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ORIGINAL ARTICLE

Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings

Koji Amano[1] · **Tatsuya Morita**[2] · **Saori Koshimoto**[3,4] · **Teruaki Uno**[1] · **Hirofumi Katayama**[1] · **Ryohei Tatara**[1]

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Abstract

Purpose Few studies have investigated nutrition impact symptoms and eating-related distress among advanced cancer patients and their families. This is a questionnaire survey to examine the severity of nutrition impact symptoms and the prevalence of eating-related distress among them in palliative and supportive care settings.

Methods Questionnaires for patients and their families were preliminarily developed. We selected 16 common symptoms of advanced cancer, i.e., 9 symptoms of the ESAS-r and 7 of the PG-SGA. Each questionnaire concerning eating-related distress consisted of 12 items.

Results A total of 140 out of 147 patients responded (95.2%). They were classified into two groups: (1) non-cachexia/pre-cachexia ($n = 57$) and (2) cachexia/refractory cachexia ($n = 83$). The top 3 out of 16 symptoms in all patients were feeling of well-being, lack of appetite, and tiredness. Significant differences were observed in 8 symptoms between the two groups: tiredness ($p = 0.007$), drowsiness ($p = 0.007$), lack of appetite ($p < 0.001$), early satiety ($p = 0.001$), diarrhea ($p = 0.025$), abnormal taste ($p = 0.02$), difficulty swallowing ($p = 0.002$), and feeling of well-being ($p = 0.003$). Regarding eating-related distress in patients, significant differences were observed in all items, except for 2, between the two groups. Concerning eating-related distress in families, significant differences were observed in all items between the two groups.

Conclusion Advanced cancer patients with cachexia have more severe nutrition impact symptoms than those without cachexia, and patients with cachexia and their families have greater eating-related distress than those without cachexia.

Keywords Advanced cancer patients · Family members · Cachexia · Nutrition impact symptoms · Eating-related distress

Introduction

Cancer cachexia is characterized by the ongoing loss of skeletal muscle mass and body weight that cannot be fully reversed by conventional nutritional support due to metabolic changes and an energy imbalance [1]. Involuntary body weight loss often follows anorexia and a decreased food intake and has been linked to deteriorations in quality of life, nutritional status, performance status, treatment outcomes, and survival in advanced cancer patients [1–8]. A large number of

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✉ Koji Amano
kojiamano4813@gmail.com

Tatsuya Morita
tmorita@sis.seirei.or.jp

Saori Koshimoto
skoshimoto-rd@umin.ac.jp

Teruaki Uno
unoteruaki.mua@gmail.com

Hirofumi Katayama
h-katayama@med.osakacity-hp.or.jp

Ryohei Tatara
r-tatara@hotmail.co.jp

[1] Department of Palliative Medicine, Osaka City General Hospital, 2-13-22 Miyakojima-hondori, Miyakojima-ku, Osaka City, Osaka 534-0021, Japan

[2] Palliative and Supportive Care Division, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Kita-ku, Hamamatsu City, Shizuoka 433-8558, Japan

[3] Section of Liaison Psychiatry and Palliative Medicine, Tokyo Medical and Dental University, 1-5-4 Yushima, Bunkyo-ku, Tokyo 113-8519, Japan

[4] Faculty of Human Science, Tokiwa University, 1-430-1 Miwa, Mito City, Ibaraki 310-8585, Japan

advanced cancer patients with cachexia and their family members have psychosocial distress, as well as physiological disorders and psychological symptoms [9–13]. In addition, the need for nutritional support and eating-related distress are the most representative types of psychosocial distress encountered during cancer [9–13]. Thus, the management of cancer cachexia needs to address psychosocial distress, particularly the need for nutritional support and eating-related distress, in advanced cancer patients and their family members [9–13]. However, to the best of our knowledge, few studies have investigated the prevalence of the need for nutritional support and eating-related distress among advanced cancer patients and their family members [11–13]. Therefore, we conducted a questionnaire survey to examine the severity of nutrition impact symptoms, which are to be palliated as part of nutritional support, in advanced cancer patients and the prevalence of eating-related distress among patients and their family members in palliative and supportive care settings, including outpatient services, palliative and supportive care teams, and the palliative care unit. We also compared these parameters between the following groups: (1) non-cachexia/pre-cachexia and (2) cachexia/refractory cachexia.

