* content. Twenty-six (31.7%) participants indicated that they were delighted, 49 (59.8%) were reasonably satisfied, 6 (7.3%) were undecided, and 1 (1.2%) said it was not very useful (Fig. 2).

Source of information

Next, we asked the respondents what information sources they had used for their diseases. Of the 283 valid responses, the most common sources were the Internet (*n* = 249, 87.7%), primary care physicians (*n* = 202, 71.1%), patient advocacy groups (*n* = 150, 52.8%), books (*n* = 104, 36.6%), study groups (*n* = 97, 34.3%), cancer consultation support centers (*n* = 34, 34.2%), and others (*n* = 13, 4.6%) (Fig. 3).

EORTC QLQ-C30 and EORTC QLQ-INFO25 scores

We examined whether there was any bias in the QLQ-C30 between users and nonusers of the *Guidebook*. The overall quality of life (QOL), function, and symptom scale scores were calculated as shown in Table 2. The calculation was performed according to the scoring manual provided by the EORTC. There were no statistically significant differences in the scores between the user and nonuser groups.

Table 2

			User		Nonuser		*p* value
			Mean	SD	Mean	SD	
Overall QOL		QL2	68.7	22.5	68.0	23.5	0.831
Function scale	Physical function	PF2	83.9	15.9	83.0	17.2	0.635
	Daily life	RF2	80.5	22.2	76.7	25	0.204
	Emotion	EF	77.8	19.7	77.4	17.8	0.878
	Cognition	CF	77.7	21.7	79.1	19.3	0.568
	Social role	SF	78	21.9	78.5	24.4	0.862
Symptom scale	Fatigue	FA	36.5	20.1	36.0	22.1	0.881
	Nausea, vomiting	NV	2.5	6.9	3.6	9.6	0.294
	Pain	PA	17.6	20.6	17.4	22.4	0.943
	Breathing difficulties	DY	22.8	23.4	26.7	25	0.215
	Insomnia	SL	23.6	23.1	20.4	24.9	0.304
	Appetite loss	AP	12.1	17.6	15.0	23.4	0.292
	Constipation	CO	17.4	24.8	18.8	23.5	0.570
	Diarrhea	DI	23.1	32.1	18.0	22.9	0.118
	Economic impoverishment	FI	28.7	32.6	25.2	29.6	0.360

We then examined the level of satisfaction with medical information using the EORTC QLQ-INFO25, following the manual provided by the EORTC (Table 3). In the QLQ-INFO25 scoring, the volume of each piece of data, source of information, and level of satisfaction with the data were calculated. Finally, the overall scores were calculated. As shown in Table 3, there were no significant differences between the user and nonuser groups in the current analysis.

In the OVERHELP individual scale of the QLQ-INFO25, we compared the scores of participants that used the *Guidebook* with those that did not. Our focus was on patient advocacy group participation and guidebook use. The results were analyzed by dividing participants into four groups according to whether they had used the *Guidebook* or had participated in patient meetings. Bonferroni's multiple comparison test was conducted for the four groups on OVERHELP and the overall satisfaction index with information. Six analyses were conducted and none of the differences were statistically significant (Fig. 4, Supplementary Table 1). However, a *t*-test comparing those who used the patient advocacy group and the *Guidebook* with those who used neither showed a statistically significant trend of higher satisfaction in the combined group ($p = 0.039$) (Fig. 5).

Table 3

			User		Nonuser		*p* value
			Mean	SD	Mean	SD	
Information volume	Disease	INFODIS	54.4	19.8	53.1	18.1	0.575
	Examination	INFOMED	64.6	24.8	62.1	22.2	0.393
	Treatment	INFOTREAT	51.1	17.1	51.3	17.7	0.937
	Other service	INFOTHSE	18.0	18.4	19.4	17.4	0.537
	Another place to receive care	INFODIFP	16.1	25.2	21.0	26.5	0.147
	Care for recovery	INFOHELP	26.5	28.9	33.8	28.7	0.051
Source of information	Document	INFOWRIN	69.5	46.3	75.1	43.3	0.333
	CD, Video	INFOCD	22.0	41.6	22.4	41.8	0.730
Degree of satisfaction	Amount of information	SATINFO	40.7	27.7	40.3	25.5	0.918
	More amount of information	RECMORE	18.3	38.9	28.4	45.2	0.078
	More less information	RECLESS	96.3	18.9	97.0	17.1	0.771
	Did the information help?	OVERHELP	58.9	26.9	54.7	22.1	0.173
Overall score		Global score	44.8	14.8	46.7	13.3	0.288

