

## Characteristics of Elderly Cancer Patients' Concerns and Their Quality of Life in Japan: A Web-based Survey

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**Objective:** Cancer incidence and the number of cancer patients are increasing in today's aging society. The purpose of this study was to investigate the characteristics of elderly cancer patients' concerns and examine the association between their concerns and quality of life.

**Methods:** This was a cross-sectional web-based survey completed by ambulatory cancer patients aged 20 years or older. The questionnaire on cancer patients' concerns, comprehensive concerns assessment tool and the European Organization for Research and Treatment of Cancer QLQ-C30 were distributed to the subjects. Multiple regression analysis was conducted to determine which patients' concerns significantly contributed to their quality of life.

**Results:** The final study population consisted of 807 cancer patients, among whom 243 (30%) were elderly (65 years or older). Elderly cancer patients had particular difficulty with self-management, psychological symptoms and medical information, and the prevalence of their concerns was generally lower than that of younger patients, with the exception of physical symptoms. Multiple types of elderly patients' concerns were independently associated with quality of life.

**Conclusions:** We found that elderly cancer patients suffered from various concerns, thus multidisciplinary intervention is important for providing them with optimal care. The results of this study suggest that elderly cancer patients' quality of life will improve if their concerns are properly handled.

*Key words:* psycho-oncology – supportive care – public health – quality of life

### INTRODUCTION

Since aging is a major risk for the development of cancer (1,2), elderly people are more likely to develop cancer than younger people (3,4). As the average life expectancy increases, the elderly population is growing, with the result that the number of older cancer patients is increasing. In 2013

in Japan, the elderly population aged 65 years or older was estimated to be 32 270 000 and the rate of aging 25.3% (as of 1 February 2014, provisional estimates) (5,6). In 2008 in Japan, the number of cancer incidence cases in patients over 65 years old was 538 061, among which 331 150 were males and 206 911 females (7,8). More and more elderly individuals will need cancer treatment in the near future.

However, there are a number of problems with the treatment of elderly cancer patients. Older patients tend to develop complications due to organ dysfunction and vulnerability (1,3,9–11), and their poor physical condition influences their tolerance to cancer therapy and increases the mortality risk (12–14). In general, cognitive impairment and depression are common disorders in elderly persons (15,16), and especially patients with cognitive dysfunction tend to develop delirium (11,17), which may hinder their ability to make proper decisions on their treatment (15). Moreover, according to a previous study, older people usually do not talk directly about their concerns (18), and another study indicates that cancer patients are reluctant to disclose their psychosocial concerns, so healthcare professionals hesitate to express their concerns (19,20). It seems to be difficult for medical staff to identify elderly cancer patients' problems and provide them with the necessary information and optimal support (20). On the other hand, elderly cancer patients need various forms of support such as understanding medical information, ameliorating physical symptoms, dealing with financial problems and coping with anxiety about the future (21,22). The Japanese government requires designated cancer care hospitals nationwide to establish a cancer care support and information service center in their hospitals based on the 'Basic Plan to Promote Cancer Control Act' of 2007 (23). The cancer care support and information service centers are intended to meet the needs of cancer patients without having to visit other institutions (24) and any cancer patient can use them freely, but their needs have not been handled appropriately (21,22). It is also reported that elderly cancer patients have economic limitations and have difficulty taking part in social activities, are physically and emotionally unstable, and are liable to feel lonely (11).

Previous Western studies found that older adults experienced significantly lower occurrence rates compared with younger adults in almost 50% of various physical and psychological symptoms associated with cancer and its treatment (25), an elderly cancer patient group showed a lower physical functioning score compared with the younger cancer patient group in the quality of life (QOL) domains (26), and that there was a moderate-to-strong association between patients' needs and psychological distress and/or QOL (27). To the best of our knowledge, few studies in Japan have comprehensively investigated and assessed elderly cancer patients' concerns including physical and psychological symptoms, medical treatment and daily life, even though these findings are essential for providing optimal care for elderly Japanese cancer patients.

The purposes of this study were: (i) to investigate what kind of concerns elderly cancer patients have, (ii) to compare elderly with younger cancer patients' concerns to clarify the characteristics of the elderly and (iii) to examine the association between elderly cancer patients' concerns and their QOL. We hypothesized that elderly cancer patients' concerns are multidimensional, that they had fewer concerns than younger cancer patients, and that there is a significant association between elderly cancer patients' concerns and their QOL.

### METHODS

#### SUBJECTS

This survey was conducted via the Internet using Lyche-web of INTAGE Inc., Tokyo, Japan. The company recruited and registered monitors who could use the Internet through advertisement. We extracted potential participants who met the eligibility criteria and performed a questionnaire investigation from 22–24 October 2012.

The eligibility criteria for inclusion in this study were as follows: (i) subjects of 20 years or older, (ii) subjects who were diagnosed with cancer (any primary site and clinical stage, at any time point after diagnosis) and under treatment and (iii) subjects who have been to the hospital for cancer treatment for at least 1 year. The exclusion criteria were: (i) workers of mass media, advertisement agencies, market research companies and (ii) healthcare providers such as doctors, nurses, social workers and so on. Monitors were paid with points in return for participating in this investigation, that is, they could earn points if they answered all questions, and then they could exchange points for cash, net points or donation to some organization.

This study was approved by the Institutional Review Board and Ethics Committee of the National Cancer Center Hospital, Japan. The return of completed forms was considered consent.

#### PROCEDURE

This was a cross-sectional survey by internet to examine the characteristics of elderly cancer patients' concerns and the association between their concerns and QOL. We defined 65 years or older as the elderly in this investigation. The subjects were asked to fill out the online self-administered questionnaire. Inappropriate returns such as duplicate responses from the same terminal, mismatch between registered information and answer contents and inappropriate response time were deleted. As the participants were required to answer all questions, there should be no missing values in this investigation. The questionnaire consisted of the three sections described below.

#### INSTRUMENTS

##### CANCER PATIENTS' CONCERNS: COMPREHENSIVE CONCERNS ASSESSMENT TOOL (CCAT)

This self-reported questionnaire was developed to comprehensively assess cancer patients' concerns for our investigation, and its validity and reliability have been confirmed in Japanese cancer patients (28). The questionnaire includes four different types of concerns: physical symptoms (five items), psychological symptoms (five items), daily living (six items), self-management (three items), medical information (five items) and two symptoms: pain (one item) and constipation (one item). Participants were asked to respond to this questionnaire which evaluated the level or frequency of their concerns in the previous week on a four-point Likert scale

(1: no concerns, 2: slight concerns [once or twice a week], 3: moderate concerns [more than half of a week], 4: serious concerns [Every day]). We defined a rating of 3 or 4 as the presence of concerns.

*QOL: EUROPEAN ORGANIZATION FOR RESEARCH AND TREATMENT OF CANCER QUALITY OF LIFE QUESTIONNAIRE-CORE 30*

European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30) is a 30-item cancer-specific questionnaire for assessing the general health-related QOL of cancer survivors (29). The questionnaire includes five functional scales (physical, role, emotional, cognitive and social) and nine symptom scales (fatigue, pain, nausea and vomiting and others) and a global health status/QOL scale. The reliability and validity of the Japanese version of the EORTC QLQ-C30 has been confirmed in a previous study (30). The present study uses a global health status score of 0–100, with a higher score indicating a higher QOL.

*SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS*

An *ad hoc* self-administered questionnaire was used to obtain information on the patients' sociodemographic status, including age, sex, marital status, educational level, cancer site (all cancer types), clinical stage (the presence of recurrence or metastasis), anti-cancer treatment (surgery, chemotherapy, hormonal therapy and radiation therapy), duration since diagnosis (<6 months, 6 months to 5 years and ≥5 years), employment status (full-time/part-time or unemployed). As to the performance status (PS) defined by the Eastern Cooperative Oncology Group (ECOG), we described physical symptoms clearly in the questionnaire and asked participants to assess themselves using a rating from 0 (no symptoms) to 4 (bedridden).

*STATISTICAL ANALYSES*

First, we conducted an unpaired *t*-test to show the demographic differences between elderly (≥65 years old) and younger (<65 years old) cancer patients. Second, we calculated the prevalence of concerns in each subscale and item of CCAT among elderly and younger cancer patients, respectively. We regarded a rating of 3 or 4 on the four-point Likert scale as the presence of concern for each item, and we defined the presence of concern as having one or more items of concern in each subscale. We subsequently conducted an unpaired *t*-test to investigate the differences between elderly and younger cancer patients' concerns. Lastly, we conducted a multiple regression analysis to examine the association between elderly cancer patients' concerns and their QOL. In this analysis, the global health status score of EORTC QLQ-C30 was entered as a dependent variable, and the concerns present in the seven subscales were entered as independent variables. Age, sex, marital status (two groups: married or others), clinical stage (two groups: presence or non-presence of recurrence/metastasis), duration since diagnosis (three groups: <6 months,

6 months to 5 years, ≥5 years), employment status (two groups: full-time/part-time or unemployed), educational level (two groups: more than high school graduate or others) were also entered as independent variables for adjustment.

All *P* values were two-sided, and a *P* value of <0.05 was regarded as being statistically significant. All statistical procedures were conducted using SPSS software for Windows (Version 21.0 J, SPSS Inc., 2012).

**RESULTS**

*PATIENT CHARACTERISTICS*

A total of 1009 cancer patients were recruited in this study and data were available for 807 cancer patients. The response rate was 80.0%. The patients' sociodemographic and clinical characteristics are shown in Table 1. Based on the data collected, 243 subjects (30%) were over 65 years old; mean (±SD) and median age were 71.3 (±4.7) and 71 years, respectively. More than 90% were married, male, and did not have any impairment of physical functioning (PS 0 or 1). About 40% were prostate cancer and ~30% were diagnosed with recurrent/metastatic cancer. The background characteristics of the two age-specific subject groups were significantly different in sex, marital status, employment status, cancer site, history of anti-cancer treatment and global health status score, as shown in Table 1.

*PREVALENCE OF CONCERNS AND DIFFERENCES BETWEEN ELDERLY (≥65 YEARS) AND YOUNGER (<65 YEARS) SUBJECTS*

The most commonly perceived concerns among the elderly cancer patients were self-management, containing 'Want to know what I can do in poor health' (46.1%), 'Want to know what I can do for curing disease by myself' (45.3%), 'Want to know what I can do to take care of myself' (35.0%), followed by psychological symptoms 'Insomnia' (34.6%) and medical information 'Want to know about other treatments' (34.2%). We also found differences between older and younger cancer patients' concerns using univariate analysis, as shown in Table 2. The elderly subject group suffered significantly more from 'Loss of weight' (*P* = 0.04) in Physical symptoms but suffered less from 'Not being insightful' (*P* = 0.01), 'Feeling down and/or depressed' (*P* < 0.01) in psychological symptoms compared with the younger subject group. The elderly group also had significantly less difficulty with self-management (*P* = 0.03), daily living (*P* < 0.01) and constipation (*P* = 0.02) compared with the younger group.

*ASSOCIATION BETWEEN ELDERLY CANCER PATIENTS' CONCERNS AND QOL*

The results of the multiple regression analysis are shown in Table 3. Five subscales other than medical information and self-management were significantly associated with the elderly cancer patients' QOL, among which the most significantly associated was pain (*P* < 0.01), followed by physical

**Table 1. Demographics and clinical characteristics of all participants**

Characteristics	All		≥65 years		<65 years		<i>P</i>
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
No.	807	100.0	243	30.1	564	69.9	
Age	Mean: 57.6 (SD = 11.6) Median: 57 (range, 23–86)		Mean: 71.3 (SD = 4.7) Median: 71 (range, 65–86)		Mean: 51.7 (SD = 8.3) Median: 52 (range, 23–64)		
Sex							
Male	433	53.7	219	90.1	214	37.9	0.00
Female	374	46.3	24	9.9	350	62.1	
Marital status							
Married	640	79.3	221	90.9	419	74.3	0.00
Education							
>12 years	513	63.5	139	57.2	374	66.3	0.93
Employment status							
Full-time/part-time	365	45.2	49	20.2	316	56.0	0.00
Cancer site							
Breast	237	29.4	8	3.3	229	40.6	0.00
Prostate	126	15.6	102	42.0	24	4.3	
Colon	58	7.2	20	8.2	38	6.7	
Stomach	48	5.9	22	9.1	26	4.6	
Lung	34	4.2	13	5.3	21	3.7	
Bladder	31	3.8	12	4.9	19	3.4	
Uterus	31	3.8	0	0.0	31	5.5	
Hematopoietic system	29	3.6	5	2.1	24	4.3	
Liver	23	2.9	10	4.1	13	2.3	
Rectum	22	2.7	10	4.1	12	2.1	
Esophagus	15	1.9	7	2.9	8	1.4	
Head and neck	12	1.5	1	0.4	11	2.0	
Kidney	10	1.2	5	2.1	5	0.9	
Ovary	10	1.2	0	0.0	10	1.8	
Pancreas	9	1.1	6	2.5	3	0.5	
Biliary system	5	0.6	2	0.8	3	0.5	
Undiagnosed	9	1.1	3	1.2	6	1.1	
Others	98	12.1	17	7.0	81	14.4	
Clinical stage							
Recurrence/metastasis	213	26.4	66	27.2	147	26.1	0.75
History of anti-cancer treatment*							
Surgery	678	84.0	175	72.0	503	89.2	0.00
Chemotherapy	384	47.6	94	38.7	290	51.4	0.00
Hormonal therapy	318	39.4	83	34.2	235	41.7	0.05
Radiation therapy	295	36.3	64	26.3	229	40.6	0.00

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Table 1. Continued

Characteristics	All		≥ 65 years		< 65 years		P
	N	%	N	%	N	%	
<b>ECOG performance status</b>							
0	453	56.1	144	59.3	309	54.8	0.44
1	323	40.0	88	36.2	235	41.7	
2	25	3.1	9	3.7	16	2.8	
3	5	0.6	2	0.8	3	0.5	
4	1	0.1	0	0.0	1	0.2	
<b>Duration since diagnosis</b>							
< 6 months	45	5.6	19	7.8	26	4.6	0.61
≥ 6 months to < 1 year	112	13.9	32	13.2	80	14.2	
≥ 1 year to < 2 years	190	23.5	50	20.6	140	24.8	
≥ 2 years to < 5 years	288	35.7	92	37.9	196	34.8	
≥ 5 years	172	21.3	50	20.6	122	21.6	
EORTC QLQ-C30	Mean: 62.2 (SD = 22.7)		Mean: 64.7 (SD = 22.3)		Mean: 61.2 (SD = 22.8)		0.04
Global health status score	Median: 66.7 (range, 0–100)		Median: 66.7 (range, 0–100)		Median: 66.7 (range, 0–100)		

ECOG, Eastern Cooperative Oncology Group; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30.  
 \*Multiple choice.

symptoms ( $P < 0.01$ ), constipation ( $P < 0.01$ ), psychological symptoms ( $P = 0.01$ ) and daily living ( $P = 0.01$ ), after adjusting for age, sex, marital status, clinical stage, duration since diagnosis, employment status and educational level. As the coefficient of determination ( $R^2$ ) in this survey was 0.31, we could not sufficiently estimate QOL from the concerns of elderly cancer patients.

