

# BMJ Open Quality Users' evaluation of Japan's cancer information services: process, outcomes, satisfaction and independence

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## ABSTRACT

**Background** Cancer information service (CIS) programmes are becoming increasingly important because patients need to obtain appropriate information and take an active role in their treatment decisions. Programme evaluation is required to determine the level of satisfaction and quality of experiences of users. The purpose of this study is (1) to identify users' evaluation of CIS programmes by both satisfaction and outcomes that reflect the quality of experience and impact of using the CIS, (2) to examine the related factors of these evaluation outcomes and (3) to analyse the differences of those relations between patients and families.

**Method** The self-reported questionnaire was answered by 447 patients and 216 families of patients who used Cancer Information Support Centres (CISCs) at 16 designated cancer hospitals from January 2016 to April 2016. We developed 12 evaluation items, including satisfaction, experience and the impact of using CISC.

**Results** Respondents evaluated the CISC highly, especially in terms of overall satisfaction, followed by the counselling process. Immediate access to CISC was the strongest factor affecting outcomes. Patients who wanted to consult about 'disease or symptoms' or 'had no specific problem' tended to provide high scores for some outcomes, but those who wanted to consult about a 'financial problem' or 'discharge or care at home' provided negative scores. These trends were also observed in families but to a more limited extent.

**Conclusion** Users' evaluation of CISCs was sufficiently high in terms of overall satisfaction, showing reasonable scores in outcome levels. Immediate access was the strongest factor affecting outcomes and topics of consultation more directly affected evaluation by patients than by families. The distribution of the scores of the measures and related factors was reasonable. The 12-item measurement tool employed in this study seems to be useful for quality monitoring of the CIS.

## INTRODUCTION

### Needs for cancer information services

People diagnosed with cancer need a wide range of cancer information at different points, even after their treatment,<sup>1</sup> and they also need psychological care.<sup>2,3</sup> The growing interest in people taking more responsibility for and being more involved in their health accelerates the need for cancer information, which is the basis of communication with their

physicians.<sup>4</sup> Advances in cancer care bring wider treatment options, making patients understand more precise and complicated cancer information.<sup>5</sup> Cancer information is becoming enriched, but not all information is adequate,<sup>6</sup> and the expansion of the internet has caused a 'flood of information',<sup>5</sup> with many websites of low quality, requiring readers to have high literacy.<sup>4,7,8</sup>

Not only the patients but also their families are involved in the cancer experiences, and they often act as carers and experience the burden of care.<sup>9,10</sup> Families also deal with patients' emotions in addition to theirs.<sup>11</sup> Care burden and psychological distress of families are often overlooked.<sup>12</sup> Psychological distress of cancer patients and that of their carers is positively related; therefore, an early intervention is needed to prevent such psychological distress.<sup>13</sup> Reducing families' care burden is also important because it affects both patients' and carers' quality of life.<sup>9</sup>

Cancer information service (CIS) programmes are becoming increasingly essential in most countries<sup>14</sup> and multidisciplinary counselling interventions are effective,<sup>15</sup> affording a place to talk about cancer issues with anonymity and empathy.<sup>3</sup> Perocchia *et al*<sup>16</sup> reported that 'patient-centred communication has been the key NCI research priority' (p. 36) and described six core functions (fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling self-management) embodied in the role of CIS.

The forms of CIS programmes differ slightly by the health policy and other conditions of a country. The National Cancer Institute (NCI) in the USA has run nationwide CIS programmes since 1975, and provides phone, email and live chats in English and Spanish.<sup>16,17</sup> The American Cancer Society also provides a nationwide cancer information helpline in the USA. The CIS in



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Australia is managed by state and territory cancer organisations and provides a cancer helpline.<sup>18 19</sup> A survey in Italy showed that 7 out of 11 designated cancer hospitals provided CIS in 2015.<sup>20</sup> Although there are some differences in national operations, the core of the CIS mission is shared internationally. Leading institutions constituted the Union for International Cancer Control in 1996 and established the International Cancer Information Service Group (ICISG),<sup>14</sup> and they expressed the core values and shared the key procedures for ensuring high-quality service. ICISG has initiated activities to improve the quality of CIS.

About 30 years later, the Japanese government started to appoint designated cancer care hospitals with the enactment of the Cancer Control Act in 2006 and the Basic Plan to Promote Cancer Control Programs in 2007, and 451 hospitals had been appointed by 2021. To provide CIS programmes, these designated hospitals must station Cancer Information Support Centres (CISCs), with at least two trained cancer information specialists. These information specialists undergo a training programme as cancer information specialists in addition to their original backgrounds as nurses, social workers or psychologists. CISCs are open to any patient with or without patient ID, and people without cancer can also access the CISCs for free.<sup>21</sup>

### Service evaluation and quality control of CIS programmes

Quality control is essential for CIS programmes. Previous studies have attempted to determine the quality of these programmes. Satisfaction surveys are the most common method of evaluation, and the results show that users of CISCs are satisfied with the services and the obtained information.<sup>19 22–24</sup> However, there is evidence that the efficacy of the service for patients<sup>25</sup> and caregivers is limited.<sup>22</sup>

Boltong *et al*<sup>23</sup> pointed out that the difficulty of CIS evaluation derives from the lack of outcome measures and barriers to using these measures. They insisted that an appropriate measure is critical for a more consistent evaluation of CIS; based on their qualitative research, they identified four themes: drivers for access, experience of using CIS, impact and an adjunct to cancer treatment.