Discussion

This study is the first to collect quantitative data on the medical information obtained from patients with lung cancer and contributes to the literature because previous studies have not quantitatively assessed the level of satisfaction with the medical information provided by healthcare professionals. As of December 1, 2021, a PubMed search for INFO25 yielded 42 results; however, no studies had examined patients with lung cancer [8]. In addition, several guidelines for patients have been prepared by professional societies and government organizations, but no previous study has quantitatively verified the usefulness of these guidelines. We examined whether the data obtained from the JLCS *Guidebook* directly led to patient satisfaction in information acquisition. Overall, over 90% of *Guidebook* users were satisfied with the content. The results showed that the *Guidebook* fulfilled a particular role.

However, we found no statistically significant difference in satisfaction between users and nonusers of the *Guidebook*. This can be attributed to several factors. First, because the survey was conducted using an Internet questionnaire, it is assumed that patients who were proficient in using the Internet mainly participated. Most respondents were 55–59 years old, which is considered younger than the average age of patients with lung cancer in Japan [9]. Therefore, we believe that many respondents had already collected information via the Internet before receiving the *Guidebook.* For patients who were capable of gathering information from the Internet, some felt that the information provided in the *Guidebook* needed to be improved.

Very few participants reported receiving palliative care in parallel with systemic chemotherapy or molecular targeted therapy (users, 2.4%; nonusers, 1%). Although we advocate and promote palliative care from the time of diagnosis, patients undergoing treatment may not feel that they are also receiving sufficient (or any) palliative care. The treating team staff should provide treatment options as well as information to ensure that patients receive effective palliative care.

Limitations

This study has some limitations. The survey was conducted after the publication of the JLCS *Guidebook*. The number of cases in this survey was insufficient to provide all *Guidebook* users the opportunity to participate in the study. In addition, our call for study participants was facilitated through the publicity efforts of patient advocacy groups and academic societies, which undeniably contributed to selection bias of respondents.

Next, although the JLCS *Guidebook* was published in paper format, the questionnaire survey was conducted in digital format. The survey respondents were relatively young. According to past reports, the most common age group of lung cancer patients in Japan is reported to be 70–79 years old [10, 11]. The participants in this study were most frequently 50–59 years old, and thus differed from the background of typical lung cancer patients in Japan. Users who preferred print books to digital books were likely to be slightly older. Therefore, the age of the participants may have affected the results, as noted in previous studies [12–14]. It may be necessary to include a questionnaire in future studies to reach more people unfamiliar with the Internet [15, 16]. In addition, the *Guidebook* content was relatively introductory and basic. It may be that much of the content is relatively easy for patients acquiring information through self-study, such as those participating in patient advocacy groups.

The EORTC QLQ-INFO25 also needs to be updated. This questionnaire includes the item “information collection through CDs and videos,” which suggests the information collection methods of a slightly earlier era [17]. Internet use is now ubiquitous, and the use of alternatives, such as artificial intelligence, and patient education using interactive communication networks and networking among patients and between patients and medical professionals has become increasingly widespread [18]. We consider that the EORTC QLQ INFO25 questionnaire may need to be revised to assess the effectiveness of the current information collection tool.

The study endpoint—patient satisfaction with information acquisition—must be interpreted with caution. The study is based on data obtained from a questionnaire, which has some limitation, such as bias in the target population. Based on the primary data obtained in this study, we believe that future efforts should provide medical and healthcare information materials with higher-quality medical validity to achieve an even higher level of patient satisfaction.

Conclusion

This study is the first quantitative national survey of the need for medical information among patients with lung cancer using the EORTC QLQ-INFO25.

We found that guidebooks developed with the participation of academic societies and patient advocacy groups were considered reliable sources of information. Furthermore, multiple reliable sources of information—such as information provided by patient support groups and experts—led to higher satisfaction. In the future, we must consider how to provide information in a manner that reflects the various backgrounds of patients, such as age and the level of information sought.

Declarations

Role of the funding source

This research was supported by the Japan Lung Cancer Society.