Methods

This study was conducted in Osaka City General Hospital, a designated cancer care hospital with 1063 beds, between May and July in 2018. We explained the objective of this study to advanced cancer patients and their family members with a document and asked them to respond to anonymous questionnaires on the first day of their referral to outpatient palliative care services/the palliative care team in general wards/the palliative care unit, i.e., their first contact with palliative and supportive care. The completion and return of the questionnaire was regarded as consent to participate in this study. The Institutional Review Board approved this study (No. 1804008).

Subjects

Primary palliative care physicians consecutively identified potential participants among patients with the following inclusion criteria: (1) adult patients receiving palliative care, (2) patients diagnosed with locally extensive or metastatic cancer (including hematological neoplasms), (3) Eastern Cooperative Oncology Group Performance Status (ECOG PS) 0–3, 4) no marked fluid retention, e.g., ascites, pleural effusion, and peripheral edema, (5) capable of replying to a self-reported questionnaire, (6) awareness of the diagnosis of malignancy, and (7) no serious psychological distress recognized by the primary palliative care physician's interview. Additionally, they identified potential participants among family members with the following inclusion criteria: (1) primary caregivers of patients meeting the inclusion criteria as above, (2) capable of replying to a self-reported questionnaire, (3) awareness of the diagnosis of malignancy, and (4) no serious psychological distress recognized by the primary palliative care physician's interview.

Questionnaires

The anonymized questionnaires for advanced cancer patients and their family members in Japanese for this study were preliminarily developed by the authors. Each ad-hoc questionnaire on eating-related distress consisted of 12 items, which were based on literature review and discussion among the authors and evaluated as 1: no, 2: seldom, 3: sometimes, 4: frequently, and 5: always [9–19]. The face validity of the questionnaires was confirmed by a pilot test with 5 patients and 5 family members; 5 physicians of palliative care, including the authors; and 5 nurses of a palliative care team in Osaka City General Hospital.

We initially asked about patient demographics/clinical characteristics, i.e., age, gender, height, current body weight, body weight 6 months ago, serum levels of albumin and C-reactive protein within 1 week, the primary cancer site, ECOG PS, setting of care, treatment status, and 16 common symptoms of advanced cancer, which are self-reported with a 0–10 point scale. Nine symptoms, i.e., pain, tiredness, drowsiness, nausea, lack of appetite, shortness of breath, depression, anxiety, and a feeling of well-being, were evaluated using the Edmonton Symptom Assessment System-revised (ESAS-r) [20], and 7 symptoms, i.e., early satiety, constipation, diarrhea, abnormal taste, abnormal smell, dry mouth, difficulty swallowing, were adopted from the Patient-Generated Subjective Global Assessments (PG-SGA) [21]. The Japanese version of ESAS-r is a reliable and valid tool for measuring the symptoms of adult patients with advanced cancer [22]. We then asked patients to answer the questionnaire for eating-related distress in patients. Additionally, if possible, we asked about family member demographics, i.e., age, gender, and relationship. We then asked family members to answer the questionnaire for eating-related distress in family members.

Statistical analysis

Descriptive statistics were conducted on demographic information for patients and family members using a mean and standard deviation (SD) for continuous variables and proportions for categorical variables. The scores of nutrition impact symptoms were respectively calculated with a median and interquartile range. The proportions of patients and family members were calculated with a 95% confidence interval (CI) with regard to the questions. A threshold of 3 or more, i.e., 3: sometimes, 4: frequently, and 5: always, was selected and considered to be significant for this study. Patients and family members were respectively classified into two groups based on criteria from the international consensus [1]. Cachexia/refractory cachexia was a body weight loss rate (BWLR) in 6 months $\geq 5\%$ or body mass index (BMI) $<$ 20 kg/m^2 + BWLR in 6 months $\geq 2\%$. Patients above or below these cutoff values were grouped as follows: (1) non-cachexia/pre-cachexia and (2) cachexia/refractory cachexia. Comparisons between groups were made using the Mann-Whitney *U* test or the chi-squared test, as appropriate. All results were considered to be significant if the *p* value was less than 0.05. All analyses were performed using IBM SPSS v. 22.0 (SPSS Inc., Chicago, IL).