To understand the CISC function achievement, we develop an original questionnaire of the CISC quality performance checklist according to the verbalised CISC role.<sup>21</sup> The purpose of this study is to (1) identify users' evaluation of CIS programmes through satisfaction and outcomes that reflect the quality of experience and impact of using the CIS, (2) examine the related factors of these evaluation outcomes and (3) analyse the differences of those relations between 'patients' and 'families'.

## METHODS

### Setting and participants

The survey included participants from 16 designated cancer hospitals and was conducted from January 2016

to April 2016. CISCs provide both face-to-face and phone counselling, but we chose participants who just used face-to-face counselling. The consultation records of the 16 CISCs showed that 50.7% of the consultations were conducted face to face, with the ratio of the consultations varying greatly from 16% to 94% across the CISCs.<sup>26</sup>

The questionnaire was distributed to the participants after obtaining ethical approval from each hospital. All CISC users who were provided face-to-face consultations participated in the survey except for those who met the following exclusion criteria: (1) cannot answer the questionnaire, (2) cannot communicate in Japanese or (3) cannot understand the survey procedure. The cancer information specialists explained the study to CISC users. Those who agreed to participate were asked to complete the questionnaire. Participants consented by posting their completed questionnaires. Among 1090 participants, 685 (62.8%) completed the questionnaires after the consultation and posted them. Among these 685 respondents, 447 were patients and 216 were families. The remaining 22 participants did not have any relationship with patients or did not specify their identities and were, therefore, excluded from the analysis.

### Variables

Japanese cancer-designated hospitals constitute a council to strengthen their cooperation. Under this council, the Information and Support Service Panel is formed to improve CISC's service level and encourage collaboration between each CISC. Information and Support Service Panel approved the tool for social recognition of CISC activities under the National Cancer Control Policy in 2015. This tool consists of measures, including outcome, process, structure and countable activities, and survey outcomes in light of the 'Prerequisite Condition of CISCs'.<sup>21</sup>

While developing this tool, 'CISC missions' were verbalised in reference to the ICISG's core values<sup>27</sup> and patient-centred communication concepts, as follows:

1. CISCs can be used by everyone, including patients, families and supporters not registered at that hospital.
2. CISCs gather and provide information about all phases of cancer trajectory and play roles in ensuring that patients have the right to know about, choose and live their own lives and to empower them to do so.
3. The role of cancer information specialists is to always support clients, consider the root of their difficulties, inform and help them. CISC information specialists are independent of doctors and nurses who are in charge of patients' treatment.
4. CISCs and information specialists contribute to the realisation of a society in which cancer patients can comfortably afford relief. The evaluation of CISCs, including e-missions and overall satisfaction, was measured using 12 items.

As Perocchia *et al*<sup>16</sup> described, CIS has six key functions. It seems that the time span of each function varies because some functions are the process of the counselling itself,

while others are the outcome of the counselling. 'Fostering healing relationships' and 'responding to emotions' are provided through the conversation between information specialists and helpline callers. 'Exchanging information' and 'making decisions' would be accomplished when the users are well informed and consider their situations throughout the counselling. 'Managing uncertainty' may take some time, and 'enabling patient self-management' may need practice and more time to be accomplished. CISC has a unique position in the hospital because it is independent of each ward and medical office, and can be used by everyone for free.

The 12 items were grouped under the dimensions: overall satisfaction; process of counselling; short-term, medium-term and long-term outcomes of CIS; and the independent position of the CISC in each hospital.

'Overall satisfaction' consisted of two items: 'do you want to use the CISC again?' and 'would you recommend using the CISC to your family or friends?'

'Process of counselling' comprised the following three items: 'did CISC provide a comfortable situation for counselling?', 'did the cancer information specialist work sincerely with your problem?' and 'did the information specialist provide an atmosphere in which it was easy to speak about everything, even that which is difficult to talk about with doctors or nurses?'

Outcomes of the counselling were measured as short-term, medium-term and long-term outcomes. Short-term outcomes comprised three items: 'did you feel you were understood by the information specialist?', 'did you receive enough cancer information that you needed?' and 'do you feel your problem is being resolved because of this counselling?'. Medium-term outcomes comprised the following two items: 'did you feel you can receive your medical treatment or home treatment support without anxiety because of this counselling?' and 'did your relationship with doctors, nurses and other medical staff get better because of this counselling?'. The long-term outcome comprised a single question: 'do you feel you will be able to handle yourself when other problems arise in the future?'

The independent position of the CISC focused on the CISC being an adjunct to cancer treatment: 'did the cancer information specialist help you independently of and better than the hospital?'