Author contributions

Dr. Sawa had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. Concept and design: Takahama, Shimizu and Sawa. Acquisition, analysis, or interpretation of data: Takahama, Shimizu and Sawa. Drafting of the manuscript: Takahama, Shimizu and Sawa. Critical review of the manuscript for important intellectual content: All the authors. Statistical analysis: Yoshimura, Takahama, Shimizu and Sawa. Obtained funding: Takahama, Shimizu, Sawa and Oizumi. Administrative, technical, or material support: Takahama, Shimizu, Sawa and Oizumi. Supervision: Sawa.

Declaration of interest statement

Dr Takahama reported receiving grant funding from Takeda Pharmaceutical Company Limited during the conduct of the study and personal fees from AstraZeneca, Chugai Pharmaceutical Co Ltd, Roche Diagnostics, and MSD and grant funding from Pfizer Inc and Takeda outside the submitted work. Dr Yoshimura reported receiving grant funding from Boehringer Ingelheim and personal fees from Chugai Pharma, Astra Zeneca and Taiho. Dr Horinouchi reported receiving grant funding from AstraZeneca, Roche/Chugai, MSD, AbbVie, BMS/Ono, Daiichi-Sankyo and personal fees from AstraZeneca, Roche/Chugai, MSD, Bristol-Myers Squibb/Ono, AbbVie. Dr Kaneda reported receiving grant funding from Eli Lilly and personal fees from Chugai, AstraZeneca, MSD, Bristol-Myers Squibb, Novartis Pharma, Eli Lilly, Ono, Takeda. Dr Watanabe reported receiving grant funding from Pfizer. Dr Hayashi reported

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Data availability statement

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Ethics statement

The research related to human use has been complied with all the relevant national regulations, institutional policies and in accordance the tenets of the Helsinki Declaration and has been approved by the authors' institutional review board or equivalent committee.

Declaration of generative AI and AI-assisted technologies

During the preparation of this work, the authors did not used AI and AI-assisted technologies.