Results

Among the 150 patients asked to participate in this survey, 3 refused and 140 out of 147 responded (response rate, 95.2%). Patient and family member characteristics are summarized in Table 1. Mean age was 66.3 ± 11.1 years and the proportion of male patients was 57.9%. The top three sites of primary cancer were the lungs, upper and lower gastrointestinal tract, and the liver/biliary system/pancreas. The proportions of ECOG PS 0–1, 2, and 3 were 35.0, 30.0, and 35.0%, respectively. The proportion of outpatient services was 40.7%, hospital palliative and supportive care teams 47.9%, and the palliative care unit 11.4%. The proportion of pre-chemotherapy was 5.7%, chemotherapy 63.6%, and never treated/previous treatment 30.7%. Mean BMI and BWLR in 6 months were 22.2 ± 3.5 kg/m^2 and 6.3 ± 8.0%, respectively. Mean serum levels of albumin and C-reactive protein were 3.2 ± 0.7 g/dL and 3.8 ± 4.9 mg/dL, respectively. As for family members, the mean age was 57.4 ± 14.7 years, 25.2% were male, and spouses made up 65.0% and children 27.2%.

Height, current body weight, and body weight 6 months ago, i.e., BMI and BWLR in 6 months, were obtained from 140 patients, and they were classified into two groups: (1) non-cachexia/pre-cachexia ($n = 57$) and (2) cachexia/refractory cachexia ($n = 83$).

The median and interquartile range of numerical rating scales of each of the 16 symptoms adopted from ESAS-r and PG-SGA are shown in Table 2. The top 3 in all patients were feeling of well-being (5, 2–7), lack of appetite (4, 0–8), and tiredness (3.5, 2–6). All nutrition impact symptoms in advanced cancer patients with cachexia were greater than those in patients without cachexia. Significant differences between the two groups were observed in 8 symptoms: tiredness (3, 0–5 vs. 4, 3–7, $p = 0.007$), drowsiness (2, 0–4 vs. 3, 1–7, $p = 0.007$), lack of appetite (1, 0–5 vs. 5, 3–8, $p < 0.001$), early satiety (2, 0–4 vs. 4, 1–7, $p = 0.001$), diarrhea (0, 0–1 vs. 0, 0–3, $p = 0.025$), abnormal taste (1, 0–2.75 vs. 2, 0–7, $p = 0.02$), difficulty swallowing (0, 0–2 vs. 2, 0–5, $p = 0.002$), and feeling of well-being (3, 1–5 vs. 5, 3–7, $p = 0.003$).

Table 1 Patient and family member characteristics

Patients ($N = 140$)	
Age in years, mean (SD)	66.3 (11.1)
Sex, *n* (%)	
Male	81 (57.9)
Female	59 (42.1)
Primary cancer site, *n* (%)	
Lungs	31 (22.1)
Upper and lower gastrointestinal tract	31 (22.1)
Liver, biliary system, pancreas	18 (12.9)
Hematological malignancy	16 (11.4)
Urinary system, prostate	14 (10.0)
Head and neck	9 (6.4)
Breast	8 (5.7)
Gynecology	5 (3.6)
Others	8 (5.7)
ECOG PS, *n* (%)	
0–1	49 (35.0)
2	42 (30.0)
3	49 (35.0)
Setting of care, *n* (%)	
Outpatient service	57 (40.7)
Hospital palliative and supportive care team	67 (47.9)
Palliative care unit	16 (11.4)
Treatment status, *n* (%)	
Pre-chemotherapy	8 (5.7)
Chemotherapy	89 (63.6)
Never treated/previous treatment	43 (30.7)
BMI (kg/m^2), mean (SD)	22.2 (3.5)
Weight loss rate in 6 months (%), mean (SD)	6.3 (8.0)
Serum levels, mean (SD)	
Albumin (g/dL)	3.2 (0.7)
C-reactive protein (mg/dL)	3.8 (4.9)
Family members ($N = 103$)	
Age in years, mean (SD)	57.4 (14.7)
Sex, *n* (%)	
Male	26 (25.2)
Female	77 (74.8)
Relationship to the patient	
Spouse	67 (65.0)
Child	28 (27.2)
Others*	8 (7.8)