Response to each item ranked on a 5-point scale: 1—strongly agree, 2—somewhat agree, 3—neither agree nor disagree, 4—somewhat disagree and 5—strongly disagree.

To ensure content validity, during the process of generating these variables, information specialists in the CISCs were appointed to check that the items adequately reflected the 'CISC missions' described above.

To consider the criterion validity, correlation of the sum of each outcome was calculated. Scores of correlation between 'overall satisfaction' and all other outcomes such as process of counselling, short-term, medium-term and long-term outcomes of CIS and the independent position of the CISC were 0.667, 0.611, 0.578, 0.381 and 0.490,

respectively. These scores showed that the outcomes were sufficiently correlated but reflected different aspects of CISCs' services, and that the correlations were reasonable.

## Analysis

Among Boltong *et al's*<sup>23</sup> four CIS themes, we treated three themes (experience of using CIS, impact and an adjunct to cancer treatment) as outcome-focused elements. In addition, we employed overall satisfaction for comparison with the distribution of previous studies. Boltong *et al's*<sup>23</sup> drivers for access were treated as independent variables. These variables included experience of using CIS, immediate access and topics to talk about at the CISC.

The relationships among demographic characteristics (age and sex), previous experience of using CISC, immediate access, topics to discuss in the consultation and evaluation of the CISC were examined by logistic analysis. Since the distribution of the evaluation items tended toward 'strongly agree', to avoid the ceiling effect, binary variables were defined as 'people who answered 'strongly agree' to all the items of a dimension' and 'others'.

Logistic regression was used to examine the relationship between previous experience using CISC and immediate access after controlling for demographic characteristics, such as sex and age. Further analysis was conducted for each topic discussed with cancer information specialists independently after controlling for demographic variables and previous experience using CIS and immediate access. Cases with missing variables were excluded from each analysis.

## RESULTS

The demographic data of the study participants are presented in [table 1](#). Families tended to have a higher ratio of female members, are younger, and have a higher ratio of first visits to a CISC. The most frequent topic discussed with CISC cancer information specialists was disease or symptoms, followed by financial problems, but the ratio of discussing discharge or care at home was significantly higher for families than for patients.

The distribution of each item is presented in [table 2](#) (patients) and [table 3](#) (families), revealing the same trends: more than 80% of the respondents answered 'strongly agree' or 'somewhat agree' for 10 out of 12 items.

When we observe the ratio of respondents who answered 'strongly agree' to all the items of each outcome, overall satisfaction was the highest for both patients (64.3%) and families (73.5%), followed by experience of using CISC for patients (59.4%) and an adjunct to cancer treatment for families (63.4%). Impact, which is understood as short-term, medium-term and long-term outcomes, ranged from 39.7% to 28.9% for patients and 51.2% to 30.7% for families.

The results of logistic analysis for the relationship between outcomes and demographic characters or the 'drivers for access' are shown in [table 4](#) (patients) and

**Table 1** Background of the study respondents

	n	(%)	n	(%)	
	Patients (n=447)		Families (n=216)		
<b>Sex</b>					
Male	182	40.7	50	23.1	p<0.000
Female	265	59.3	166	26.9	
<b>Age (years)</b>					
20–39	30	6.8	21	9.7	p<0.000
40–59	158	35.6	103	47.7	
60–79	231	52.0	90	41.7	
80+	25	5.6	2	0.9	
<b>Previous experience of using CIS</b>					
First time	253	58.3	157	72.7	p<0.01
Once or twice	70	16.1	30	13.9	
More than three times	111	25.6	29	13.4	
<b>Could consult CISC immediately</b>					
Strongly agree	266	61.0	144	68.6	n.s
Somewhat agree	116	26.6	51	24.3	
Neither agree nor disagree	34	7.8	10	4.8	
Somewhat disagree	11	2.5	4	1.9	
Strongly disagree	9	2.1	1	0.5	
<b>Topics discussed with cancer counsellors (multiple answers)</b>					
About disease or symptoms	302	67.9	145	68.7	n.s
About financial problems	152	34.2	67	31.8	n.s
About social life	68	15.3	28	13.3	n.s
About relationship with medical staff	53	11.9	22	10.4	n.s
About discharge or care at home	28	6.3	38	18.0	p<0.000
No specific problem but willing to talk with someone	65	14.6	19	9.0	p<0.05
Other	7	1.6	0	0.0	n.s

CIS, cancer information service; CISC, Cancer Information Support Centre.

table 5 (families). Among these variables, immediate access to CISC showed the strongest relationship with all outcomes (process, short-term outcomes, medium-term outcomes, long-term outcomes, overall satisfaction and independent position of CISC) for both patients and families. When users had visited CISC before, process of counselling, short-term outcomes, medium-term outcomes and overall satisfaction was high in comparison with those who were new to CISCs, but these relationships were seen only in patients who were not family members.