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Figures

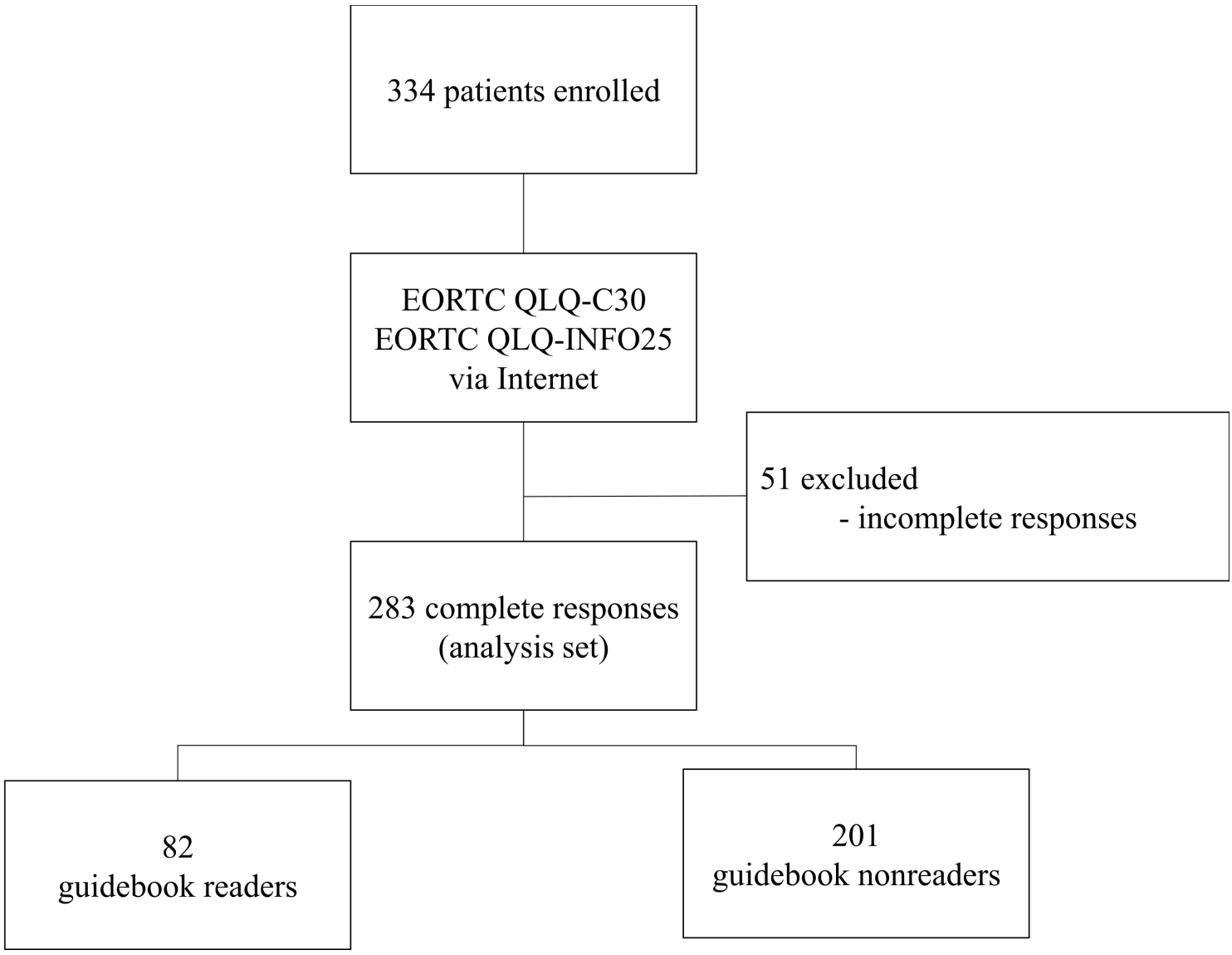


Figure 1

Consort diagram for the study.