Values represent mean ± SD or *n* (%) where appropriate

SD standard deviation, *ECOG PS* Eastern Cooperative Oncology Group Performance Status, *BMI* body mass index

*Others include parents, siblings, and grandchildren

Concerning eating-related distress in advanced cancer patients, the proportions of patients who answered 3: sometimes,

Table 2 Nutrition impact symptoms

	Total ($N = 140$)	Non-cachexia/pre-cachexia ($n = 57$)	Cachexia/refractory cachexia ($n = 83$)	p
Pain	1 (0–4)	1 (0–3)	2 (0–5)	0.145
Tiredness	3.5 (2–6)	3 (0–5)	4 (3–7)	0.007
Drowsiness	3 (1–5.75)	2 (0–4)	3 (1–7)	0.007
Nausea	1 (0–3)	0 (0–2)	1 (0–5)	0.121
Lack of appetite	4 (0–8)	1 (0–5)	5 (3–8)	< 0.001
Shortness of breath	1 (0–4)	1 (0–3)	1 (0–5)	0.377
Depression	3 (1–5)	3 (0–5)	4 (1–5)	0.278
Anxiety	3 (1–5)	3 (0–5)	3 (1–5)	0.622
Early satiety	3 (1–5)	2 (0–4)	4 (1–7)	0.001
Constipation	3 (0–5)	3 (0–5)	3 (0–5)	0.987
Diarrhea	0 (0–2)	0 (0–1)	0 (0–3)	0.025
Abnormal taste	1 (0–5)	1 (0–2.75)	2 (0–7)	0.02
Abnormal smell	0 (0–3)	0 (0–2)	1 (0–3)	0.413
Dry mouth	1 (0–4)	0 (0–3)	1 (0–4)	0.089
Difficulty swallowing	1 (0–3.25)	0 (0–2)	2 (0–5)	0.002
Feeling of well-being	5 (2–7)	3 (1–5)	5 (3–7)	0.003

Values represent median and interquartile range

4: frequently, and 5: always are shown in Table 3. The top 5 out of 12 items in all patients were “Although I know that I have to eat enough, I cannot do that” (68.1%, 95% CI 60–75), “I feel that a lack of nutrition makes my condition worse” (57.6%, 95% CI 49–66), “I want attention to be paid to my eating-related distress” (53.2%, 95% CI 45–61), “I wonder what kinds of food I can eat” (50.7%, 95% CI 42–59), and “I wonder how I can eat more” (49.6%, 95% CI 41–58). Significant differences were observed in all items, except for 2, between the two groups, i.e., “I do not know why I cannot eat enough” and “I wonder which nutrients I should preferentially consume.” The mean number of items in which patients answered 3: sometimes, 4: frequently, or 5: always was significantly higher in cachexia/refractory cachexia group (3.4 ± 3.7 vs. 6.6 ± 3.7,