**DISCUSSION**

As to the elderly cancer patients' concerns, about half of them had difficulty with self-management, psychological symptoms and medical information. In terms of self-management, it appears that they would like to decide their own treatment and they are likely to do something on their own without relying on others. As for psychological symptoms and medical information, a previous study reported that the prevalence of unmet needs among cancer patients aged over 70 years was high in the Psychological and Health system and Information domains and slightly > 50% of them appeared to be unsatisfied (26), which is consistent with our findings. This indicates that they have not obtained sufficient information for living with medical treatment, even though cancer care support and information service centers play an important role in providing cancer patients and their families with useful information such as how to deal with side effects at home, available treatment or treatment options and interpersonal communication. The reasons for this are that many cancer patients are still not

familiar with the centers (31), or older patients with cognitive dysfunction might not be able to approach the centers because of their inadequate health literacy (32), so it may be necessary to simply remind them about the centers. With regard to psychological symptoms of older cancer patients such as insomnia, medical staff must handle this properly, for example, by regularly making assessments in clinical practices and objectively asking the families or visiting nurses about the patient's home life (33). Moreover, it would be necessary for oncologists to receive training on the primary approach for dealing with psychological symptoms of older cancer patients (34).

With respect to the comparison between elderly and younger cancer patients' concerns, a previous study reported that the elderly had less trouble with psychological symptoms and social functioning than younger cancer patients (25), and another study suggested that the elderly showed lower physical functioning scores in the QOL domains compared with the younger cancer patients (26), and these results are in agreement with our study. The reason for this seems to be that older cancer patients in Japan receive their pension or financial support from their children, which alleviates concerns about money. In addition, since they have finished raising their children and are retired from work, they have fewer demands on their time and resources compared with younger cancer patients (35,36). Since younger individuals still have work and family responsibilities, they seem to have more difficulty with psychosocial problems, financial problems, social functioning and so on (35,36). Regarding QOL, it is generally considered

Table 2. Prevalence of concerns<sup>a</sup> and differences between elderly (≥ 65 years) and younger (< 65 years) cancer patients—univariate analysis

Concerns	All		≥ 65 years		< 65 years		P
	n = 807	%	n = 243	%	n = 564	%	
<b>Physical symptoms (having one or more concerns in the following five items)</b>							
Loss of weight	51	6.3	22	9.1	29	5.1	0.04
Loss of appetite	49	6.1	16	6.6	33	5.9	0.69
Dyspnea	43	5.3	9	3.7	34	6.0	0.18
Diarrhea	35	4.3	12	4.9	23	4.1	0.58
Nausea and/or vomiting	21	2.6	6	2.5	15	2.7	0.88
<b>Psychological symptoms (having one or more concerns in the following five items)</b>							
Insomnia	391	48.5	114	46.9	277	49.1	0.57
Being tired and/or feeling sluggish	257	31.8	84	34.6	173	30.7	0.28
Not being insightful	226	28.0	51	21.0	175	31.0	0.00
Feeling down and/or depressed	146	18.1	31	12.8	115	20.4	0.01
Feeling agitated and/or nervous	123	15.2	21	8.6	102	18.1	0.00
71	8.8	16	6.6	55	9.8	0.15	
<b>Daily living (having one or more concerns in the following six items)</b>							
Concerns about medical fees	241	29.9	51	21.0	190	33.7	0.00
Inability to do job	179	22.2	35	14.4	144	25.5	0.00
Inability to do housework and/or to take care of family	133	16.5	18	7.4	115	20.4	0.00
69	8.6	12	4.9	57	10.1	0.02	
Concerns about nursing care insurance	66	8.2	24	9.9	42	7.4	0.25
Inability to take care of oneself	58	7.2	11	4.5	47	8.3	0.06
Having no means of going to hospital	37	4.6	7	2.9	30	5.3	0.15
<b>Self-management (having one or more concerns in the following three items)</b>							
Want to know what I can do for curing of disease by myself	494	61.2	135	55.6	359	63.7	0.03
423	52.4	110	45.3	313	55.5	0.01	
Want to know what I can do in poor health	414	51.3	112	46.1	302	53.5	0.05
334	41.4	85	35.0	249	44.1	0.02	
<b>Medical information (having one or more concerns in the following five items)</b>							
Want to know about other treatments	373	46.2	103	42.4	270	47.9	0.15
289	35.8	83	34.2	206	36.5	0.52	
Want to know about other hospitals	235	29.1	73	30.0	162	28.7	0.71
Unable to understand explanation about disease and/or treatment	149	18.5	54	22.2	95	16.8	0.07
Unable to communicate well with doctor	140	17.3	42	17.3	98	17.4	0.98
Want to know about fertility	66	8.2	15	6.2	51	9.0	0.17
<b>Pain</b>							
Painful	142	17.6	41	16.9	101	17.9	0.72
<b>Constipation</b>							
Constipated	126	15.6	27	11.1	99	17.6	0.02

<sup>a</sup>Rated 3 or 4 on the four-point Likert scale on each item of the comprehensive concerns assessment tool.

to be lower in elderly compared with younger cancer patients, because the physical functions of elderly patients are weakened and they tend to have more comorbidities than younger patients (37), and the severity of comorbidities adversely affects QOL (38). In a previous study, however, the QOL of elderly cancer patients was the same degree as in younger cancer patients after adjustment for PS (39), and another study reported that QOL was not significantly different between

elderly and younger cancer patients (26). In our study, QOL was higher in the elderly than in the younger cancer patients. One of the reasons for this seems to be that older cancer patients are better able to adapt to severe situations compared with younger patients, although the elderly are more strongly affected by cancer itself or the treatment (40,41).

Regarding the association between concerns and QOL of elderly cancer patients, we found that there is a significant

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Table 3. Association between elderly cancer patients' concerns and quality of life<sup>a</sup>—multiple regression analysis<sup>b</sup>

Concerns	Coefficient ( $\beta$ )	Standardizing coefficient ( $\beta$ )	T	P	Partial $R^2$
Physical symptoms	-11.77	-0.19	-3.23	0.00	0.14
Psychological symptoms	-6.70	-0.15	-2.53	0.01	0.11
Daily living	-8.34	-0.15	-2.53	0.01	0.11
Self-management	-4.67	-0.10	-1.61	0.11	0.08
Medical information	-3.44	-0.08	-1.20	0.23	0.06
Pain	-12.23	-0.21	-3.64	0.00	0.11
Constipation	-11.96	-0.17	-3.07	0.00	0.05
					Total $R^2 = 0.31$

<sup>a</sup>Global health status score of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30.

<sup>b</sup>Adjusted for age, sex, marital status (two groups), clinical stage (two groups), duration since diagnosis (three groups), employment status (two groups) and educational level (two groups).

association, but self-management and medical information, which are highly prevalent concerns among the elderly subjects, do not significantly contribute to QOL. Nevertheless, elderly subjects have great difficulty with these two subscales. On the other hand, the other five subscales that are significantly associated with QOL do not pose much difficulty for the elderly cancer patients. Therefore, we consider it important to comprehensively intervene in their multiple concerns. Several previous studies have suggested that the more adequate information cancer patients obtain, the more satisfied they are (20), and the more able they are to adapt to their psychological and emotional states (42); therefore the QOL of elderly cancer patients is expected to improve with multifaceted intervention and the provision of sufficient information about their concerns.

The present study has several limitations. First, there was the potential for selection bias in that the subjects were outpatients, over 90% of them were diagnosed > 6 months earlier, ~90% of them were male and 40% were prostate cancer, and moreover, they were all able to participate in this internet survey. Based on these factors, it was estimated that most of the subjects were physically and mentally stable, and they had little cognitive dysfunction and high health literacy because they were capable enough to use the internet. As more men than women use the internet in general, it is believed that most subjects in this study were men. That is to say, subjects in this study were not representative elderly cancer patients in Japan. Further investigations need to be conducted other than through the internet, such as by interviews with not only outpatients but inpatients in clinical sites, in the future. In addition, we should point out that there was a possibility that most of the study subjects had normal cognitive function. In fact, the number of cognitive deficit patients in Japan was estimated to be 4 620 000 in 2013 (43), and many elderly cancer patients have cognitive impairment. Therefore, we should evaluate the cognitive function of elderly cancer patients first, positively detect their concerns including concerns of patients with cognitive dysfunction by using assessment tool like

comprehensive geriatric assessment (CGA) after that, and examine whether we can clarify their concerns.

Second, the CCAT questionnaire for cancer patients' concerns proved to be valid and reliable in a previous study, but it is not specific to elderly cancer patients (28). Finally, since our investigation was cross-sectional in design, we cannot conclude the causal relationship between patients' concerns and their QOL. This problem needs further investigation in a longitudinal study; for example, we should reinvestigate after an interval of several months. In addition, further research needs to focus on various patients and clinical characteristics such as age, sex, cancer type, PS and so forth.

Despite these limitations, this study has several strengths. To our knowledge, it is the first study to comprehensively assess elderly cancer patients' concerns in Japan; in doing so, we could understand the characteristics of elderly cancer patients' concerns in detail. The response rate of this study was 80%, which was considered to be relatively high.

In today's aging society, multidisciplinary intervention and training for healthcare professionals will be required to deal with different and complex concerns of elderly patients with cancer. We should also make an active effort to investigate concerns of elderly cancer patients who do not complain, predict their possible problems such as upset, and intervene in them. This will make it possible to provide them with optimal oncological care to improve their QOL.

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#### Conflict of interest statement

None declared.

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## Comprehensive Assessment of Cancer Patients' Concerns and the Association with Quality of Life

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**Objective:** Comprehensive assessment of perceived concerns can be used to guide supportive care appropriate to individual cancer patients. This study sought to determine the prevalence of cancer patients' concerns and the degree to which these concerns contribute to patients' quality of life.

**Methods:** Participants were patients with all types of cancer, who completed an Internet survey questionnaire regarding comprehensive concerns about physical, psychological, psychosocial and economic aspects of having cancer. The questionnaire was based on the newly developed Comprehensive Concerns Assessment Tool and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire.

**Results:** We obtained complete data from 807 patients. Factors related to 'self-management' concerns were the most common (61.2%), followed by concerns about 'psychological symptoms' (48.5%), 'medical information' (46.2%), 'daily living' (29.9%), 'pain' (17.6%), 'constipation' (15.6%) and other 'physical symptoms' (15.2%). Multiple regression analysis revealed that all concerns except those about 'medical information' significantly contributed to quality of life.

**Conclusions:** Cancer patients' concerns were shown to be multidimensional and significantly associated with quality of life. Thus, assessment of patients' concerns should be multidimensional in nature, and a multidisciplinary care team should help patients improve their quality of life.

**Key words:** quality of life – patient care team – social support – needs assessment

### INTRODUCTION

Cancer patients face various symptoms and problems in daily life that involve the physical, psychological and socio-economic effects of treatment complications and extended survival.

Numerous symptoms and problems must be managed, including pain (1), distress (2), insufficient social support (3)

and treatment location (4). Almost all of these are reported to be factors significantly related to quality of life (QOL) (5–8). Recent studies have also dealt with a wide range of cancer patients' care needs, and having many needs is one of the factors reported to worsen cancer patients' QOL (9,10). These findings suggest that medical professionals should focus on the various symptoms and problems that cancer patients face in order to better support them.

However, past studies have shown that patients' symptoms and problems are often not appropriately addressed by medical professionals (11–13). Also, patients frequently report that they have not received the support they needed during treatment and follow-up (14–16). These problems result in part from a lack of appropriate, brief assessment tools of symptoms and problems, which leads to insufficient guidance for effective and efficient care. Cancer patients experience one or more symptoms and several problems simultaneously, and how they feel and respond to these symptoms and problems differs between individuals. Therefore, their symptoms and problems must be assessed comprehensively from the patient's viewpoint as 'perceived concerns'. The comprehensive assessment of perceived concerns can offer some advantages. First, patient-important outcomes can be directly assessed. Second, it can help with the prioritization of necessary care by more specifically indicating the support resources needed to improve the patient's QOL. However, as mentioned above, few tools are available for such assessment.

The framework of this study is based on the premise of appropriate supportive care, which is defined as care based on patients' perceived concerns to improve QOL. The study objectives were 3-fold: to develop a questionnaire that comprehensively assesses cancer patients' concerns; to examine the prevalence of concerns in cancer patients; and to explore the contribution of concerns to cancer patients' QOL.

### PATIENTS AND METHODS

#### SUBJECTS

Subjects were patients on the registered cancer patient list of Intage Inc., Tokyo, Japan, a company that specializes in Internet surveys and recruits monitors from among Internet users by advertisements placed on various websites in Japan. From the registered monitors, we selected patients that matched the eligibility criteria of this study. Inclusion criteria were persons aged 20 years or older, who were diagnosed with cancer (any primary cancer site, all stages and at any time point after diagnosis) and had visited a hospital for cancer treatment within the past year. Exclusion criteria were patients who were either healthcare professionals or who worked in the areas of media, advertisement or web investigation. The reward for responding to the questionnaire was given according to a point system. Respondents could save points if they completed all questions. They could then exchange points for money or save their accumulated points.

This study was approved by the Institutional Review Board and Ethics Committee of the National Cancer Center, Japan. Because this was an Internet survey, responding to the survey constituted informed consent to participate in this study.