Patients who wanted to consult about disease or symptoms rated the process of counselling, overall satisfaction and independent position of CISC positively. Patients who had no specific problem tended to rate the process of counselling highly. In contrast, users who wanted to consult about financial problems rated the process of counselling and overall satisfaction negatively, and the same trend was seen for those who wanted to discuss discharge or care at home. Families who wanted to consult about disease or symptoms positively rated the process of

counselling, while those who wanted to discuss financial problems rated the medium-term outcomes of counselling negatively.

## DISCUSSION

### Quality of CIS evaluated by users' satisfaction

In this study, 12 items were used to measure the quality of CIS. The ratio of respondents who answered 'strongly or relatively agree' was relatively high for all items, ranging from 67% to 97%, and the proportion that gave this rating for 10 items was above 80%.

The scores in this study indicate that the Japanese CISC service provides sufficient satisfaction compared with the global standard, which has been reported to be relatively high.<sup>25</sup> Among CIS users of the NCI, 95% have been reported to be strongly or relatively satisfied.<sup>28</sup> For the cancer helpline of the Cancer Council Victoria, 93% of the respondents reported feeling that the helpline had assisted them to feel better about their situation.<sup>14</sup>

**Table 2** 12-item evaluation of CISCs (patient)

	Score of outcome				Distribution of each item				
	Ratio of full score outcome (%)	Range	Mean	Standard deviation	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Overall satisfaction	64.8	2–10	9.25	1.24	71.2	21.9	5.7	0.2	0.9
Want to use the CISC again					71.3	20.4	7.8	0.2	0.2
Recommend using the CISC to families and friends									
Process of counselling	59.4	3–15	13.98	1.61	72.8	21.6	4.7	0.6	0.3
CISC provided a comfortable counselling situation					81.0	16.0	2.5	0.0	0.5
Counsellor worked sincerely with problem					65.3	25.4	7.9	1.1	0.2
Counsellor provided atmosphere in which it was easy to speak about everything									
Short-term outcome of counselling	39.7	5–15	13.34	1.92	63.0	31.5	4.3	0.7	0.5
Felt understood by counsellor					58.0	32.9	7.7	0.7	0.7
Received enough information					47.8	38.1	12.0	1.1	0.9
Problem is being resolved									
Medium-term outcome of counselling	35.6	2–10	8.39	1.54	52.0	32.6	12.5	2.5	0.5
Feels can receive medical treatment without anxiety					40.1	27.1	29.9	2.1	0.7
Relationship with medical staff improved									
Long-term outcome of counselling	28.9	–5	3.93	0.89	28.9	41.3	25.0	3.7	1.1
Able to manage future problems									
Independent position of CISC	53.8	1–5	4.35	0.81	53.8	28.9	15.9	0.9	0.5
Helped independently of and better than hospital									

CISC, Cancer Information Support Centre.

**Table 3** 12-item evaluation of CISCs (families)

	Score of outcome				Distribution of each item				
	Ratio of full score outcome (%)	Range	Mean	Standard deviation	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Overall satisfaction	73.9	2–10	9.49	0.98	77.5	18.8	3.3	0.5	0.0
Want to use the CISC again					77.5	18.8	3.3	0.5	0.0
Recommend using the CISC to families and friends					80.8	15.0	3.8	0.5	0.0
Process of counselling	58.1	3–15	14.1	1.38					
CISC provided a comfortable counselling situation					74.0	21.4	4.7	0.0	0.0
Counsellor worked sincerely with problem					87.9	9.8	2.3	0.0	0.0
Counsellor provided atmosphere in which it was easy to speak about everything					65.6	25.1	8.4	0.9	0.0
Short-term outcome of counselling	51.2	5–15	13.73	1.74					
Felt understood by counsellor					71.8	24.4	2.3	1.4	0.0
Received enough information					67.3	27.6	3.7	1.4	0.0
Problem is being resolved					58.9	29.9	9.3	0.9	0.9
Medium-term outcome of counselling	31.2	2–10	8.34	1.46					
Feels can receive medical treatment without anxiety					45.0	38.3	15.8	1.0	0.0
Relationship with medical staff improved					39.6	28.2	30.7	1.0	0.5
Long-term outcome of counselling									
Able to manage future problems		1–5	4.00	0.86	34.0	35.4	27.8	2.8	0.0
Independent position of CISC	63.7	1–5	4.45	0.81					
Helped independently of hospital rewards					63.7	18.1	16.0	1.4	0.0

CISC, Cancer Information Support Centre.