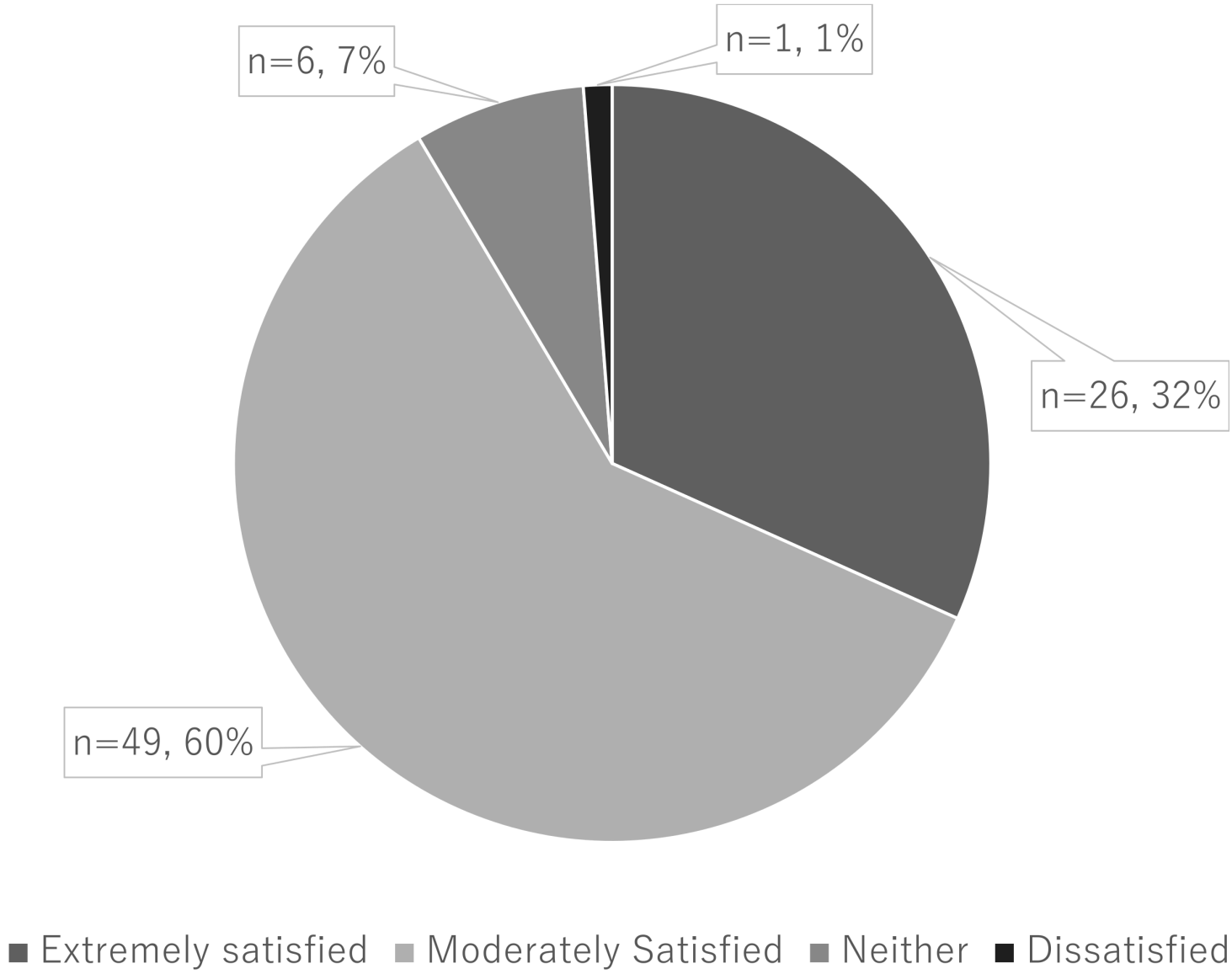


Figure 2

Pie chart showing the distribution of satisfaction levels, based on interviews with 283 users of the guidebook.

Figure 3

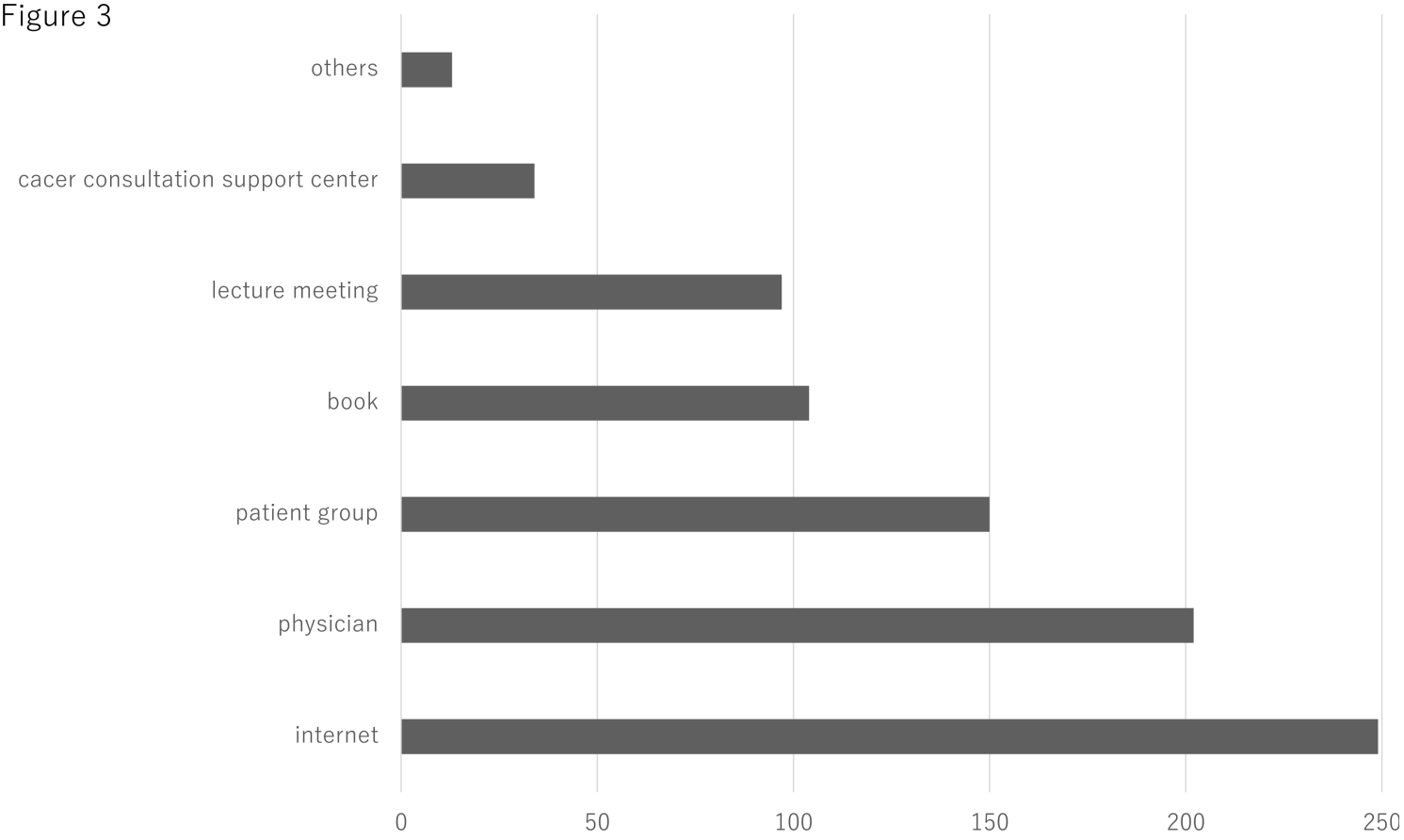


Figure 3

Bar graph showing sources of medical information obtained by patients; 283 patients were included and multiple responses were allowed.