#### PROCEDURE

In this cross-sectional study, the survey was conducted over the Internet between 22 and 24 October 2012. In total, 1009

eligible cancer patients were asked to complete the self-administered questionnaires.

We excluded data when answers were transmitted repeatedly from the same terminals, when attributes were different from those of the answer or when the answer time was inappropriate. Missing values were not possible because the web investigation was structured to require participants to answer all of the questions.

#### INSTRUMENTS

##### CANCER PATIENTS' CONCERNS

We developed a self-reported questionnaire, which we named the Comprehensive Concerns Assessment Tool (CCAT), to comprehensively assess the concerns of patients across all types of cancer throughout all phases of the cancer experience. After reviewing existing patient and family support sheets compiled by the National Cancer Center Japan and a needs assessment tool [Short-form Supportive Care Needs Survey Questionnaire: SCNS-SF34-J (17)], we selected 50 items encompassing physical, psychological and psychosocial concerns of cancer patients. We then selected 26 of these items using a focus group of experts that included psycho-oncologists, nurses and medical social workers. We explored subcategories by factor analysis and examined the internal consistency of each subscale.

On the CCAT, respondents were asked to indicate the level or frequency of their concerns over the last week. The four response options were (i) no concern, (ii) mild concern (1 or 2 days a week), (iii) moderate concern (more than half the week) and (iv) serious concern (every day).

The CCAT will be published on the homepage (<http://pod.ncc.go.jp>).

##### QUALITY OF LIFE

We assessed patient QOL using the European Organization for the Research and Treatment of Cancer (EORTC) QLQ-C 30 (18). The EORTC QLQ-C 30 consists of 30 items on self-reported aspects of QOL in cancer patients. The validity and reliability of the Japanese version of the EORTC QLQ-C 30 had been confirmed (17). In this study, we used the Global Health Status score ranging from 0 to 100, with higher scores representing higher QOL.

##### SOCIO-DEMOGRAPHIC AND CLINICAL CHARACTERISTICS

We used an *ad hoc* self-administered questionnaire to obtain data on the patients' socio-demographic status, including marital status, employment status and educational level. We also obtained other medical information, including primary cancer site, time since diagnosis and presence of recurrence or metastasis from this questionnaire.

STATISTICAL ANALYSIS

First, we evaluated factor validity of the CCAT using factor analysis with Promax rotation. The number of factors was determined by Keiser's criterion (eigenvalue of 1.0 or greater). To evaluate the internal consistency of each factor, we calculated Cronbach's alpha coefficients. We calculated the prevalence of each subscale and each item to clarify the prevalence of concerns. We defined 'presence of each concern subscale' as the presence of one or more items receiving a score of 3 or 4 on each factor, and 'presence of each concern item' as an item receiving a score of 3 or 4.

Next, to explore the contribution of each concern to cancer patients' QOL, we conducted multiple regression analysis, where the dependent variable was the Global Health Status score of the EORTC QLQ-C 30 and the independent variables were the presence of each concern subscales. In this analysis, age, sex, marital status (married or other), occupation (employed or unemployed), educational level (college graduate or other), time since diagnosis (<6 months, 6 months to <5 years and >5 years) and presence of recurrence or metastasis were entered as independent variables for adjustment, with reference to past studies.

A *P* value of <0.05 was considered statistically significant, and all reported that *P* values were two tailed. All statistical analysis was conducted using SPSS 21 version software for Windows (IBM Inc., 2012).

RESULTS

PATIENT CHARACTERISTICS

Complete data were available for 807 patients. The response rate was 80.0%. Table 1 shows the participants' socio-demographic and clinical characteristics. Mean (±SD) and median age of the study population were 57.6 (±11.6) and 57.0 years, respectively. The male-female ratio was about 1 : 1. Approximately 80% were married, and ~60% had a graduate education. As for cancer site, most had breast cancer (~30%), followed by prostate cancer (15.6%) and colorectal cancer (9.9%). A few subjects had lung, stomach or liver cancer. Most subjects were survivors whose time since diagnosis fell within 2-5 years, and 5.6% of participants were in the early stages of cancer treatment. Mean (±SD) and median (range) of the Global Health Status score of EORTC QLQ-C 30 were 62.2 (±22.7) and 66.7 (0-100), respectively.

FACTOR STRUCTURE OF PERCEIVED CONCERNS

Factor analysis indicated a five-factor solution. Table 2 shows the final factor pattern, factor name and internal consistency of each factor (Cronbach's alpha coefficient).

The first six items comprising concerns related to daily living during cancer treatment showed significant loading onto Factor 1. The next five items related to concerns about

Table 1. Characteristics of the study participants (n = 807)

Characteristics	No. of participants	%
Age (years)		
Mean: 57.6 (SD = 11.6), median: 57.0, range: 23-86		
Sex		
Man	433	53.7
Woman	374	46.3
Marital status		
Married	640	79.3
Unmarried	90	11.2
Separated/divorced	55	6.8
Widow/widower	22	2.7
Occupation		
Unemployed	442	54.8
Employed	365	45.2
Educational level		
Junior high school	13	1.6
High school	281	34.8
Technical school	60	7.4
Junior college	97	12.0
College	331	41.0
Graduate school	25	3.1
Primary cancer site		
Breast	237	29.4
Prostate	126	15.6
Colon	58	7.2
Stomach	48	5.9
Lung	34	4.2
Urinary bladder	31	3.8
Uterus	31	3.8
Hematologic cancer	29	3.6
Liver	23	2.9
Rectum	22	2.7
Esophagus	15	1.9
Head and neck	12	1.5
Kidney	10	1.2
Ovary	10	1.2
Pancreas	9	1.1
Gall bladder	5	0.6
Not yet diagnosed	9	1.1
Others	98	12.1
Time since diagnosis		
<6 months	45	5.6
6 months to <1 year	112	13.9

Continued

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Table 1. Continued

Characteristics	No. of participants	%
1 year to <2 years	190	23.5
2 years to <5 years	288	35.7
>5 years	172	21.3
Recurrence/metastasis		
Yes	213	26.4
No	594	73.6

medical information loaded onto Factor 2. Five items including 'being tired and/or feeling sluggish' related to concerns about psychological symptoms loaded onto Factor 3. Three items related to concerns about self-management loaded onto Factor 4, and five other items related to concerns about physical symptoms loaded onto Factor 5. Items for 'pain' and 'constipation' did not belong to any factor. 'Pain' might reflect not only physical symptoms but also various aspects of cancer patients' concerns. 'Constipation' might not have been a symptom related to the kind of cancer and cancer treatment found in this study population. However, pain and constipation are very common and important symptoms for all cancer patients so we included these two items as individual subscales in the other analysis in this study. Factors 1-4 showed good internal consistency ( $\alpha > 0.70$ ), and Factor 5 showed moderate internal consistency ( $\alpha = 0.67$ ).

PREVALENCE OF PERCEIVED CONCERNS

Table 3 shows the prevalence of each subscale and item. The subscale related to concerns about 'self-management' was the most common (61.2%), followed by 'psychological symptoms' (48.5%), 'medical information' (46.2%), 'daily living' (29.9%), 'pain' (17.6%), 'constipation' (15.6%) and 'physical symptoms' (15.2%). Among the items, 'Want to know what I can do for curing the disease by myself' was the most common, followed by 'Want to know what I can do in poor health', and 'Want to know what I can do to take care of myself'. The prevalence of these items was over 40% and all of them belonged to the 'self-management' subscale. Half of the subjects had 'psychological concerns' and one-third of subjects suffered from 'insomnia' and 'being tired and/or feeling sluggish'. About half of the subjects also had some difficulties with 'medical information' and wanted to know about other treatments and hospitals. However, the prevalence of items about communication with medical staff, such as being 'unable to communicate well with doctor', was <20%. About one-third of subjects had some concerns about 'daily living'. Comparatively, more subjects had economic concerns such as 'concerns about medical costs' and an 'inability to work'. The prevalence of the subscale related to concerns about 'physical symptoms' was <20% as was those for 'pain' and 'constipation'.

Table 2. Factor pattern for the questionnaire items and reliability data

Item number in the questionnaire and item	Factor loadings <sup>a</sup>
Factor 1 Daily living (six items); Cronbach's $\alpha = 0.84$	
C5 Concerns about nursing care insurance	0.78
C3 Inability to take care of oneself	0.73
C2 Inability to do housework and/or to take care of family	0.72
C6 Having no means of going to hospital	0.72
C4 Concerns about medical costs	0.66
C1 Inability to do job	0.62
Factor 2 Medical information (five items); Cronbach's $\alpha = 0.85$	
D2 Unable to communicate well with doctor	0.94
D1 Unable to understand explanation about disease and/or treatment	0.92
D3 Want to know about other hospitals	0.63
D8 Want to know about fertility	0.47
D4 Want to know about other treatments	0.44
Factor 3 Psychological symptoms (five items); Cronbach's $\alpha = 0.79$	
B2 Feeling down and/or depressed	0.98
B3 Feeling agitated and/or nervous	0.72
B4 Being not insightful	0.68
B1 Insomnia	0.47
A3 Being tired and/or feel sluggish	0.37
Factor 4 Self-management (three items); Cronbach's $\alpha = 0.91$	
D6 Want to know what I can do for curing the disease by myself	0.96
D7 Want to know about what I can do in poor health	0.85
D5 Want to know what I can do to take care of myself	0.71
Factor 5 Physical symptoms (five items); Cronbach's $\alpha = 0.67$	
A2 Loss of appetite	0.66
A8 Loss of weight	0.55
A5 Nausea and/or vomiting	0.50
A7 Dyspnea	0.50
A6 Diarrhea	0.47
Factor 6 Pain (one item) <sup>b</sup>	
A1 Painful	
Factor 7 Constipation (one item) <sup>b</sup>	
A4 Constipated	

Loading after Promax rotation (n = 807).

<sup>a</sup>Factor loadings for the items where a cross-loading of >0.30 were demonstrated.

<sup>b</sup>[Pain] and [constipation] belonged to neither factor in the first factor analysis.

ASSOCIATION BETWEEN PERCEIVED CONCERNS AND QOL

The seven subscales are considered to be independent of each other as multicollinearity was ruled out because tolerances were sufficiently large (0.77-0.93) and variance inflation

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Table 3. The prevalence of concerns of the study participants (n = 807)

Concerns <sup>a</sup>	No. of participants	%
<b>Physical symptoms</b>		
Having one or more concerns in the following items	123	15.2
1 Loss of weight	51	6.3
2 Loss of appetite	49	6.1
3 Dyspnea	43	5.4
4 Diarrhea	35	4.4
5 Nausea and/or vomiting	21	2.6
<b>Psychological symptoms</b>		
Having one or more concerns in the following items	391	48.5
1 Insomnia	257	31.9
2 Being tired and/or feeling sluggish	226	28.1
3 Being not insightful	146	18.1
4 Feeling down and/or depressed	123	15.2
5 Feeling agitated and/or nervous	71	8.8
<b>Daily living</b>		
Having one or more concerns in the following items	241	29.9
1 Concerns about medical costs	179	22.2
2 Inability to work	133	16.5
3 Inability to do housework and/or to take care of family	69	8.5
4 Concerns about nursing care insurance	66	8.2
5 Inability to take care of oneself	58	7.1
6 Having no means of going to hospital	37	4.6
<b>Self-management</b>		
Having one or more concerns in the following items	494	61.2
1 Want to know what I can do for curing the disease by myself	423	52.4
2 Want to know what I can do in poor health	414	51.3
3 Want to know what I can do to take care of myself	334	41.4
<b>Medical information</b>		
Having one or more concerns in the following items	373	46.2
1 Wanting to know about other treatments	289	35.8
2 Wanting to know about other hospitals	235	29.1
3 Unable to understand explanation about disease and/or treatment	149	18.4
4 Unable to communicate well with doctor	140	17.3
5 Wanting to know about fertility	66	8.2
<b>Pain</b>		
1 Painful	142	17.6
<b>Constipation</b>		
1 Constipated	126	15.6

<sup>a</sup>Rated three or more on the four-point Likert scale on each questionnaire item.

factors were sufficiently small (1.07–1.30). Except for the subscale related to concerns about 'medical information', each subscale contributed to QOL with meaningful variables

Table 4. Concerns associated with the participant's quality of life (QOL)<sup>a</sup> in the multiple regression analysis<sup>b</sup>

Participant's concerns <sup>c</sup>	Coefficient (β)	Standardized coefficient (β)	t	P	Partial R <sup>2</sup> (rank)
Physical symptoms	-11.07	-0.18	-5.46	0.00	0.06 (2)
Psychological symptoms	-10.69	-0.24	-7.25	0.00	0.09 (1)
Daily living	-6.84	-0.14	-4.14	0.00	0.05 (4)
Self-management	-3.72	-0.08	-2.39	0.02	0.03 (5)
Medical information	-2.03	-0.05	-1.35	0.18	0.02 (7)
Pain	-10.77	-0.18	-5.87	0.00	0.06 (2)
Constipation	-5.07	-0.08	-2.67	0.01	0.03 (5)
					Total R <sup>2</sup> = 0.34

<sup>a</sup>Global QOL score of the EORTC QLQ-C30.

<sup>b</sup>Adjusted for age, sex, marital status (two groups), educational level (two groups), occupation (two groups), time since diagnosis (three groups) and presence of recurrence/metastasis.

<sup>c</sup>Independent variables are presence of concerns; having one or more items rated three or more on the four-point Likert scale of each subscale.

( $P < 0.05$ ), and explained 33.8% of patients' QOL ( $R^2 = 0.34$ ). The subscale related to concerns about 'psychological symptoms' most contributed to QOL ( $\beta = -0.24$ ), followed by 'physical symptoms' ( $\beta = -0.18$ ), 'pain' ( $\beta = -0.18$ ), 'daily living' ( $\beta = -0.14$ ), 'self-management' ( $\beta = -0.08$ ) and 'constipation' ( $\beta = -0.08$ ) after adjusting for age, sex, marital status, occupation, educational level, time since diagnosis and presence of recurrence/metastasis (Table 4).

## DISCUSSION

We began this study by developing a questionnaire to comprehensively assess cancer patients' concerns. The findings support the validity and reliability of the CCAT developed and revealed that patients' concerns are multidimensional (e.g. physical, psychological and social).