**Table 4** Relation between topics discussed with cancer counsellors and each outcome (patient)

	Overall satisfaction		Process of counselling		Short-term outcome of counselling		Medium-term outcome of counselling		Long-term outcome of counselling		Independent position of CISC	
	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI
Sex (male)	0.89	0.56 to 1.43	0.86	0.54 to 1.37	0.67	0.43 to 1.06	0.75	0.47 to 1.19	0.99	0.62 to 1.58	0.62	0.40 to 0.96*
Age (≥60 years)	0.94	0.59 to 1.50	0.95	0.60 to 1.51	0.97	0.62 to 1.51	1.02	0.64 to 1.63	1.03	0.64 to 1.64	0.87	0.56 to 1.35
Previous experience of using CISC	2.00	1.26 to 3.16**	2.37	1.50 to 3.73***	1.07	0.70 to 1.66	1.64	1.04 to 2.56*	1.03	0.65 to 1.63	1.47	0.96 to 2.23
Immediate access to CISC	4.60	2.96 to 7.14***	5.37	3.44 to 8.39***	6.80	4.16 to 11.11***	7.16	4.14 to 12.37***	6.23	3.51 to 11.06***	3.99	2.60 to 6.12***
About disease or symptoms (1)	1.61	1.01 to 2.58*	2.20	1.37 to 3.53**	0.92	0.58 to 1.45	1.61	0.99 to 2.64	0.80	0.49 to 1.29	1.79	1.15 to 2.81*
About financial problem (2)	0.62	0.39 to 0.98*	0.63	0.39 to 0.39*	1.36	0.87 to 2.13	0.80	0.50 to 1.28	1.32	0.83 to 2.11	0.79	0.51 to 1.22
About social life (3)	0.74	0.39 to 1.41	1.20	0.62 to 2.30	0.81	0.43 to 1.50	1.05	0.56 to 2.00	0.89	0.46 to 1.71	0.59	0.32 to 1.08
About relationship with medical staff (4)	0.77	0.39 to 1.52	1.87	0.89 to 3.95	1.02	0.53 to 1.96	0.86	0.43 to 1.72	0.75	0.37 to 1.53	0.97	0.51 to 1.84
About discharge or homecare (5)	0.76	0.32 to 1.82	0.32	0.13 to 0.77*	1.01	0.43 to 2.35	0.60	0.24 to 1.48	0.76	0.32 to 1.82	0.54	0.24 to 1.24
No specific problem (6)	1.89	0.96 to 3.74	2.45	1.23 to 4.86*	0.73	0.38 to 1.37	1.26	0.66 to 2.41	0.94	0.48 to 1.84	1.83	0.99 to 3.39

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

Each of (1) through (6) was added to the analysis independently after controlling for sex, age, patient, experience of consulting with CISC and immediate access to CISC. CISC, Cancer Information Support Centre.

**Table 5** Relation between topics discussed with cancer counsellors and each outcome (families and others)

	Overall satisfaction		Process of counselling		Short-term outcome of counselling		Medium-term outcome of counselling		Long-term outcome of counselling		Independent position of CISC	
	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI	Exp(B)	95% CI
Sex (male)	0.98	0.42 to 2.29	1.52	0.73 to 3.14	0.91	0.45 to 1.85	0.83	0.40 to 1.75	0.92	0.45 to 1.90	1.59	0.75 to 3.37
Age (≥60 years)	1.47	0.71 to 3.04	2.55	1.36 to 4.75	1.44	0.78 to 2.67	0.98	0.52 to 1.87	0.90	0.48 to 1.69	0.89	0.48 to 1.66
Previous experience of using CISC	1.50	0.67 to 3.38	1.35	0.68 to 2.67	1.93	0.97 to 3.83	1.46	0.73 to 2.94	1.10	0.55 to 2.19	1.08	0.54 to 2.14
Immediate access to CISC	6.43	3.18 to 13.01***	3.07	1.62 to 5.85***	4.70	2.40 to 9.21***	3.49	1.58 to 7.74**	4.78	2.18 to 10.47***	2.94	1.57 to 5.50**
About disease or symptoms (1)	0.95	0.44 to 2.06	2.44	1.27 to 4.70**	0.98	0.51 to 1.87	1.20	0.60 to 2.38	0.95	0.44 to 2.06	1.19	0.61 to 2.31
About financial problem (2)	0.61	0.29 to 1.29	0.6	0.32 to 1.13	1.06	0.56 to 2.01	0.42	0.21 to 0.87*	0.61	0.29 to 1.29	0.64	0.34 to 1.24
About social life (3)	1.47	0.50 to 4.31	2.17	0.83 to 5.69	1.24	0.51 to 3.03	0.79	0.30 to 2.08	1.47	0.50 to 4.31	1.82	0.70 to 4.73
About relationship with medical staff (4)	1.23	0.36 to 4.21	1.30	0.48 to 3.51	0.77	0.29 to 1.99	1.22	0.47 to 3.21	1.23	0.36 to 4.21	1.13	0.42 to 3.05
About discharge or homecare (5)	0.84	0.35 to 2.05	0.79	0.36 to 1.70	0.91	0.42 to 1.98	1.15	0.50 to 2.61	0.84	0.35 to 2.05	1.04	0.47 to 2.31
No specific problem (6)	0.53	0.17 to 1.68	1.28	0.42 to 3.89	1.44	0.50 to 4.17	0.80	0.26 to 2.45	0.53	0.17 to 1.68	1.26	0.41 to 3.90

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001.

Each of (1) through (6) was added to the analysis independently after controlling for sex, age, patient, experience of consulting with CISC and immediate access to CISC. CISC, Cancer Information Support Centre.