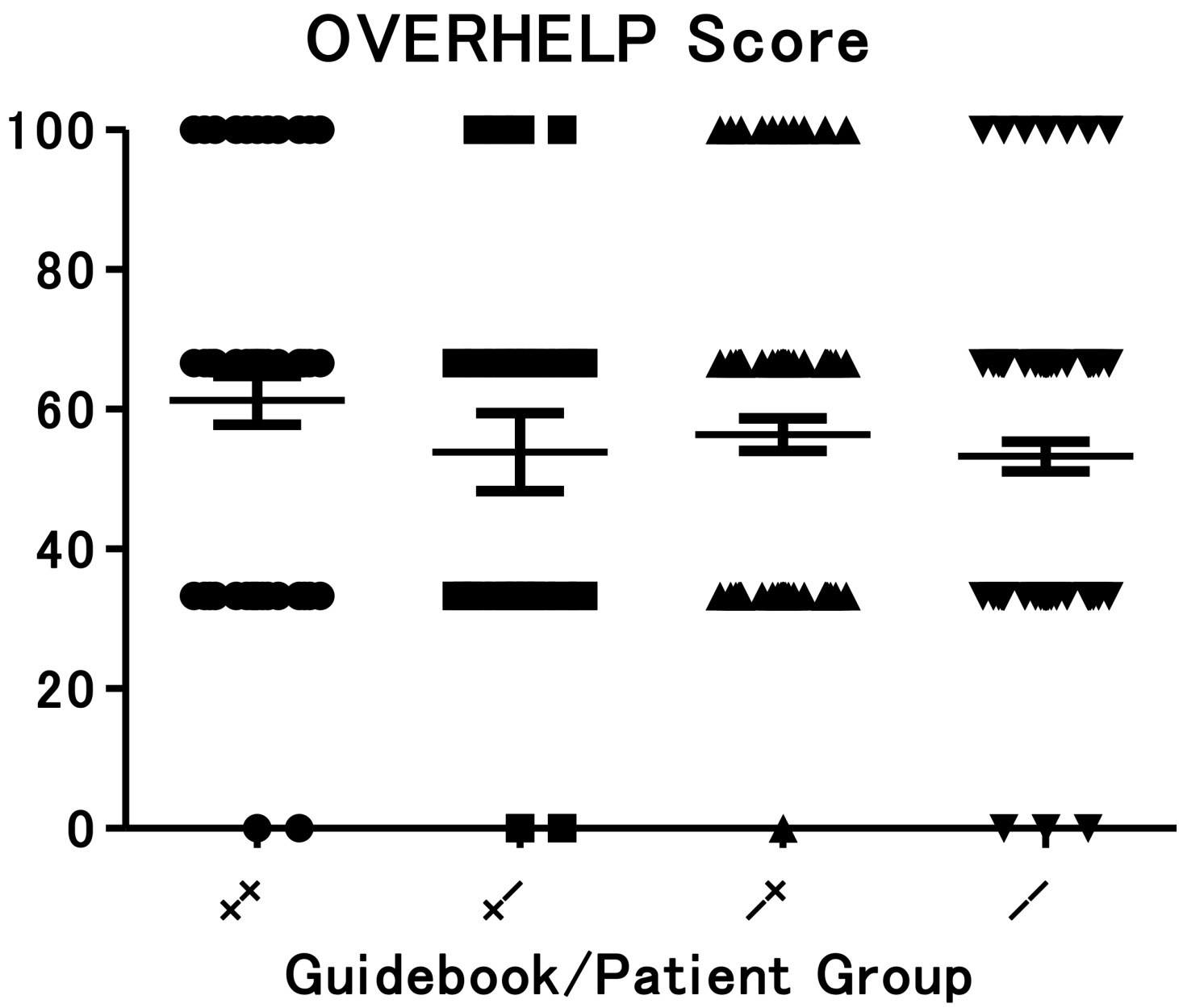


Figure 4

Results of Bonferroni's multiple comparison test for the overall satisfaction index using the OVERHELP score: "+" indicates guidebook users or patient group participants, "-" indicates guidebook non-users and patient group non-participants.