In regard to examining the prevalence of concerns as a next step, we found that cancer patients can experience a wide range of perceived concerns. In particular, more than half of our ambulatory cancer patients were concerned about 'self-management'. Indeed, cancer treatment has expanded to include the home setting because of longer survival, the increased number of ambulatory patients treated with chemotherapy and shortened hospital stays. Because cancer patients are primarily responsible for managing their treatment, 'self-management' has become an important factor in cancer self-care. Thus, self-management skills and information on beneficial exercise (19,20) and appropriate nutrition and meal planning should be provided to help patients manage their cancer. The second most prevalent concern was

'psychological symptoms'. About half of the subjects had psychological concerns, and 30% suffered from 'insomnia'. Because insomnia is a common problem in cancer patients (1,21), medical personnel should routinely ask them whether they are suffering from insomnia. Providing information on sleep hygiene (22) is especially recommended as part of a routine care for patients with insomnia. In addition to medication, psychotherapy including cognitive behavioral therapy (23,24) and relaxation therapy (22,25) could offer alternative support if these services are available. Many subjects also had concerns about medical and socio-economic information. Information demand is not limited to the early stages of disease but continues throughout cancer treatment (26,27). Therefore, this information should be easy for patients to obtain and easy to understand. More medical personnel having sufficient knowledge and good communication skills are needed to settle the concern about information. We found a relatively low prevalence of concern about 'physical symptoms', including 'pain' and 'constipation', which might reflect the large majority of participants who were at relatively earlier stage of cancer. It might also reflect concern about 'current' physical symptoms, not about possible 'future' symptoms. Based on our findings, we conclude that there is a need to improve support for cancer patients' self-management, psychiatric concerns and access to information on medical care and daily living.

In relation to our third objective of identifying which concerns contribute to patients' QOL, our findings indicate that all concerns except those related to 'medical information' significantly contributed to QOL. These results suggest that addressing patients' multidimensional concerns can help them effectively improve their QOL. On the other hand, considering the multidimensionality of patients' concerns, intervention would ideally involve multidisciplinary team support for each patient. Multidisciplinary care teams have recently been operating in various contexts of cancer care, including nutrition support teams, rehabilitation and palliative care (28,29). With the aim of improving the quality of cancer treatment that includes QOL, the multidisciplinary care team could consist of, for example, an oncologist, palliative care specialist, psycho-oncologist, expert nurse, pharmacist, dietician and medical social worker. Because patients' concerns and sense of values have become more diverse with the advancement and diversification of cancer treatment, patients' problems should be screened comprehensively and efficiently, with subjects prioritized, and the right persons placed in the right positions to support them. The Cochrane Database Systematic Review revealed that each psychosocial intervention had only a small effect on QOL of cancer patients, and therefore suggested the need to select the most effective interventions and assign the most appropriate support staff (30).

This study has several limitations. First, patients were recruited over the internet. It was based on relatively little data from patients diagnosed with common cancers (e.g. stomach, colon, lung and liver) and those in the early stages of cancer treatment. The CCAT was only conducted at the website,

namely not face to face. Therefore, our results included the availability of CCAT might not be applicable to patients with all types and all stages of cancer treatment in actual critical scenes. However, data were obtained from patients across the country, minimizing institutional bias. Second, the investigation was cross-sectional in design, which precludes any conclusions about causality between concerns and QOL. Third, the contribution rate of the factor analysis was not extremely high. Thus, other factors might be associated with cancer patients' improved QOL. Future studies are warranted to extend our findings to other cancer sites and cancer treatment stages in actual critical scenes. Also, concrete intervention plans must be prepared when we use this tool and longitudinal study is needed to investigate whether intervention based on the results of cross-sectional studies will affect patients' QOL. Because CCAT is only Japanese version, English version will require future research in order to confirm its utility.

In conclusion, through comprehensive assessment, we have demonstrated the prevalence of cancer patients' concerns. The questionnaire developed in this study can serve as a screening tool to identify cancer patients' concerns. Concerns about psychological symptoms, physical symptoms, daily living, self-management and medical information contributed to patients' QOL directly or indirectly. Intervention by multidisciplinary care teams would be ideal, and experts on these teams should work closely together to support cancer patients.

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## Conflict of interest statement

None declared.

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## Prevalence, associated factors and source of support concerning supportive care needs among Japanese cancer survivors

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### Abstract

**Background:** The current study aimed to describe cancer survivors' supportive care needs in Japan, to identify associated factors of unmet needs, and to describe the source of support that are preferred and actually used by cancer survivors.

**Methods:** Using a web-based questionnaire, we examined unmet supportive needs and its associated factors among 628 adult Japanese cancer survivors. The questionnaire comprised 16 items representing five domains (medical-psychological, financial, social-spiritual, sexual, and physical needs).

**Results:** Prevalence of unmet need ranged from 5 to 18%, depending on different domains. The prevalence was high in medical-psychological and financial domains and relatively low in physical and sexual domains. Poor performance status, psychiatric morbidity and low income status were associated with unmet needs of most domains. Most cancer survivors preferred and actually sought support from their family and friends. Financial needs were preferred to be provided by non-medical professionals. Call for peer support was intense, especially for medical-psychological, social-spiritual, and sexual needs; however, peer support was not well-provided.

**Conclusions:** This study illustrated characteristics of Japanese cancer survivors who are likely to have unmet needs. The study demonstrated need for expanded involvement of non-medical professionals and peer support, especially in the domains of medical-psychological, social-spiritual, financial and sexual needs.

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### Background

The number of cancer survivors has been increasing because of rising incidence of cancer and advances in cancer treatment [1]. This emphasizes the importance of recognizing concerns among cancer survivors.

Supportive care need is defined as 'requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being' [2]. Needs are considered unmet if required actions/resources have not been provided. Up to 30 to 50% of cancer survivors have unmet supportive needs [3–7], leading to poor quality of life and psychological distress [8]. Therefore, knowledge about their supportive needs and possible source of support is critical for better patient care and policy making.

The understudied topics in this area include the following [2–11]: First, past studies mostly addressed only specific populations in terms of time from cancer

diagnosis – either addressing survivors within 1 year from diagnosis [3,4,7] or long-term survivors [6]. Few studies have examined supportive care needs across the 'stages' of cancer survivorship (active treatment, re-entry, and long-term survivorship [12]). Second, findings have been scarce regarding the sources of support that cancer survivors use to meet their needs. Third, while supportive care services must be considered in cultural and health service contexts [13], only a few surveys have been done in Japan, limited to patients with breast and colorectal cancer, or inpatient settings [8,11,14]. In Japan, the National Basic Plan to Promote Cancer Control Programs [15] came to effect in 2007, aiming to establish basic structure of cancer treatment in the country. The plan, revised in 2012, explicitly describes quality of life of cancer survivors as an important agenda.

Therefore, the current study aimed (1) to describe cancer survivors' unmet supportive care needs in

Japan, (2) to identify its associated factors, and (3) to describe the source of support that cancer survivors prefer and actually use.

### Methods

#### Participants and procedure

This study was conducted as a part of a larger study [16,17] that aimed to measure quality of life of short-term and long-term cancer survivors in the community. Participants were eligible if they were diagnosed with cancer within 10 years. The participants were recruited through a nationwide commercial-based website-monitoring system (INTAGE research monitor, Inc., <http://intage.co.jp>). This is a registry used for multiple purposes, ranging from scientific research to commercial marketing. The registrants were recruited through social media and self-selectively registered. The registrants are reimbursed if they participate in surveys. Approximately 1,300,000 people were registered, among whom 2059 people were registered as having been diagnosed with cancer within 10 years.

We aimed to recruit 600 cancer survivors using a stratified sampling method by gender (male:female = 1:1) and time since cancer diagnosis (200 survivors each from the following three categories: within 2 years from cancer diagnosis, 2 to 5 years, and 5 to 10 years). We used a cutoff of 2 years in the assumption that patients with certain types of cancers can take more than 1 year until they complete treatment. A cutoff of 5 years is a widely used definition of long-term cancer survivors [18]. The sample size was set because majority of past studies enrolled up to 200 participants [5]. We randomly selected and invited 900 potential participants, with estimation of 60% response rate (based on the previous statistics of the database). The survey was conducted over a week in December 2012 after approval by the institutional review board of Tohoku University.

### Measures

#### Supportive care need

Prior to this study, we reviewed existing supportive care need questionnaires and identified two well-used questionnaires as candidates – the Supportive Care Needs Survey Questionnaire [19,20] and the Cancer Survivors' Unmet Needs measure [21]. However, the former scale lacks important domains for long-term survivors (e.g. employment issues, financial burden, fertility). The latter scale is highly inclined to psycho-social and existential issues and included domains that are not relevant to most Japanese cancer survivors (e.g. parking issue). Furthermore, it has not been validated in Japan. Therefore, we decided to develop an original scale.

We developed a questionnaire based on the items of the Quality of Life Cancer Survivors Instrument (QOL-CS) [22], which was used as an outcome measure in a part of this survey. The QOL-CS comprises 41 items representing four domains (physical, social, psychological, and spiritual well-being) of cancer-specific quality of life. Because the QOL-CS contains multiple items that cover similar concepts and for the purpose of reducing burden of respondents, the research team elaborately rephrased and merged these 41 items into 16 items. We merged six items of physical symptoms (fatigue, appetite, pain, constipation, nausea and overall physical health) into a single item 'physical problems, such as fatigue, appetite, pain, constipation, nausea'. We replaced ten items on psychological well-being (e.g. coping, quality of life, anxiety and depression) by a single item 'psychological issues provoked by cancer'. We merged three items assessing level of distress during each stage of treatment (initial diagnosis, cancer treatments, and time after treatment completion) into one item 'level of distress through cancer diagnosis and treatments'. We merged four items assessing level of fear toward diagnostic tests, cancer recurrence, metastasis and secondary cancer, into a single item of 'your level of fear on diagnostic tests and cancer progression or recurrence'.

We replaced seven items assessing spiritual well-being by two items of 'interpersonal and social issues' and 'religious and spiritual issues'. This item was rephrased as such because concept of spirituality was considered unfamiliar to most Japanese survivors, and meaning of life is generally described in societal and interpersonal perspectives [23]. The rest of the items were left unchanged, which included eight items on social concerns (e.g. personal relationship, sexuality, employment, and financial burden), menstrual changes or fertility, and sleep.

Responses to these questions were adopted from Zebrack's web-based need surveys [24,25]. Respondents were asked to endorse one of the following responses: (a) 'Have not used any service and have not had need in that domain', (b) 'Have already used a service and have no further need', (c) 'Have not used any service so far but would like to use in the future', and (d) 'Have used service(s) and would like to use more'. Participants who answered (a) were categorized as having no need. Participants who answered (b) or (d) were categorized as participants with 'service used'. Participants who answered (c) were categorized as having 'unmet need'.

We conducted an exploratory factor analysis in the current sample to see the structure of the questionnaire using the principal component analysis with promax rotation. Based on the scree plot, we considered five-component structure as appropriate. Those five factors were named medical-psychological needs (four items, Cronbach's alpha coefficient = 0.88), financial needs (three items, 0.78), social-spiritual needs (five items, 0.83), sexual needs (two items, 0.80), and physical needs (two items, 0.62). The

correlation coefficients between each factor were weak to moderate ( $r=0.40-0.79$ ). (Supplementary table)

#### Source of support – preference and actual use

We asked the participants who had used any service before the survey (i.e. those who answered either (b) or (d)) about the source of support they had used. We asked those who had any needs at the time of survey (i.e. those who answered either (c) or (d)) about the kind of support they would like to use further. The participants were allowed to choose as many answers as they liked from among (1) medical professionals, (2) non-medical professionals, (3) peer support, and (4) family or friends.

#### Psychological distress

Psychological distress was measured using the K6 scale [26], a self-rated six-item questionnaire exploring the frequency of psychological distress during the past 30 days. The K6 scores range from 0 to 24. Those who scored 15 or more were classified as having psychiatric morbidity [27].

#### Perceived social support

Participants' perceived social support was assessed with the short-version Multidimensional Scale of Perceived Social Support [28]; a well-validated seven-item questionnaire with seven-point scales. The participants were divided into two groups according to the median score.

#### Demographic and medical characteristics

We asked the participants of their demographic and clinical information, as listed in Table 1.

#### Statistical analysis

First, we conducted descriptive analyses to characterize the overall study sample, summarizing the proportions of patients indicating no need, service used and unmet need in each of the 16 need areas. Ratios of service used:unmet need were calculated for each need to describe proportion of participants who received appropriate services. Also, we compared prevalence of unmet needs according to time since last treatment, using chi-squared test and Fisher's exact test where appropriate. Second, we conducted binary logistic regression analyses to explore associated factors of unmet needs. Demographic and clinical variables, psychiatric morbidity and social support, were entered as independent variables. A backward stepwise selection method was used to reduce non-significant variables from the models, with a  $p$ -value of  $<0.1$  on the Wald statistics. Participants with missing values were excluded from this analysis. Further, we conducted descriptive analyses on source of support which the participants (1) preferred

**Table 1.** Demographic background ( $n = 628$ )

Characteristics	n	%
Age		
<50	190	30.3
50–64	267	42.5
≥65	171	27.2
Gender		
Male	314	50
Female	314	50
Marital status		
Married	502	79.9
Single or divorced/ widowed	126	20.1
Having child(ren)		
Yes	464	73.9
No	164	26.1
Age of youngest child ( $n = 464$ )		
<College graduation	164	35.3
≥College graduation	300	64.7
Household size		
Living alone	70	11.1
Two or more	558	88.9
Occupational status		
Employed	277	44.1
Unemployed	351	55.9
Annual income		
<4m yen	214	34.1
≥4m yen	368	58.6
Unknown	46	7.3
Change in income status ( $n = 464$ )		
No change	397	63.2
Decreased	216	34.4
Increased	15	2.4
Cancer site		
Lung	23	3.7
Gastrointestinal	163	26.0
Breast	165	26.3
Urological	126	20.0
Gynecological	44	7.0
Other	107	17.0
Years since diagnosis		
<2 years	211	33.6
2–5 years	208	33.1
5–9 years	209	33.3
Performance status		
0	413	65.8
1	200	31.8
2	13	2.1
3	2	0.3
Received treatment (absolute number)		
Surgery	530	84.4
Radiation therapy	194	30.9
Chemotherapy	248	39.5
Hormonal therapy	201	32
Treatment combination		
Surgery (=Sur) only	187	30
Radiation therapy (=Rt) only	8	1
Chemotherapy (=Cx) only	12	2
Hormonal therapy (=Hor) only	11	2
Sur + Rt + Cx + Hor	52	8
Sur + Rt + Cx	39	6
Sur + Rt + Hor	49	8
Sur + Rt	26	4
Sur + Cx + Hor	28	4
Sur + Cx	104	17
Sur + Hor	45	7
Rt + Cx + Hor	1	0
Rt + Cx	8	1
Rt + Hor	11	2
Cx + Hor	4	1
No treatment	43	7

and (2) actually used. Data were analyzed with the SPSS version 21.0 (IBM). All the tests were two-tailed, with  $p$ -value of  $<0.05$ .