Table 3 Eating-related distress in advanced cancer patients

	Total		Non-cachexia/pre-cachexia		Cachexia/refractory cachexia		
	n (%, 95% CI)	*N*	*n* (%, 95% CI)	*N*	*n* (%, 95% CI)	*N*	*p*
Distress originating from the feelings of patients themselves							
Although I know that I have to eat enough, I cannot do that.	94 (68.1, 60–75)	138	26 (46.4, 34–59)	56	68 (82.9, 73–90)	82	< 0.001
I want attention to be paid to my eating-related distress.	74 (53.2, 45–61)	139	23 (41.1, 29–54)	56	51 (61.4, 51–71)	83	0.018
I do not know why I cannot eat enough.	55 (39.9, 32–48)	138	18 (32.1, 21–45)	56	37 (45.1, 35–56)	82	0.126
I feel that a lack of nutrition makes my condition worse.	80 (57.6, 49–66)	139	22 (39.3, 27–52)	56	58 (69.9, 56–79)	83	< 0.001
Distress originating from concerns regarding information about the patient’s diet							
I wonder what kinds of food I can eat.	70 (50.7, 42–59)	138	20 (35.7, 24–49)	56	50 (61.0, 50–71)	82	0.004
I wonder which nutrients I should preferentially consume.	59 (43.1, 35–52)	137	19 (34.5, 23–48)	55	40 (48.8, 38–60)	82	0.099
I wonder how I can eat more.	68 (49.6, 41–58)	137	17 (30.3, 20–43)	56	51 (63.0, 52–73)	81	< 0.001
I feel that more medical support about my daily diet is needed.	54 (39.7, 32–48)	136	10 (18.2, 10–30)	55	44 (54.3, 43–65)	81	< 0.001
Distress originating from the relationship between patients and their families							
I am burdened by the meals that my family serves me.	56 (44.8, 36–54)	125	12 (24.0, 14–38)	50	44 (58.7, 47–69)	75	< 0.001
I have experienced conflict about my meals with my family.	28 (22.4, 16–31)	125	5 (10.0, 4–22)	50	23 (30.7, 21–42)	75	0.007
I feel that I disregard the effort that my family shows by making my meals.	53 (42.7, 34–52)	124	10 (20.4, 11–34)	49	43 (57.3, 46–68)	75	< 0.001
I feel sad because I cannot enjoy dinner with my family.	43 (34.4, 27–43)	125	7 (14.0, 7–26)	50	35 (46.7, 36–58)	75	< 0.001

Values represent *n* (%, 95% CI) of “sometimes,” “frequently,” and “always.” *CI* confidence interval

$p < 0.001$). Patients with cachexia had significantly greater eating-related distress than those without cachexia.

Concerning eating-related distress in family members, the proportions of patients who answered 3: sometimes, 4: frequently, and 5: always are shown in Table 4. The top 5 out of 12 items in all family members were "I wonder how the patient can eat more" (68.3%, 95% CI 59–77), "I wonder what kinds of food the patient can eat" (67.3%, 95% CI 58–76), "I wonder which nutrients the patient should preferentially consume" (67.0%, 95% CI 57–76), "Although I know that I have to help the patient eat enough, I cannot do that" (66.0%, 95% CI 56–75), and "I feel that a lack of nutrition makes the patient's condition worse" (65.0%, 95% CI 55–74). Significant differences were observed in all items between the two groups. The mean number of items in which family members answered 3: sometimes, 4: frequently, or 5: always was significantly higher in cachexia/refractory cachexia group (3.3 ± 3.6 vs. 7.7 ± 3.7, $p < 0.001$). Family members of patients with cachexia had significantly greater eating-related distress than those without cachexia.

Discussion

To the best of our knowledge, this study is the first to conduct a questionnaire not only to investigate the severity of nutrition impact symptoms in advanced cancer patients and the prevalence of eating-related distress among patients and their family members, but also to compare these parameters between the non-cachexia/pre-cachexia and cachexia/refractory cachexia groups in palliative and supportive care settings.

We demonstrated that the severity of nutrition impact symptoms was moderate in advanced cancer patients and that nutrition impact symptoms were greater in advanced cancer patients with cachexia than in patients without cachexia. In the present study, the top 3 out of 16 symptoms adopted from ESAS-r and PG-SGA in all patients were feeling of well-being, lack of appetite, and tiredness. A cohort of 151 cancer patients referred to a cancer cachexia clinic reported the frequency and management of nutrition impact symptoms. The most common symptoms were early satiety (62%), constipation (52%), nausea or vomiting (44%), and mood changes (42%) [23]. A study investigating 52 patients in a nutrition-fatigue clinic reported that the five most frequent nutrition impact symptoms were taste and smell alternations (27%), constipation (19%), abdominal pain (14%), dysphasia (12%), and epigastric pain (10%) [24]. In addition, the present study showed that the severity of 8 symptoms, i.e., tiredness, drowsiness, lack of appetite, early satiety, diarrhea, abnormal taste, difficulty swallowing, and feeling of well-being, were significantly greater in the cachexia/refractory cachexia group. A large cohort study compared 9 symptoms of ESAS-r between the non-cachexia group ($n = 462$) and cachexia group ($n = 399$). The frequencies of all symptoms, except for