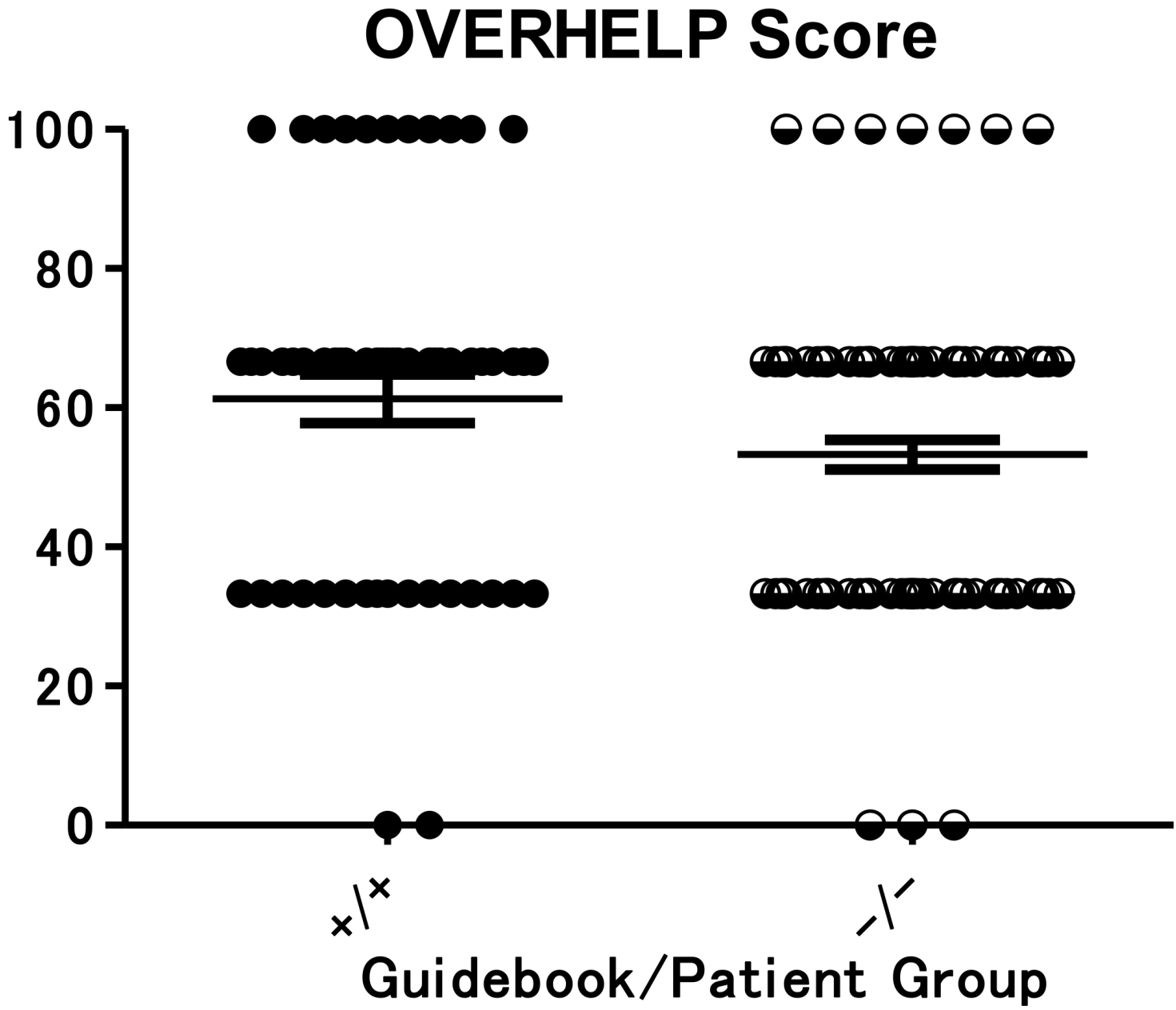


Figure 5

T-test results for OVERHELP scores: comparison between patient support groups and guidebook users. "+" indicates guidebook users or patient group participants, "-" indicates non-users and non-participants.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryTable1.docx