## Results

### Participants' characteristics

Of 900 candidate participants, 628 responded and completed the questionnaire (response rate: 69.7%). Data of 46 survivors with missing values were excluded from the logistic analysis. The participants' mean age was 56 years. Most participants were in good performance status. Type of cancer was skewed toward breast and prostate cancers, and proportion of lung and gastric cancers were smaller than Japanese general population sample [29] (Table 1).

### Prevalence of no need, service used, and unmet need

Approximately 5 to 18% of the participants had unmet need in any of the 16 areas of needs (Table 2). The prevalence was generally high in medical-psychological and financial domains and low in physical and sexual domains. Ninety-five participants (15.1%) endorsed one domain of unmet needs, and 162 participants (25.7%) endorsed two or more domains (data not shown). The ratio of service used:unmet need shows that services were relatively well used for medical-psychological needs, social-spiritual needs, and physical needs and relatively less for sexual needs (Table 2). The prevalence of unmet needs was constant after treatments (Table 3).

**Table 2.** Prevalence of no need, service used and unmet need

	No need		Service used		Unmet need		Service used: Unmet need
	n	%	n	%	n	%	
Factor 1: medical-psychological needs							
Concerns about illness or treatment	373	59.4	174	27.7	81	12.9	2.1:1
Psychological problems	386	61.5	166	26.4	76	12.1	2.2:1
Fear of recurrence	306	48.7	213	33.9	109	17.4	2:1
Concerns about family	344	54.8	209	33.3	75	11.9	2.8:1
Factor 2: financial needs							
Financial burden	338	53.8	178	28.3	112	17.8	1.6:1
Interference in employment	401	63.9	136	21.7	91	14.5	1.5:1
Interference in home activities	388	61.8	185	29.5	55	8.8	3.4:1
Factor 3: social-spiritual needs							
Personal relationship problems	408	65.0	178	28.3	42	6.7	4.2:1
Religious and spiritual problems	530	84.4	69	11.0	29	4.6	2.4:1
Support from other people	268	42.7	318	50.6	42	6.7	7.6:1
Social problems	420	66.9	123	19.6	85	13.5	1.4:1
Isolated feeling	411	65.4	154	24.5	63	10.0	2.4:1
Factor 4: sexual needs							
Menstrual changes and fertility	508	80.9	64	10.2	56	8.9	1.1:1
Sexuality	481	76.6	84	13.4	63	10.0	1.3:1
Factor 5: physical needs							
Sleep problems	460	73.2	117	18.6	51	8.1	2.3:1
Physical problems	440	70.1	144	22.9	44	7.0	3.3:1

Table 3. Prevalence of unmet needs according to time since latest treatments

Time since last administration of each type of treatment	None	<3 months	3 months–1 year	1–5 years	5–10 years
	n (%)	n (%)	n (%)	n (%)	n (%)
<b>Factor 1: medical-psychological needs</b>					
Surgery	22 (22.4)	9 (16.4)	27 (28.7)	58 (22.8)	26 (20.5)
Chemotherapy	88 (23.2)	17 (28.3)	8 (21.1)	22 (21.8)	7 (14.3)
Hormonal therapy	91 (21.3)	25 (24.5)	5 (26.3)	14 (26.4)	7 (25.9)
Radiation therapy	98 (22.6)	9 (33.3)	6 (24)	21 (21)	8 (19)
<b>Factor 2: financial needs</b>					
Surgery	20 (20.4)	16 (29.1)	24 (25.5)	71 (28)	27 (21.3)
Chemotherapy*	85 (22.4)	21 (35)	15 (39.5)	29 (28.7)	8 (16.3)
Hormonal therapy	101 (23.7)	30 (29.4)	4 (21.1)	18 (34)	5 (18.5)
Radiation therapy	102 (23.5)	11 (40.7)	7 (28)	30 (30)	8 (19)
<b>Factor 3: social-spiritual needs</b>					
Surgery	19 (19.4)	10 (18.2)	17 (18.1)	59 (23.2)	25 (19.7)
Chemotherapy	74 (19.5)	15 (25)	9 (23.7)	21 (20.8)	11 (22.4)
Hormonal therapy	88 (20.6)	22 (21.6)	4 (21.1)	13 (24.5)	3 (11.1)
Radiation therapy	85 (19.6)	8 (29.6)	7 (28)	21 (21)	9 (21.4)
<b>Factor 4: sexual needs</b>					
Surgery	7 (7.1)	5 (9.1)	11 (11.7)	35 (13.8)	20 (15.7)
Chemotherapy	42 (11.1)	7 (11.7)	6 (15.8)	15 (14.9)	8 (16.3)
Hormonal therapy	46 (10.8)	12 (11.8)	4 (21.1)	11 (20.8)	5 (18.5)
Radiation therapy	51 (11.8)	5 (18.5)	3 (12)	11 (11)	8 (19)
<b>Factor 5: physical needs</b>					
Surgery	9 (9.2)	6 (10.9)	9 (9.6)	38 (15)	16 (12.6)
Chemotherapy	44 (11.6)	10 (16.7)	1 (2.6)	17 (16.8)	6 (12.2)
Hormonal therapy	53 (12.4)	15 (14.7)	1 (5.3)	7 (13.2)	2 (7.4)
Radiation therapy	52 (12)	5 (18.5)	4 (16)	12 (12)	5 (11.9)

\*p < .05; chi-squared test and Fisher's exact test.

especially for medical-psychological, social-spiritual, and sexual needs; however, peer support was generally not well-provided.

Discussion

This survey demonstrated prevalence of unmet supportive care needs among Japanese cancer survivors as 4.6 to 17.8%, depending on different domains. These figures are lower than those of survivors who are under treatment [3–5,7] and are comparable with those of long-term cancer survivors [6]. The prevalence was high in psychological domain and low in sexual domain. Prevalence of unmet needs was generally not different either according to time since cancer diagnosis or since last administration of treatments. Cancer survivors should be examined for their unmet needs long after cancer diagnosis and completion of treatment.

Medical professionals and family/friends are the two major sources of support. In contrast, gaps between preference and actual use of peer support and support by non-medical professionals were remarkable. Call for support by non-medical professionals is remarkable for financial needs. In Japan, approximately 30% of patients with

cancer quit their job after cancer diagnosis, and the large proportion of the rest was obliged to change their work status from full-time to part-time employment [30,31]. As conceptualized in the reviews by Feuerstein et al. [32] and Mehnert [33], cancer survivors need multifactorial support for employment by multiple disciplines [30,31,34].

Need for peer support has long been questioned in Japan because Japanese people have been considered as less likely to share their illness experience with others [35]. Only 20% of all designated cancer centers in Japan are equipped with peer support programs as of 2013, despite the recommendation in Japanese Basic Plan to Promote Cancer Control Programs [15,36,37]. Our results argue for further promotion of peer support programs. Peer support is expected to supplement professional psychological services, where patients with cancer are often reluctant to consult [38].

Cancer survivors with unmet sexual needs are frequently not provided with any service. Sex-related issues are infrequently discussed in clinical practice in Japan [39], and increasing clinicians' awareness and clinical skills are imperative. Considering that cancer survivors perceive family and friends as an important source of

Table 4. Associated factors of unmet needs (n = 582)

	Factor 1: medical-psychological needs		Factor 2: financial needs		Factor 3: social-spiritual needs		Factor 4: sexual needs		Factor 5: physical needs	
	OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI	OR	95%CI
Age (reference: ≥65)										
<50	—	—	—	—	—	—	2.49*	1.03–6.00	—	—
Age of youngest child (reference: ≥college graduation)										
<College	—	—	—	—	2.12**	1.22–3.70	—	—	—	—
Employment status: employed (reference: unemployed)	1.90**	1.23–2.94	—	—	—	—	—	—	—	—
Annual income: <4m yen (reference: ≥4m yen)	1.99**	1.27–3.13	2.26***	1.51–3.38	1.93**	1.20–3.12	—	—	—	—
Cancer site (reference: others)										
Urological	—	—	—	—	—	—	4.67**	1.71–12.79	—	—
Time since latest surgery (reference: no surgery)										
5–10 years	—	—	—	—	—	—	3.46*	1.30–9.25	—	—
Performance status (PS): ≥1 (reference: PS = 0)	2.02**	1.31–3.13	2.25***	1.48–3.42	2.85***	1.80–4.50	—	—	4.24***	2.43–7.35
Psychiatric morbidity (K6 ≥ 15)	3.55***	2.29–5.46	1.72*	1.12–2.64	4.65***	2.95–7.35	2.59**	1.49–4.52	2.72***	1.59–4.65
Cox-Snell R2	0.114		0.108		0.160		0.068		0.087	
Nagelkerke R2	0.176		0.160		0.254		0.130		0.166	

Only significant variables were demonstrated.

OR, odds ratio.

\*p < .05

\*\*p < .01

\*\*\*p < .001

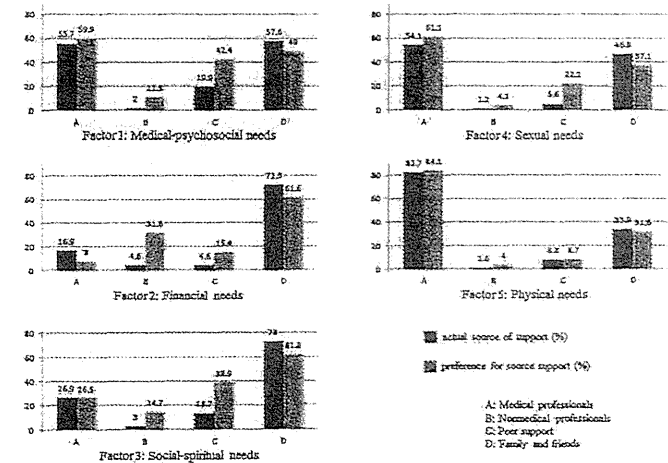


Figure 1. Preference and actual use of support

support, proactive education to family can be helpful. Topics including treatment-induced sexual challenges and intercouple communication should be covered in family education [40] and probably in peer support as well.

The strength of our study is relatively large sample size with well-balanced distribution of participants in regards to time since their cancer diagnoses. Use of web-based survey is also advantageous because this

enabled to access cancer survivors who do not come to clinics on regular basis.

The most important study limitation is representativeness of the sample. The participants were limited to those who have internet literacy and those who were self-selectively registered to a database. Distribution in age and type of cancers is slightly different from that of general cancer population in Japan. The participants were limited to those in good performance status; therefore, we may have underestimated unmet needs. No difference was made between survivors during and past primary treatment. The second limitation is that our need assessment instrument has not been validated. The items of interest were selected somewhat arbitrarily, although they were derived from a validated quality-of-life instrument and have been selected on agreement of multidisciplinary study team. The questionnaire lacked items on information needs, which have been listed as an important domain of needs in other need instruments. Majority of participants endorsed multiple domains of unmet needs, suggesting need for investigating the impact of different need combinations. Finally, the cross-sectional design provides no information on causal relationship. In particular, variables of time since cancer diagnosis/last treatment should be examined further in longitudinal studies.

## Conclusions

Despite its limitations, our study is noteworthy because this is the first study in Japan that assessed unmet needs of cancer survivors along with preference and usage of service. The study depicted survivors at risk for unmet needs in different domains. The study also highlighted need for continued and expanded involvement of non-medical professionals and peer support in the care of cancer survivors, especially in the domains of medical-psychological, social-spiritual, financial and sexual needs.

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## Conflict of interest

The authors have declared no conflicts of interest.