Table 4 Eating-related distress in family members

	Total		Non-cachexia/pre-cachexia		Cachexia/refractory cachexia		
	n (%, 95% CI)	*N*	*n* (%, 95% CI)	*N*	*n* (%, 95% CI)	i	*p*
Distress originating from the feelings of family members themselves							
Although I know that I have to help the patient eat enough, I cannot do that.	68 (66.0, 56–75)	103	18 (46.2, 31–62)	39	50 (78.1, 66–87)	64	0.001
I want attention to be paid to my distress about the patient's eating.	45 (43.7, 34–53)	103	7 (17.9, 9–33)	39	38 (59.4, 47–71)	64	< 0.001
I do not know why the patient cannot eat enough.	33 (32.4, 24–42)	102	5 (12.8, 6–27)	39	28 (44.4, 33–57)	63	0.001
I feel that a lack of nutrition makes the patient's condition worse.	67 (65.0, 55–74)	103	15 (38.5, 25–54)	39	52 (81.3, 70–89)	64	< 0.001
Distress originating from concerns regarding information about the patient's diet							
I wonder what kinds of food the patient can eat.	68 (67.3, 58–76)	101	16 (42.1, 28–58)	38	52 (82.5, 71–90)	63	< 0.001
I wonder which nutrients the patient should preferentially consume.	67 (67.0, 57–76)	100	16 (42.1, 28–58)	38	51 (82.3, 71–90)	62	< 0.001
I wonder how the patient can eat more.	69 (68.3, 59–77)	101	17 (44.7, 30–60)	38	52 (82.5, 71–90)	63	< 0.001
I feel that more medical support about the patient's daily diet is needed.	52 (51.5, 42–61)	101	10 (26.3, 15–42)	38	43 (68.3, 56–79)	63	< 0.001
Distress originating from the relationship between patients and their family members							
I feel that the patient is burdened by the meals that I serve him/her.	44 (43.6, 34–53)	101	10 (26.3, 15–42)	38	34 (54.0, 42–66)	63	0.007
I have experienced conflict about the patient's meals with him/her.	27 (26.7, 19–36)	101	4 (10.5, 4–24)	38	23 (36.5, 26–49)	63	0.004
I feel that the patient disregards the effort that I show by making his/her meals.	36 (35.6, 27–45)	101	4 (10.5, 4–24)	38	32 (50.8, 39–63)	63	< 0.001
I feel sad because the patient cannot enjoy dinner with me.	46 (45.5, 36–55)	101	5 (13.2, 6–27)	38	41 (65.1, 53–76)	63	< 0.001

Values represent *n* (%, 95% CI) of "sometimes," "frequently," and "always." *CI* confidence interval shortness of breath, depression, and anxiety, were significantly higher in the cachexia group [25]. In summary, although the broad spectrum of impediments to oral food intake may be conceptualized as nutrition impact symptoms [26], pain, lack of appetite and early satiety, tiredness and drowsiness, nausea and vomiting, constipation and diarrhea, abnormal taste and smell, difficulty swallowing, and a feeling of well-being may be particularly important in palliative and supportive care for advanced cancer patients with cachexia.