Clinton-McHarg *et al*<sup>25</sup> reported that 83%–96% of callers as caregivers were satisfied with the service in western countries. A survey of the Leukemia & Lymphoma Society reported that among users of the Information Resource Center, 86% felt more hopeful and 83% felt more confident in managing care than before the intervention.<sup>29</sup>

### Usefulness of CISC role-specific evaluation measures

In this study, the process of counselling, short-term, medium-term and long-term outcomes of counselling and independent position of CISC was employed as CISC role-specific evaluation measures. Both patients and families rated rather high the process of counselling and independent position of CISC, while medium-term and long-term outcomes of counselling were rated relatively low. These distribution trends are reasonable, because medium-term and long-term outcomes do not always appear directly after counselling.

The relationship between outcomes and variables treated as drivers for access was also reasonable. The respondents who wanted to consult about disease or symptoms gave higher ratings for the process of counselling (both patients and families) and independence of CISC (patients). In contrast, the ratings of those who wanted to talk about financial problems and discharge or care at home tended to be low in the dimension of the process of counselling. CISCs can provide information about disease or symptoms and give direct advice on the use of medical resources; therefore, disease-related or symptom-related matters have a high chance of receiving appropriate support. Japanese CISCs are located in designated cancer hospitals and this study's participants used the face-to-face service; these characteristics may be reflected in our results.

However, financial problems are sometimes difficult to resolve through counselling. Japan has a universal health insurance system, and patients apply for a pre-fixed ceiling amount.<sup>30</sup> Although the ceiling is set according to the patient's income, insurance is not affordable for everyone. Some patients and their families face a decrease in income or unemployment, and/or indirect costs derived from cancer.<sup>31</sup> In Japan, returning to work with/after cancer treatment has been encouraged since 2012. Nonetheless, a significant number of patients quit their jobs immediately after their diagnosis, and it is difficult for them to find re-employment.<sup>32</sup> These difficulties may be related to the low evaluation of CISC services because CISCs could not provide a solution to their difficult situation.

Only patients (not families) who wanted to discuss discharge or care at home gave negative ratings for the process of counselling. This may reflect certain aspects of the Japanese medical and social-welfare service system. Recently, cancer care in Japan has shifted from inpatient to outpatient care, similar to other countries, and patients tend to be discharged before they can get accustomed to their condition, which may result in anxiety. Patients being discharged before they are sufficiently recovered often

results in burdening the family caregivers.<sup>31</sup> The need for informal caregivers is often ignored and excluded from healthcare planning.<sup>33</sup> Patients may feel concern regarding burdening their family caregivers; however, it is difficult for information specialists to provide direct solutions. These circumstances can be attributed to patients' anxiety after their discharge. Therefore, those who wanted to prepare for their discharge rated the process of counselling negatively because home care burden of their families could not be resolved perfectly in CISC consultations.

The relationship between financial problem and discharge may reflect the evaluation of the Japanese healthcare system rather than the services provided by the CISC. In other words, the responses we received as an 'evaluation of CISCs' activities' may be an overall evaluation of the medical service. We need further research to distinguish the direct effect of CISCs from the medical service as a whole.

As shown in [table 5](#), immediate access to the CISC was the strongest factor for all evaluation dimensions. The findings are consistent with the results of previous studies. It has been reported that accurate and timely information decreases anxiety and fear about cancer,<sup>34–36</sup> and immediate access to a self-help support programme indicated a better outcome.<sup>37</sup> Treiman *et al*<sup>39</sup> found that telephone helplines could provide 'timely and accurate information and support', and our research confirms that 'timeliness' is very important for CISC users. This means smooth access to CISCs brings the users benefit as well as results in high evaluation. In other words, it is suggested that systematic procedures are employed to help patients and families with needs visiting the CISCs.

### Limitations and implications

Some review articles have discussed the lack of evidence on whether CIS or information provision contributes to users' health.<sup>25 38</sup> This study is based on a self-reported evaluation of CIS and does not employ objective symptoms or established psychological status of CISC users. This means that this study is also limited in the subjective evaluation and cannot provide objective evidence of the usefulness of CIS. Future research on objective variables should examine the evidence of the usefulness of CISCs. However, the purpose of this study was to develop the service quality of CIS, and the scores of the measures and related factors are reasonable. This shows that the measures employed in this study can be used for quality control of CISCs.

Tsianakas *et al*<sup>39</sup> reported that a local survey is useful as a screening tool to identify the problem, but it does not always provide sufficient detail of what to do to improve the service; the authors advised combining open comments and in-depth interviews, which can elicit patients' whole experiences. Our 12-item survey tool can be employed for screening use, scores of study results can be a benchmark of CISC service quality and each CISC can use this tool in combination with the original feedback systems. Trends

of the gradual manner of short-term, medium-term and long-term outcomes, and the distribution of the topics that users want to discuss may reflect the feature of each CISC. For example, CISCs with high proportion of users seeking counsel for physical symptoms and negatively evaluating the CISC experience should reconsider the information specialists' training, which may bridge the gaps in their medical knowledge. Each CISC score indicates its features, strengths, as well as weaknesses.