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## Supporting information

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## ディーズマネジメント

## ① がん緩和：がんとうつ病の関係

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「がん対策基本法」が2007年に施行され、2012年にはがん対策のマスタープランである「がん対策推進基本計画」が改定され、実地の声を反映させるべく各都道府県での医療計画も作成された。今回の基本計画の改定では、がん患者・家族の強い意向を反映して、「早期からの緩和ケア」が「診断時からの緩和ケア」とより明確に示された点と、「精神心理的苦痛の軽減」がより明確に掲げられた。患者・家族の精神的苦痛を軽減するために、うつ病への対策をはじめ、精神心理的ケアの充実が求められている。本稿では、がん領域のうつ病への対策の現状を紹介したい。

## がん患者と心理・社会的問題

がん患者とその家族は様々な精神的、心理・社会的問題を抱えている。実際にはがん患者の20～40%に重度の心理・社会的問題が認められ、その問題に対して適切な援助が提供されている患者は10%にも満たない<sup>1)</sup>。適切な提供がなされていない背景には、「精神的」や「心理的」、「感情の問題」といった言葉にスティグマ、負のイメージがついてまわり、患者が医療者に対して相談を躊躇すること、多忙な診察のなかで医師が患者に心理・社会的問題について尋ねる余裕のないことが指摘されている<sup>2)</sup>。その反省を受け、がんの

臨床をとらえなおし、患者を全人的にとらえるためにbiological (生物学的)、psychological (心理学的)、social (社会的)と多層的な視点からアプローチを試みる分野が精神腫瘍学(サイコオンコロジー；psycho-oncology)である。

これらの臨床・研究の成果を踏まえ、がんに関連する心理・社会的問題への障壁を取り払い、等しくケアが提供されることを目標として、米国のNCCN (National Comprehensive Cancer Network) は心理・社会的問題を「Distress (つらさ)」として包括し、評価と治療のガイドラインを作成・公開している<sup>3)</sup>。

## うつ状態・うつ病

がん治療全般をとおして、様々な精神症状が出現する。がん患者のおよそ30～40%に何らかの精神医学的問題が認められる。特に頻度の高い疾患は、せん妄と大うつ病、適応障害である<sup>3)</sup>。抑うつ状態はがんの原発部位にかかわらず、あらゆる時期に出現する。わが国の有病率調査では、大うつ病は約5%で、適応障害が15～25%であった。がん医療において、うつ病の診断・治療の重要性が繰り返し指摘される背景には、いくつかの原因があげられる。

## 総集 メンタルケアを取り入れたディーズマネジメント

## ■ 抑うつ状態は一般的であるにもかかわらず、しばしば見落とされる

がん患者においても、うつ病の主たる身体症状は不眠、食欲不振、全身倦怠感である。これらの症状はがん自体で生じる症状や、がん治療の有害事象と重なるため、患者自身も医療者も抑うつ状態に伴う身体症状と考えず、見落とされることが知られている<sup>4)</sup>。

また、抑うつ状態は喪失体験による心理的反応に伴い出現することも多い。そのため、「喪失体験があるならば、抑うつ状態に陥っても当然である」といった医療者側の誤解も生じやすい。加えて、医療者の知識不足による抑うつ症状の過小評価、医療者が精神症状を評価することをためらうことにより、抑うつ状態が見落とされ、誤った対応をされがちであることも知られている<sup>5)</sup>。

## ■ QOLの低下を招く

抑うつ症状自体がQOLの低下を招くと同時に、無価値感や自責感により積極的ながん治療を拒否することをとおして、身体治療の成績にも影響する<sup>6)</sup>。また、患者が抑うつ状態であること自体が家族の精神的苦痛を悪化させる。

## ■ 器質的な原因が重畳する

がん患者の抑うつ状態の背景を評価する際に、ストレス因子など心理的要因との関連に注意が向きがちだが、同時に原疾患による脳転移や腫瘍随伴症候群、高カルシウム血症、歴史的な要因の強い薬剤性(ステロイドや抗悪性腫瘍薬、降圧薬)、全脳照射も抑うつ状態を引き起こす。抑うつ状態を評価するときには、治療内容の変化との時間関係や治療効果、今後の治療計画を総合的に評価することが重要である。

## ■ 疼痛との関連

疼痛が適切に緩和されていないと、抑うつ状態を生じることが示されている。疼痛が緩和されないために、「生きる価値がない、生きていてもしかたがない」と感じ、希死念慮を生じることがある。疼痛の軽減を図ることで抑うつも軽減することができるため、うつ病を疑う場合には身体症状の評価も同時に行う必要がある。

## ■ 自殺

がん患者の自殺率は一般人口に比べて高く、特に告知後1週間以内では1.2倍、1年以内でも3倍に及ぶ<sup>7)</sup>。がん患者が自殺企図や希死念慮を訴える背景には、抑うつ状態の合併や疼痛の合併、進行がん、診断から早期(3～6か月以内)、貧弱なソーシャルサポートがあることが指摘されている。特に絶望感は抑うつ状態とは独立した要因である。自殺を予防するために、たとえば進行がんの初回治療時から精神症状緩和をはじめ、身体症状緩和、ソーシャルサポートの構築など、身体症状・精神症状・社会的問題に対する包括的な支援が必要である。

## ■ 高齢がん患者の抑うつ状態

加齢は発がんのリスクであると同時に、うつ病や自殺のリスク因子でもある。高齢者の抑うつ状態は、若年者と異なり抑うつ気分を自覚・訴えることは少ない。代わりに興味の喪失や認知機能の低下(記憶力の低下、集中困難)、身体不定愁訴を訴えることが多い。

## スクリーニング

臨床的な問題として、主治医や看護師など多様なプライマリーチームは抑うつ状態を見落としが

ちであることから、NCCNガイドラインではがん患者全員に対して精神症状のスクリーニングを実施することを推奨している。しかし、陽性的中率の低いスクリーニングは負担が大きく、費用対効果の面でも課題は多い<sup>2)</sup>。

がん患者は身体的にも重篤であることが多く、患者の負担に配慮した簡便なスクリーニングが望まれる。患者の負担を軽減するために、VAS (Visual Analog Scale) やツークエスチョンインタビュー (two question interview) 、つらさと支障の寒暖計、PHQ-2、PHQ-9 (本誌p.64、資料参照) などが用いられ、どのツールでもほぼ同程度の性能である。

### うつ病への対応

うつ病への治療は、薬物療法と支持的精神療法、認知行動療法、環境調整を組み合わせて行うことが推奨されている。医療スタッフからの継続的な支援が、がん患者の適応に影響することも示されており、チームとして患者を支える体制を構築することも重要である<sup>9)</sup>。

薬物療法に関しては、無作為化比較試験の結果から抗うつ薬による改善効果が報告されている。抗うつ薬はどの種類でもほぼ同程度の治療効果が得られると考えられているが、実際の薬剤選択にあたっては身体症状を評価したうえで副作用対策も踏まえた選択を行う必要がある。実際に、悪心・嘔吐を避けたい場合には食欲増進作用もあるNaSSA (ノルアドレナリン作動性/特異的セロトニン作動性抗うつ薬) や吐き気の少ないタイプのSSRI (選択的セロトニン再取り込み阻害薬)、神経傷害性疼痛を合併する場合にはSNRI (選択的セロトニン・ノルアドレナリン再取り込み阻害薬) が選ばれることが多く、三環系抗うつ薬や四

環系抗うつ薬が第一選択になることはほとんどなくなった。予後が短い場合には十分な治療が困難な場合もあるが、投与経路や予後の推定を総合的に評価し、QOLを損なわない治療計画を立てる。

あわせて身体症状への対応も重要である。特に疼痛はうつ病の身体症状の一つでもあり、疼痛とうつ病の重症度 (特に希死念慮) には相関関係がある。がん患者のうつ病を評価する場合には同時に疼痛の重症度評価を行う。

また、終末期においては、せん妄との鑑別に注意したい。特に低活動型せん妄は、活動性が落ちることから、うつ病と誤診されがちである。せん妄は注意力障害があることから、細かい精神症状評価をすることが重要である。

### 今後に向けた課題

現在のがん臨床において最も問題となっているのは、多忙な臨床現場において有効な精神症状緩和を図るためのシステムを構築することである。英国の厚生労働省にあたるNICE (National Institute for Health and Clinical Excellence) は、「緩和ケア専門職だけでは心理的な症状はしばしば同定されず、患者は心理社会的支援サービスへのアクセスが不十分である」との反省にたち、精神症状緩和を介入レベルに従って分類し、プライマリチームから専門家の介入まで4段階を設定した<sup>9)</sup>。わが国においても、がん対策推進基本計画に基づき10万人の医師を対象とした緩和ケア研修が進められている。

同時に求められるのが、専門家へのアクセスを確保する方法である。具体的には、必要な場合に専門家へ紹介するスクリーニングシステムになる。スクリーニングシステムの重要性は以前から指摘されていたが、スクリーニングが有効に機能

### 特集 メンタルケアを取り入れたディジーズマネジメント

する条件として、①全例に対する定期的なスクリーニングの実施、②紹介先の確保、の2点があり、わが国で実施するためにはマンパワーの問題のハードルがある。改定されたがん対策推進基本計画に則って、都道府県拠点病院を中心に、スクリーニングとアクセスの改善を目的に緩和ケアセンターの設置が検討されており、解決の糸口となるか注目したい。

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## 第77回 日本皮膚科学会 東京支部学術大会

テーマ：挑戦する皮膚科学

会長：照井正 (日本大学医学部 皮膚科学系皮膚科学分野)

日時：2014年2月15日 (土)、16日 (日)

会場：東京国際フォーラム ホールB

問合先：株式会社メディカル東友

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### 注目セッション

#### 皮膚科エキスパート・ナース

日常診療を円滑に行うにはコ・メディカルとの協力が必要なことはいまでもありません。では、どのように育てたらよいでしょうか? 皮膚科に特化して活躍されている看護師の方にお集まり頂き、皮膚科エキスパート・ナースの重要性や育て方などについてお話しして頂きます。是非、所属する医療機関や診療所に勤務される看護師さんを集まって頂き、ディスカッションしていただきたいと思います。参加ついでに東京観光をご一緒に計画されてはいかがでしょうか?



## 精神科医療と緩和ケア\*

認知症の緩和ケアを考える

小川朝生\*\*

### Keywords

Palliative care, Dementia, Consultation psychiatry, Supportive care

### はじめに

精神科医療、精神障害と緩和ケアについて考えるとき、みなさまはどのようなイメージを持たれるだろうか。総合病院に勤務をされている方では、精神科医が関わる緩和ケアチームで、せん妄やうつ病への対応をすることを考えられるだろうか。あるいは、精神科病院にお勤めされている方では、統合失調症の患者のがん治療や終末期医療を考えられるのかもしれない。

精神科医療と緩和ケアとの関係は、次のようにいくつかに分けて考えることができる。

- ①がん患者へ提供する緩和ケアの一領域としての精神症状緩和：せん妄の治療やうつ病への対応に加え、より広い精神心理的支援
- ②精神疾患を抱えた患者のがん治療・緩和ケア：具体的には統合失調症を持った患者ががんに罹患した場合のケア
- ③がん以外(非悪性腫瘍)の疾患の緩和ケア  
おそらく、精神科医が考える緩和ケアのイメージは大きくは①、加えて②となるのかもしれない。わが国においては、2007年に施行された「が

ん対策基本法」の影響を受けて、緩和ケアはがん医療とほぼ一体となって推進されている実態がある。たしかに、緩和ケア病棟や緩和ケアチームが対象とする疾患は、診療報酬上悪性腫瘍と後天性免疫不全症候群(acquired immune deficiency syndrome; AIDS)に限定されている。薬物療法の大規模な進歩により、HIV感染症で緩和ケアを必要とする場面は非常に限定されるに至った結果、事実上わが国では緩和ケアと言えればがん医療と同一視されるのもっともと言える。

しかし、海外をみると、緩和ケアをとりまく状況は全く異なる。たとえば、英国では2010年に開催された英国緩和ケア関連学会(8th Palliative Care Congress)において、高齢化社会の主たる課題を「認知症」とするとともに、緩和ケアの主たる対象を「認知症の緩和ケア」にすでにあてていた。2013年6月には、ヨーロッパ緩和ケア学会(European Association for Palliative Care; EAPC)が、認知症の緩和ケアに関する提言を公開し、11の領域で57の提言を掲げている(White paper defining optimal palliative care in older people with dementia)<sup>42)</sup>。高齢化社会を軒並み

\* Supportive Care for the Patients with Dementia

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迎えている先進国では、緩和ケアの主たる対象はもはやがんではなく、認知症なのである。

海外においては、緩和ケアの主たる対象は、がんから認知症に移ろうとしている。しかし、日本においては、「認知症患者は意思決定ができないから緩和ケアの対象ではない」という誤解もあり、さらに自体を複雑にしている。

このように、海外とわが国では、精神科医療と緩和ケアの関係は大きく異なる。このような差が生じた背景には、緩和ケアのアプローチに対する認識のギャップも影響しているのかもしれない。わが国においては、緩和ケアは「終末期ケア」の色彩が濃い。言いかえれば、緩和ケアは治療の施しようがなくなった時に、症状を緩和する対症療法ととらえられがちである。しかし、ヨーロッパを中心に、緩和ケアは健康政策の一環として公衆衛生的な取り組みと認識され、人の生死に当たる「苦悩からの予防」が強調されている。

上記のようなギャップを埋めるためには、緩和ケアの背景を振り返るのが有益かもしれない。本稿では、緩和ケアの展開の歴史をみつつ、主に認知症に対する緩和ケアのアプローチを紹介したい。

### 緩和ケアとは

WHO(世界保健機関)が2002年に緩和ケアの定義を定めている。その定義を紹介すると、「緩和ケアとは、生命を脅かす疾患による問題に直面している患者とその家族に対して、痛みやその他の身体的問題、心理社会的問題、スピリチュアルな問題を早期に発見し、的確なアセスメントと対処(治療・処置)を行うことによって、苦しみを予防し、和らげることで、クオリティ・オブ・ライフ(QOL:生活の質)を改善するアプローチである<sup>47)</sup>」となる。

従来、緩和ケア、緩和医療は、悪性腫瘍(がん)を対象に、施設(ホスピス、緩和ケア病棟)を中心に発展してきた<sup>48)</sup>。90年代には、緩和ケアプログラムの利用者のほとんどががん患者であった。緩和医療ががん患者を主な対象としてきた理由は、

病状が常に変化すること、特に身体症状の変化が著しいこと、心理社会的な苦痛が強いこと、死が急速に迫る経過であることが指摘されている<sup>49)</sup>。

しかし、2002年にWHOが改訂した緩和ケアの定義をみると、緩和ケアの対象は「進行性の生命を脅かす疾患」と示され、特定の疾患群を対象にしていない。ここに緩和ケアの特徴がある。一般に医学の専門分野は、臓器別あるいは疾患別に対象を絞るのに対して、緩和ケアは患者を心理社会面でもとらえ、身体的な問題のみを医療の対象とはしていない。

1990年以降、欧米では終末期医療に対する取り組みが進められ、緩和ケアの対象はがんから後天性免疫不全症候群(acquired immune deficiency syndrome; AIDS)、神経疾患(筋萎縮性側索硬化症)、救急、集中治療領域、アルツハイマー病を中心とした老年医療、心血管疾患、呼吸器疾患、腎疾患などに広がっていった。2000年を越えて、緩和ケアの対象の20~30%は非悪性疾患となっている。

現在悪性疾患以外に広く緩和ケアが提供されている代表的な地域は米圏である。米圏ではホスピスプログラム(米圏では緩和ケアは施設ではなく在宅を中心に提供されるためプログラムと称される)を利用した患者は2012年で154万人であったが、その63.1%は非悪性腫瘍が占めていた[悪性腫瘍(がん)36.9%、老衰14.2%、認知症12.8%、心疾患11.2%、呼吸器疾患8.2%]<sup>1)</sup>。

### 緩和ケアの歴史

どうして緩和ケアががんに限らず広い疾患を対象とするのか、その疑問に答えるには、緩和ケアの歴史を振り返ると分かりやすいかもしれない。

緩和ケアの歴史は、中世イングランドやヨーロッパのホスピスに始まる。当時のホスピスは、主に宗教団体が主体となり、地域文化と博愛主義に基づき、巡礼者や貧困者、高齢者などに身の回りの世話を提供する施設であり、医療を提供する施設ではなかった。つまり、ホスピスは地域文化

の上に成立する社会支援体制を元に組織され、広く救済的な意味合いを持っていた。このことが、その後のホスピス・緩和ケアのあり方にも色濃く出ている。

その後、第二次世界大戦を経て、1967年 Cicely Saunders は、医療サービスを提供する近代ホスピスを設置した (St. Christopher's Hospice)。近代ホスピスは、地域団体を主体とし (主には宗教団体)、各地に建設されていった。当初のホスピスは、静かに過ごすための場所を提供する意味合いが強く、医療体制 (英国の場合は NHS) とは別に位置した。

当初、施設としてホスピスを設置する動きが各地で進んだ一方、死にゆく人々を生活の場から遠ざけ、特殊な施設に収容する問題点も挙がった<sup>48)</sup>。その結果、ケアの方向性は、収容型の施設から在宅療養支援チームを形成する方向に進み、近代ホスピス設置から2年後に St. Christopher's Hospice は在宅サービスを提供し始める。その後、サッチャーの経済改革の際に医療体制が危機的な状況になるも、90年代から地域ケア、プライマリ・ケアの強化が図られる中、地域医療の一翼を担うようになった。

このように、英国では、緩和ケアはもともと①地域ネットワークを基盤として発達してきたこと、②在宅療養を志向していること、③がんに限らず広く対応する姿勢を持っていたことが分かる。

また、もう一点強調したいのは、緩和ケアの提供が、公衆衛生的なアプローチを重視するように変換した点である。1970年代を通して、ホスピスが乱立し、地域の医療体制が考慮されずに進んだことへの反省もあり、地域のニーズをふまえた提供体制が組まれるようになった。この点も、地域を志向していることを表してもいる。

### 死亡原因の変化と疾病の経過 (illness trajectory) の理解

20世紀前半までは、人の死は、感染や事故などが一般的であった。20世紀後半を過ぎ現在で

は、急性感染症による死亡はまれとなり、死への経過は長期にわたり緩徐に進行するものとなった。従来死の病と恐れられてきたがんであっても、乳がんや前立腺がんのように、数年にわたり穏やかに進行し、ほぼ慢性疾患と同じ様相を呈するようになったものもある。

現在、先進国の死亡原因を見ると、ほとんどが悪性腫瘍や心疾患、呼吸器疾患、脳血管性障害で占められる。たとえば、わが国では、2011年に年間125万3,066人が死亡している。そのうち、35万7,305人が悪性腫瘍である。非悪性腫瘍の代表的な疾患である心疾患は19万4,926人、脳血管疾患は12万3,867人、肺炎は12万4,749人、老衰は5万2,242人であり、腎不全や肝不全を含め非悪性腫瘍による死亡数の7割を占める<sup>19)</sup>。このように、先進国では、急激に進む高齢化により、がん、臓器不全など老化・衰弱に関連する死亡が多数を占めている。

これらの慢性疾患の進行は、大まかに下の3つのパターンに分類して検討すると考えやすい<sup>21)</sup>。すなわち、

- ①死亡前、数週間から数か月前に身体機能が急激に低下するパターン (進行期の悪性腫瘍)
- ②数か月から数年にわたり、急激な状態の悪化と回復を繰り返しつつ穏やかに進行する (心不全や呼吸不全)
- ③数年以上の単位でゆるやかに低下する (認知症)

となる (図1 Lynn, 2001)。

このような疾病の経過 (illness trajectory) を把握することは、さまざまな身体症状による苦痛に加え、患者がどのような体験をしようかを予測し、苦痛を予防するために今後起こりうることを先読みして対応する上で必要である。特に正確に予後が推測することができれば、患者や家族の自発的な意思決定がより容易になる。米国のナーシングホームにおいて、進行期認知症患者の予後や合併症について、家族が理解している場合と理解していない場合とを比較して、積極的な延命治療が3分の1にとどまるとの報告がある<sup>50)</sup>。

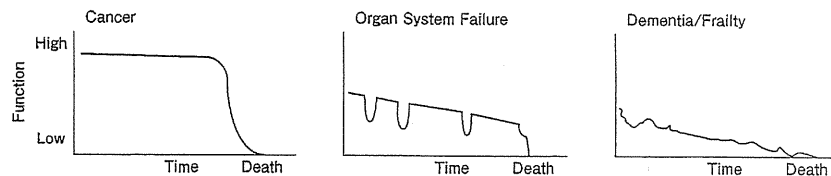


図1 疾患の進行と全身機能の変化

一般に、がんであれば、全身機能の低下はほとんどなく経過をし、最後の1、2か月になって臓器機能障害に併せて急速に全身機能が低下する。この症状や臨床経過は共通性を持つため、今後の予測を立てやすいのが特徴である。

悪性腫瘍と比較すると、非悪性腫瘍は、細胞や臓器機能の低下による脆弱性の進行が背景にあるため、機能低下の出現部位やその進行の個体差が大きい。認知症の場合は、ゆるやかに全身機能が低下していく経過をとる。特にアルツハイマー病では、中核症状の進行とともに身体症状も一定の順序を踏んで進行する。

大事なことは、患者がその疾病の経過のどの時期にいるのかを把握し、患者とともに現在進めている治療が何を目標にしているのか、この治療に反応しない場合にどのような選択肢が残されているのか、その方向を目指すのか、をその治療の過程において繰り返し検討し確認することである。今患者が生きている上で優先順位が高い課題は何かを、患者と医療者が共通の見通しをもって検討することが重要である。

### 認知症の緩和ケア

認知症は、確実な治療法がなく、緩徐に進行しやがて死に至る疾患である<sup>41,49,51)</sup>。認知症自体は、基礎疾患が多数に及び、基礎疾患ごとに経過は異なること、栄養や輸液など補正できる可能性はあるもの、寿命を規定する疾病である<sup>31)</sup>。緩和ケアは、認知症患者とその家族の抱える問題やニーズに対応することが可能である。

今まで伝統的には、緩和ケアは進行期のがん患者を対象とし、がん患者に早期から適切な緩和ケ

アを提供することで、療養生活の質の向上が図れ、また生命予後も改善する可能性が指摘されている<sup>38)</sup>。

もちろん、このようながん領域で築かれた高いエビデンスが認知症に対してそのまま適用できるものではない。当然ではあるが、がん患者と認知症患者では疾患の経過が異なる。がん患者は、一般に身体機能は予後数週間で保たれており、その進行の仕方はある程度分かっており、予後予測も可能である。

一方、認知症では、認知機能障害が徐々に進行することは予測されるものの、その進行は一般に年単位である。また、生命予後も報告によってまちまちであり、3年から10年である。個々の症例の経過におとすと、患者は認知症の終末期には重度の身体的・精神的機能障害を抱えつつ生活することになるが、一方、より早期では肺炎や摂食不良による栄養障害、合併症などの認知症に関連する健康問題から死亡することがある。それゆえ、認知症患者の予後予測は非常に難しい。さらに、身体的問題や認知機能障害に加えて、アパシーや抑うつなどのBPSD症状が認知症の経過を修飾する。

このように、認知症患者では、「生活の質の向上」を目指した取り組みが適応となる。緩和ケアが目標とする「生活の質」は幅広い概念である。特に身体症状の目立たない初期においては、患者個人個人の生活の質そのものとなる。認知症が進行するにつれて、身体や精神機能の維持、併存症に伴うさまざまな苦痛の除去も加わる。さらに、疾病の経過を通じて、患者とその家族には具体的なニーズがあり、それらも把握され、適切に対応さ



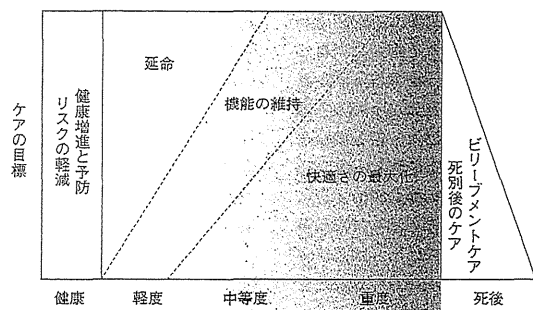


図2 認知症の進行と推奨するケアの目標の優先順位  
 認知症の疾患の過程を通して変化するケアの目標とその優先順位を図示した。ケアの目標は同時に複数の適用が可能であるが、認知症の段階に応じてその妥当性は異なる。そのため優先順位をつける必要がある。  
 特に機能の維持という目標(疾患の進行を可能な限り遅らせることと患者の不快感を最大限取り除くこと)は生活の質を重視する取り組みを最もよく示している。また、患者が死亡した後は、遺族に対する死別へのケアが行われるが、家族に対して持続する悲嘆に対しては早期の段階から継続した支援が必要になる。

れる必要がある。たとえば、合併症の治療に際して、治療方針を決定することが必要となる。意思決定をめぐり、患者とその家族間のコミュニケーションを調整することは重要だが難しい課題である。意思決定の代理人になることは家族にとって負担となるため、その支援も重要な問題である<sup>20)</sup>。

認知症における緩和ケアの有効性に関する研究はまだ少ない現状であるが<sup>26), 27)</sup>、家族から報告で、認知症患者に対してもホスピスプログラムの提供が有益であるとの報告がある<sup>18), 39)</sup>。

1. 認知症と予後

認知症は明らかに予後を悪くすることが知られている。中国上海の疫学調査では、65~74歳においては、アルツハイマー病を合併すると死亡リスクは5.4倍、血管性認知症では7.4倍に上昇した<sup>10)</sup>。また、同様に75歳を超えると、アルツハイマー病で2.5倍、血管性認知症で3.5倍であった。一般に75歳以上になると、認知症関連疾患は広く認められるようになり、総死亡の23.7%に認知症が何らかの形で関連している<sup>10)</sup>。

Larsonらは、アルツハイマー病患者521例を追跡したところ、アルツハイマー病患者の平均余命は、男性で診断から4.2年、女性で5.7年であり、同年代の認知症を合併していない患者の半分であることを報告した<sup>20)</sup>。また、Xieらは、英国において大規模なコホート調査を行い、認知症を発症した患者で平均余命は男性で診断から4.1年(発症時平均年齢83歳)、女性で4.6年(発症時平均年齢84歳)であった<sup>50)</sup>。予後の短縮と関連した要因は、認知機能の低下と歩行障害、転倒、虚血性心疾患の既往が関連していた<sup>21)</sup>。

ここで注目したいのは、認知症の診断時からの予後はかなり短いこと、認知症の大半は認知症の進行によって死亡する前に、併存症や合併症により死亡している点である。より具体的には、併存症や身体症状管理との相互作用が疑われるため、認知症の身体症状評価とその管理の重要性を示している。

2. 認知症患者への心理的支援

認知症患者への心理的支援で特に注意を払いたい点は、認知症の患者は軽度でも、またある程度

進行した段階でも、自らの疾患に対して違和感を認識し、苦痛を感じており、特にその苦痛に対応した精神心理的支援が必要である点である<sup>27)</sup>。認知症においては、本人が認識できないとの先入観から、見落とされていたこともあり、現在のところどのような介入が効果があるのかは明らかになっていない<sup>39)</sup>。重度の認知症の場合でも、目に見える形での象徴や具体的な行事を通して、精神的ケアを提供できる可能性がある<sup>3, 40)</sup>。回想法は患者よりも家族に対して現実を受け入れることを促進する上で効果があるかもしれない<sup>22)</sup>。

3. 認知症と身体機能、合併症

認知症(アルツハイマー病)と身体疾患との関連は詳しくは明らかになっていない。認知症患者は、一般的な加齢に関連する老年症候群を合併する。しかし、一部の疾患はアルツハイマー病でより多く認められ、特に進行期で目立つようになる。7,000人規模のケースコントロールでは、アルツハイマー病の患者には、パーキンソン病やてんかん、感覚障害、感染、低栄養、大腿骨頭骨折を含む外傷、褥瘡が、対照群に比較してより多く発症していたとの報告がある<sup>9)</sup>。これらの合併症は、大きく神経学的合併症と感染、低栄養の3つに分けることができる。大腿骨頭骨折や外傷は、運動機能障害と関連し、活動が低下すれば感染の発生リスクとなる。褥瘡も運動障害と低栄養に関連する。

1) 感染

認知症患者で感染症の合併は多く、主に尿路感染、上・下気道感染、皮膚・皮下組織の感染、消化管、眼がある<sup>29)</sup>。全身感染症は認知症患者で最も多い死因であり、気管支肺炎はアルツハイマー病患者の死因の60%を占める。認知症に感染が合併する背景には、身体機能面では免疫機能の変化や失禁、活動量の低下、誤嚥が関連する。それゆえ、感染症は認知症の進行に伴い避けられない事態である。

認知症患者の生存期間中央値は今まで考えられてきた以上に短く、3~6年と報告されている<sup>25)</sup>。認知症が進行し、Global Deterioration Scale

(GDS)で7になると、摂食・嚥下障害に伴う低栄養・免疫不全と誤嚥性肺炎などの感染症が問題になる。Mitchellらは、重症認知症患者を観察し、その86%に摂食・嚥下障害があり、障害を持つと生存率がきわめて低いことを明らかにした<sup>24)</sup>。

アルツハイマー病患者では細胞調節性免疫機能やサイトカイン分泌能の低下、急性期タンパク分泌の低下がある。これらの低下は、免疫機能の低下を招く。認知症患者がコミュニケーションが困難になった場合やトイレの使用が困難になった場合、便失禁は避けることができない事態であり、尿路感染はカテーテルの使用や便失禁に伴い増加する。便失禁は皮膚統合の障害を招き、褥瘡の発生にもつながる。

活動量の低下は、歩行の問題と知覚障害の両者の結果として生じる。歩行の不安定化や歩幅の狭小化は、筋緊張の増加や固縮に引き続いて生じる。歩行が困難になることは尿路感染のリスク、肺炎のリスクを高める。活動量の低下は、また褥瘡の発生にも関連する。