Although CISCs in Japan provide counselling not only on site but also by phone, email and fax, this study included only onsite counselling. As mentioned above, half of the consultations were conducted face to face and the ratio of such consultations varied across CISCs. This implies that half of the consultations provided by CISCs were not included in this study. In NCI's study, the satisfaction level of email and chat users was the same as that of telephone users, but the knowledge improvement level was higher among email and online chat users.<sup>17</sup> Further research should be conducted on other types of CISC users in Japan.

Lastly, this survey was conducted in 2016 and since then 5 years have passed. CISCs in Japan started operations in 2006 and the survey reports data from the first 10 years. It can be assumed that the evaluation of CISCs has not differed much in these 5 years. However, the current guidelines for designated cancer hospitals were implemented in 2018, which expanded the role of CISCs to include information prescription about cancer genomic medicine and treatment of rare cancer. We should continuously monitor CISCs' evaluation by patients and families under their expanded roles.

## CONCLUSION

A 12-item evaluation tool generated based on CISC's roles and missions was employed for the CISC users' evaluation survey. Six dimensions were identified to reflect the CISC's functions. Users' evaluation of CISCs was sufficiently high in terms of overall satisfaction compared with the global standard. As for the outcome of CISC counselling, short-term outcome was rated the highest, followed by medium-term and long-term outcomes.

Regarding other related factors, timely access is the most important factor affecting all the dimensions of the evaluation. Financial and homecare problems negatively affect the evaluation, and may reflect the difficulty of providing effective resolution by CISCs. Although the related factors reported were similar in patients and families, evaluation by patients was more directly affected by their chosen topics of discussion.

The distribution of the scores of the measures and related factors was reasonable. Thus, the 12-item measurement tool employed in this study seems to be useful for quality monitoring of the CISC.

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**Contributors** CY was involved in the entire process of conducting this research, including designing, data collection, analysis of data and preparation of the manuscript. TT was the co-designer of this study, chief secretariat of data collection admission office and adviser for the analysis and writing processes. MH was the co-secretariat of data collection admission office and adviser for the analysis and writing processes. FW organised the research team and checked and provided advice for each step of the study. Each author contributed sufficiently toward the study's intellectual content, analysis of data and preparation of the manuscript, and takes public responsibility for it. The authors have also reviewed the final version of the manuscript, believe that it represents valid work and approve it for publication. CY is the corresponding author and guarantor.

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## REFERENCES

- 1 Fletcher C, Flight I, Chapman J, *et al*. The information needs of adult cancer survivors across the cancer continuum: a scoping review. *Patient Educ Couns* 2017;100:383–410.
- 2 Chambers SK, Girgis A, Occhipinti S, *et al*. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. *Eur J Cancer Care* 2012;21:213–23.
- 3 Ekberg K, McDermott J, Moynihan C, *et al*. The role of helplines in cancer care: intertwining emotional support with information or advice-seeking needs. *J Psychosoc Oncol* 2014;32:359–81.
- 4 Kuenzel U, Monga Sindeu T, Schroth S, *et al*. Evaluation of the quality of online information for patients with rare cancers: thyroid cancer. *J Cancer Educ* 2018;33:960–6.
- 5 Ogasawara R, Katsumata N, Toyooka T, *et al*. Reliability of cancer treatment information on the Internet: observational study. *JMIR Cancer* 2018;4:e10031.
- 6 Arif N, Ghezzi P. Quality of online information on breast cancer treatment options. *Breast* 2018;37:6–12.
- 7 Charow R, Snow M, Fathima S, *et al*. Evaluation of the scope, quality, and health literacy demand of Internet-based anal cancer information. *J Med Libr Assoc* 2019;107:527–37.
- 8 Saeed F, Anderson I. Evaluating the quality and readability of Internet information on meningiomas. *World Neurosurg* 2017;97:312–6.