上気道分泌物の誤嚥は、睡眠中に生じやすい。誤嚥は、特に頸部の拘縮や過伸屈と関連し、どれも認知症の進行に伴い生じやすくなる。高齢者肺炎の70%以上が誤嚥性肺炎であるが<sup>25)</sup>、誤嚥性肺炎を防ぐには、口腔衛生を保ち、喫煙を避け、咳嗽反射を保持し、軌道分泌物を維持することである。歯周病とプラークは、肺炎を招くリスクファクターである。

2) 低栄養

アルツハイマー病やその他の認知症関連疾患では、体重減少を伴う<sup>15)</sup>。体重減少は、認知症の診断がなされる数年前から始まっている可能性がある<sup>15)</sup>。アルツハイマー病の体重減少は、代謝亢進によるものではない。というのも、認知症患者と健常者で、食事摂取量も身体活動度も変わらないからである。おそらく認知症の体重減少は、食事摂取量の低下と、エネルギー消費の増大に伴うものと考えられている<sup>30)</sup>。認知症患者はしばしば独居で、食事摂取を忘れることがある。また、視空間認知能力の低下は、食べ物を認識することを困

難にする。食事摂取を拒否することは認知症ではしばしばあるが、それは抑うつや自発性の低下が影響する。失行が進むと、患者は食事自体とすることができなくなり、介助を要する状態となる<sup>17)</sup>。認知症患者に多い摂食障害には、抑うつ症状に伴う食物への興味・関心の喪失、空腹感の欠如による摂食拒否、便秘に関する食欲低下、嚥下第1相、第2相の障害による嚥下困難や誤嚥、それらによるますますの食欲低下がある<sup>24)</sup>。

エネルギー消費は、徘徊や落ち着きのなさが影響する。早歩きは、エネルギー消費量を1,600 kcalまで高める。徘徊のある患者は体重を維持するのに2,800 kcal/日必要となる<sup>17)</sup>。パーキンソン病を合併すると、固縮によるエネルギー消費量の増大がある。体重減少は、必ずしもすぐに合併する栄養状態ではないが、身体疾患に関連して頻度が高くなる病態でもない。認知症患者では、介助なしに歩行をすることが困難になり、筋肉量の減少が体重減少を起こすのかもしれない。理想体重を設定することに無理な場合も多い<sup>17)</sup>。

#### 4. BPSDと身体症状

多くの患者が、痛み、呼吸困難および興奮/不安に苦しむ。身体症状において、認知症患者は過小診断と過小治療の危険がある<sup>6, 25, 33)</sup>。認知症の行動心理症状は身体症状と併せて対処される必要がある。なぜなら、認知症において行動的症狀は顕著で典型的であり、相互に関連しているからである。たとえば、疼痛緩和は興奮を抑える場合があり<sup>32)</sup>、抑うつ症状または身体的活動の変化が興奮のレベルを変えることもある<sup>34, 43)</sup>。したがって、行動の変化があれば身体症状評価を行う必要があり、疼痛が疑われれば積極的に鎮痛薬を試みることが望まれる。

認知症患者の身体症状を拾い上げ、患者の不快感を最大限取り除くために、多職種のアセスメントを統合することが重要であり、複数の視点から行動の変化とその原因を推測することで鑑別しやすくなる。介護者が患者と親密になることで不快の原因は特定しやすくなることも報告されている<sup>23)</sup>。

#### 5. 疼痛評価の必要性

非常に見落とされがちなこと、認知症患者は疼痛を過小に評価される<sup>4, 40, 41)</sup>。軽度および中等度の認知症の場合には、疼痛評価に自己評価法を利用することができるが、重度認知症の場合は自己評価が困難となり、身振りや顔つきが手掛かりとして対応せざるを得ない<sup>14, 28)</sup>。認知症の痛みの評価に関してはこれまでにさまざまなツールが開発され、その一部は複数の研究で検証されて肯定的な成果が得られている<sup>12, 13, 52, 53)</sup>。具体的には、Pain Assessment in Advanced Dementia Scale (PAINAD)<sup>40)</sup>やPain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)<sup>9)</sup>、Doloplus<sup>45)</sup>が挙げられる。

#### 6. 認知症の経過と家族への支援

認知症の経過と関連する健康上の問題について、家族の多くはほとんど理解していない<sup>4, 10)</sup>。特に、認知症の進行に伴い、家族は意思決定の共有あるいは代理をせざるを得なくなることを事前に知り、あらかじめ心構えを持つことは、家族の生活の質を高めるために重要な取り組みである<sup>11)</sup>。

また、認知症は文化的な背景、恥などスティグマとも関連し、家族の恥という意識が介護者の負担を増大させる点にも注意が必要である<sup>7, 46)</sup>。

### わが国の現状と課題

わが国では2013年に高齢化率が25%を超える未曾有の超高齢化社会を迎えた。高齢化社会の到来が近年強調されるがゆえに、20%という数字にともすれば慣れがちで当たり前に感じられるかもしれない。しかし、近代医療の発展期である1900年代の高齢者比率は1%であること、近代ホスピスが展開しだした1950年代の英国でもただか10%であったことを考えると、今我々は全く異なる次元に入っていることが改めて分かる。欧米では、高齢化率が今後20%を超えることを危惧し、国家戦略を立てている。わが国の現状は、全く猶予のない段階である。

わが国では、認知症に対するアプローチとして、

主に老年精神医学からは精神疾患として、介護領域からは生活支援が取り上げられることが多い。精神疾患として認知症を取り上げた場合には、診断と治療が話題の中心となり、老年症候群として認知症が取り上げられた場合には、介護支援の話題となる。どちらも認知症への対応を考える上で避けて通れない面である。一方、認知症は老年症候群の一面であり、身体合併症を併存することは非常に多い。身体治療とケアを進める上で、疼痛管理の必要性は急性期・慢性期を通して認識されつつあるものの、認知症ケアにおいて認識はどれくらい進んでいるだろうか。厚生労働省が進めているオレンジプランには、医療者に対する研修が盛り込まれているものの、その内容は主に認知症の病態や治療にとどまり、身体合併症を持つ場合の身体管理上の問題や疼痛管理などは、ほとんど行われていない。総合病院では、認知症患者に疼痛に評価を行おうとしてもVAS (Visual Analog Scale) が付けられないから対応困難であるとしてそのまま放置をされていたり、BPSDとして誤って認識され、抗精神病薬で不適切な対応をなされている事例をしばしば見聞きする。身体ケアを含めたトータルケアの視点を取り入れたあり方の検討が急務であろう。

また認知症の告知は進んできた一方、認知症に伴う精神的苦痛への対応も見落とされてきた面がある。特に、西欧とは異なる背景を意識し、わが国の文化に即したケアの開発も必要である。

高齢者ケアの課題は、わが国が世界に先駆けて直面している課題であり、世界に向けて貢献できる領域でもある。精神医学と緩和ケアが、より密に連携できる分野であり、積極的な交流と発展を是非期待したい。

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## MEDICAL BOOK INFORMATION

医学書院

&lt;精神科臨床エキスパート&gt;

## 多様化したうつ病をどう診るか

編集 野村総一郎  
シリーズ編集 野村総一郎・中村 純・青木省三・  
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精神科診療のエキスパートを目指すための新シリーズの1冊。多様化、複雑化した現在のうつ病診療の諸問題を整理し、臨床家が日々感じている実践的な疑問に答える内容。現代型のうつ病、双極スペクトラム、非定型うつ病、生活習慣病としてのうつ病、老年期うつ病、発達障害や統合失調症とうつ病の関係など、いま知りたいテーマを気鋭の執筆者が縦横無尽に論ずる。

## 特集

## CGAを考慮した高齢者に対するがん治療の特性と適応

# 高齢がん患者の サイコオンコロジー\*

小川 朝生\*\*

Key Words : cancer, psycho-oncology, dementia, delirium, comprehensive geriatric assessment

## はじめに

わが国は、2013年には65歳以上の老年人口は3,079万人となり、全人口の24.1%を占めるにいたった<sup>1)</sup>。がんは45歳から89歳までの男性、40歳から84歳までの女性の最大の死因であるように広い年齢に分布する。その中で特に高齢者の罹患に注目すると、全悪性新生物死亡数のうち、65歳以上が78%を占めている。がんはまさに高齢者の疾患である。

平均寿命が延びることは、高齢者のがん発症率・有病率が増大することを意味する。同時に高齢者の人口が増加することは、がん治療において高齢がん患者が増加することを示唆する。超高齢化社会を迎えたわが国は、高齢がん患者特有の問題を考慮に入れたがん治療のあり方を検討する必要に迫られている。

高齢がん患者に対して、適切に包括的ながん治療を提供するために、高齢者総合的機能評価(comprehensive geriatric assessment ; CGA)の実施が強く奨められている。

CGAの実施が推奨される理由に、加齢はがん医療の不均衡に強く関連することがあげられる。一般に患者の年齢が高くなるほど、治療をひか

える傾向がある。担当医は、高齢がん患者では治療の有益性を低く見積もり、高齢者には若年者と異なる選択肢を提示する傾向がある<sup>2)</sup>。しかし、高齢がん患者でも適切な手術、薬物療法により生存期間を改善することは可能である<sup>3)</sup>。単に高齢というだけで、quality of life(QOL)の改善や生命予後の改善を期待できる治療を受ける機会を失うことがあってはならない<sup>4)</sup>。一方、明らかに有益性のない治療は避けなければならない。

高齢がん患者に対する適切ながん治療を考える上で、身体症状のみならず、患者をとりまく精神医学的問題、心理・社会的問題に対する適切な評価が望まれる。がんと精神心理的問題との関連を扱う分野である精神腫瘍学(サイコオンコロジー ; psycho-oncology)においても、高齢者特有の問題に配慮をした支持療法を考慮する必要がある。本稿では、高齢者の精神症状として重要な課題である認知機能障害・認知症を中心に紹介を進めたい。

## 高齢者総合的機能評価 (comprehensive geriatric assessment ; CGA)

CGAとは、comprehensive geriatric assessmentの略で、疾患のある高齢者に対して、機能的、社会的、精神心理的観点からその高齢者の生活機能障害を総合的に評価する手法である<sup>5)</sup>。CGA

\* Supportive care for the elder patients with cancer.

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が必要とされるようになった背景には、生活機能障害を持つ高齢患者数が著しく増加したことにより、疾患や生活機能障害相互の関連を把握し、適切なケアを幅広く提供する必要が高まったことによる。特にがん医療においては、CGAを実施することにより、合併症(たとえば神経障害性疼痛による転倒)や社会的支援不足(日中独居の患者への支援)、栄養不良(認知症によるアパシー(意欲低下))などが治療の阻害因子となりうる問題をあらかじめ同定することができる。

精神心理的問題としては、認知機能障害(認知症、せん妄)とうつ病、意欲低下(アパシー)への対応が重要である。認知機能障害を持つがん患者は、セルフケア能力が低下するため、体調が悪化した場合の対応が遅れたり、困難になりやすい。また認知機能障害自体が、社会適応を困難にするため、抑うつ状態や意欲低下を招きやすく、治療のアドヒアランスを低下させたり、死亡リスクの上昇を招く<sup>6)</sup>。そのためNCCN(National Comprehensive Cancer Network)の推奨するCGAにおいても、認知機能障害と抑うつ、意欲低下のスクリーニングが盛り込まれている<sup>7)</sup>。

## 認知機能障害

### 1. せん妄

せん妄は、急性に生じる注意力障害を主体とした精神神経症状の総称である。せん妄はがん患者において最も高頻度に認められる精神神経症状であり、治療の初期段階から終末期まであらゆる時期に出現する。せん妄では、注意力の障害に加えて、不眠や昼夜逆転などの睡眠覚醒リズムの障害、感情の変動、精神運動興奮、幻視や錯視などの知覚障害、妄想など多彩な症状が夜間を中心に出現し、数時間から数日のレベルで変動する。

せん妄は、精神症状による苦痛に加えて、家族や医療者とのコミュニケーションを阻害する因子となり、身体症状のコントロールを不良にする<sup>8)</sup>。また、せん妄自体が全身状態の不良を示す兆候であり、早期に発見し対応することは、身体症状管理上も重要である。

### (1) 疫学

急性期一般病院においては、入院中のがん患

者の有病率は15%(95%CI 9~18%)である<sup>9,10)</sup>。より進行して、緩和ケアへ移行する段階では一般病棟よりも高くなり、緩和ケア病棟入院時点で28%であった<sup>11)</sup>。

緩和ケア病棟入院後は20~45%で、最終的に全身状態が悪くなるにつれて上昇し、死亡前には83%に達する<sup>12,13)</sup>。

### (2) アセスメント

せん妄の診断は診断基準(アメリカ精神医学会精神疾患の分類と診断の手引き(Diagnostic and Statistical Manual of Mental Disorders, 5th Edition ; DSM-5)あるいはICD-10)がgold standardである<sup>14)</sup>。

日常臨床では、Confusion Assessment Method(CAM)が用いられる。CAMはDSM-IVの操作基準のうち4つ(①急性発症と症状の変動、②注意力障害、③まとまりのない思考、④意識レベルの変化)を用いて演繹的に判定する方法で、使用方法のトレーニングを受けた医療者が使用することで、感度(94~100%)、特異度(90~95%)と高い判定率を持つ<sup>15)</sup>。

### (3) マネジメント(薬物療法、非薬物療法、日常生活の支援)

せん妄は診断をつけると同時に、せん妄の原因を探索し、回復・修正可能な原因を同定する必要がある。

がん患者の場合、単独要因のみでせん妄を発症することはなく、潜在的な関連要因が絡むことがほとんどである。見落としてはならないのは、アルコールと薬剤(特にオピオイド、ベンゾジアゼピン系薬剤、抗コリン薬)である。次にせん妄のリスク因子である身体合併症や脆弱性の評価、認知症の有無、多剤併用、感染、脱水、腎機能障害、電解質異常(NaやCa)、肝機能障害、低栄養などを評価する。症候性でんかんを疑う場合には脳波を、頭蓋内病変を疑う場合には画像検査を併用する。

がん患者においては、オピオイドが関連するせん妄が20~50%と多い。オピオイドのタイトレーションとあわせてせん妄への対応を進める必要があり、せん妄の評価と同時に疼痛のアセスメントも実施する。