- 9 Borges EL, Franceschini J, Costa LHD, *et al.* Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *J Bras Pneumol* 2017;43:18–23.
- 10 Livingston PM, Osborne RH, Botti M, *et al.* Efficacy and cost-effectiveness of an outcall program to reduce carer burden and depression among carers of cancer patients [PROTECT]: rationale and design of a randomized controlled trial. *BMC Health Serv Res* 2014;14:5.
- 11 Thomas C, Morris SM, Harman JC. Companions through cancer: the care given by informal carers in cancer contexts. *Soc Sci Med* 2002;54:529–44.
- 12 Heckel L, Fennell KM, Orellana L, *et al.* A telephone outcall program to support caregivers of people diagnosed with cancer: utility, changes in levels of distress, and unmet needs. *Support Care Cancer* 2018;26:3789–99.
- 13 Hodges LJ, Humphris GM, Macfarlane G. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Soc Sci Med* 2005;60:1–12.
- 14 Morra ME, Thomsen C, Vezina A, *et al.* The International cancer information service: a worldwide resource. *J Cancer Educ* 2007;22:S61–9.
- 15 D'Egidio V, Sestili C, Mancino M, *et al.* Counseling interventions delivered in women with breast cancer to improve health-related quality of life: a systematic review. *Qual Life Res* 2017;26:2573–92.
- 16 Perocchia RS, Hodorowski JK, Williams LA, *et al.* Patient-centered communication in cancer care: the role of the NCI's cancer information service. *J Cancer Educ* 2011;26:36–43.
- 17 La Porta M, Hagood H, Patt J, *et al.* The NCI's cancer information service: meeting the public's cancer information needs via the Internet. *J Cancer Educ* 2007;22:S26–34.
- 18 Stacey D, Chambers SK, Jacobsen MJ, *et al.* Overcoming barriers to cancer-helpline professionals providing decision support for callers: an implementation study. *Oncol Nurs Forum* 2008;35:961–9.
- 19 Jefford M, Black C, Grogan S, *et al.* Information and support needs of callers to the cancer Helpline, the cancer Council Victoria. *Eur J Cancer Care* 2005;14:113–23.
- 20 Cipolat Mis C, Truccolo I, Ravaioli V, *et al.* Making patient centered care a reality: a survey of patient educational programs in Italian cancer research and care Institutes. *BMC Health Serv Res* 2015;15:298.
- 21 Takayama T, Yamaki C, Hayakawa M, *et al.* Development of a new tool for better social recognition of cancer information and support activities under the National cancer control policy in Japan. *J Public Health Manag Pract* 2021;27:E87–99.
- 22 Heckel L, Heynsbergh NL, Livingston PM. Are cancer helplines effective in supporting caregivers? A systematic review. *Support Care Cancer* 2019;27:3219–31.
- 23 Boltong A, Ledwick M, Babb K, *et al.* Exploring the rationale, experience and impact of using cancer information and support (cis) services: an international qualitative study. *Support Care Cancer* 2017;25:1221–8.
- 24 Ward JA, Baum S, Ter Maat J, *et al.* The value and impact of the cancer information service telephone service. Part 4. *J Health Commun* 1998;3 Suppl:50–70.
- 25 Clinton-McHarg T, Paul C, Boyes A, *et al.* Do cancer helplines deliver benefits to people affected by cancer? A systematic review. *Patient Educ Couns* 2014;97:302–9.
- 26 Information and Support Service Panel. Document3. 7th information and support service panel. Document3, 2016. Available: [https://ganjoho.jp/med\\_pro/liaison\\_council/bukai/shiryoy7/pdf/20160519\\_03.pdf](https://ganjoho.jp/med_pro/liaison_council/bukai/shiryoy7/pdf/20160519_03.pdf)
- 27 ICISG. What we do. Available: <https://icisg.org/about-icisg/what-we-do/2020> [Accessed 22 Nov 2020].
- 28 La Porta M, Hagood H, Kornfeld J, *et al.* Evaluating the NCI's Cancer Information Service contact centers: Meeting and exceeding the expectations of the public. *J Canc Educ* 2007;22:S18–25.
- 29 Treiman K, Husick C, Sarris-Esquivel N, *et al.* Meeting the information and support needs of blood cancer patients and caregivers: a longitudinal study of a model of patient-centered information delivery. *J Cancer Educ* 2021;36:538–46.
- 30 Ministry of Health, Labour and Welfare. High-Cost medical expense benefit (eligibility certificate for Ceiling-Amount application) or Kogaku Ryoyohi Seido (Gendogaku Tekiyo Ninteisho). Available: [https://www.mhlw.go.jp/seisakunitsuite/bunya/kenkou\\_iryoyu/iryoyu/kokusai/setsumeisiryoyu/dl/en09.pdf](https://www.mhlw.go.jp/seisakunitsuite/bunya/kenkou_iryoyu/iryoyu/kokusai/setsumeisiryoyu/dl/en09.pdf) [Accessed 5 Jul 2021].
- 31 Ohno S, Chen Y, Sakamaki H, *et al.* Humanistic and economic burden among caregivers of patients with cancer in Japan. *J Med Econ* 2020;23:17–27.
- 32 Onishi K. Financial burden and employment support for patients with cancer in Japan: a review. *Jpn Hosp* 2016;53–76.
- 33 Wang T, Molassiotis A, Chung BPM, *et al.* Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care* 2018;17:96.
- 34 D'haese S, Vinh-Hung V, Bijdekerke P, *et al.* The effect of timing of the provision of information on anxiety and satisfaction of cancer patients receiving radiotherapy. *J Cancer Educ* 2000;15:223–7.
- 35 Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 2011;22:761–72.
- 36 Mills ME, Sullivan K. The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs* 1999;8:631–42.
- 37 Williams C, McClay C-A, Matthews L, *et al.* Community-based group guided self-help intervention for low mood and stress: randomised controlled trial. *Br J Psychiatry* 2018;212:88–95.
- 38 McKnight M. Information prescriptions, 1930-2013: an international history and comprehensive review. *J Med Libr Assoc* 2014;102:271–80.
- 39 Tsianakas V, Maben J, Wiseman T. Using patients' experiences to identify priorities for quality improvement in breast cancer care: patient narratives surveys or both? *BMC Health Serv Res* 2012;22:271.