These nutrition impact symptoms not only decrease food intake and disarrange the metabolic and energy balance, which are specific characteristics of cancer cachexia, in advanced cancer patients, but also exacerbate eating-related distress in family members. The European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines on nutrition in cancer patients recommend routine screening for all advanced cancer patients, and if patients are found to be at nutritional risk, the guidelines recommend assessing them further for treatable nutrition impact symptoms and metabolic derangements [6]. Therefore, the management of nutrition impact symptoms as part of nutritional support is vital in palliative and supportive care settings. Thus, we defined nutritional support for advanced cancer patients as the palliation of nutrition impact symptoms, nutritional counseling, and nutritional treatment to increase calorie intake and suppress the negative impacts of cancer cachexia [13].

We also revealed that many advanced cancer patients and their family members had eating-related distress and that patients with cachexia and their family members had significantly greater eating-related distress than those without cachexia. Additionally, results of this study seem to show that cancer cachexia is more distressing for family members than for patients in some items, such as those relating to information about the patient's diet, although it is difficult to compare the severity of each item between patients and their family members. Previous studies indicated that various types of eating-related distress in advanced cancer patients and their family members are caused by a gap between reality and expectations, a lack of knowledge about cancer cachexia, unsuccessful attempts to increase body weight, and the expected occurrence of death. Furthermore, a reduced food intake by patients frequently becomes a source of conflict within families [9–19].

Our previous findings suggested that advanced cancer patients wished to receive nutritional support from medical staff with specific knowledge when they became unable to take sufficient nourishment orally and the negative impact of cachexia became apparent. Most patients wished to receive parenteral nutrition and hydration in these cases [13]. Additionally, in our previous surveys at palliative care units, 76 and 73% of advanced cancer patients and bereaved families, respectively, required nutritional support [11, 12], and nutritional support was also found to have potentially beneficial effects on selected groups of advanced cancer patients [27, 28]. Moreover, a previous study describing the meaning of hydration in hospice care reported that patients and their family members viewed hydration as hope for prolonging dignity and enhancing quality of life by reducing fatigue and increasing patients' alertness and energy [29]. Furthermore, previous studies indicated that advanced cancer patients' perceptions and beliefs concerning nutritional support are related to their cultural backgrounds and age [30–32]. Therefore, guidelines on the ethical aspects of artificial nutrition and hydration by the ESPEN suggest that decisions on artificial nutrition and hydration have to consider social, cultural, emotional, and existential aspects as well as the patients' spiritual and ethnic backgrounds and needs [33]. Hence, to palliate nutrition impact symptoms in advanced cancer patients and eating-related distress in patients and their family members, it is important for medical staff to understand their need for comprehensive nutritional support from the viewpoint of cancer cachexia in palliative and supportive care settings. Although the role of nutritional support to alleviate the negative impact of cancer cachexia remains unclear, we consider it to be important in these settings.

Palliative and supportive care for eating-related distress experienced by advanced cancer patients and their family members is summarized as follows. Management strategies for cancer cachexia need to address their eating-related distress. If multimodal treatments reduce the negative impact of cachexia, their eating-related distress may be alleviated. The main causes of their eating-related distress are a lack of knowledge about cachexia, unsuccessful attempts to increase body weight, the expected occurrence of the patient's death, and conflicts over food between patients and family members. Supportive, communicative, and educational interventions may alleviate their eating-related distress. Palliative and supportive care for their eating-related distress needs to be tailored to the severity of the patient's cachexia, particularly in cases of cachexia/refractory cachexia.

There are several limitations to the present study. First of all, the questionnaires for this study were preliminarily developed by the authors. A main limitation is that the measures for eating-related distress in both advanced cancer patients and their family members have not been previously validated. Second, the present results are not definitive and cannot be generalized because this was a single institution study. Third, since this survey was cross-sectional, there is no longitudinal description of nutrition impact symptoms and eating-related distress among advanced cancer patients and their family members, which may change during the disease trajectory. Fourth, items related to distress originating from the relationship between patients and their families may have been underestimated because patients who have no family members or do not eat together with their family members, if they have, were not separated in the analysis due to the characteristics of an anonymous questionnaire survey. However, this may have had a negligible effect on the results of the present study because several respondents may not have answered these items on their own judgment because of a lack of family members. Fifth, body weight measurements may have underestimated the frequency of cancer cachexia in patients who had gained weight due to fluid retention and overestimated it in overweight or obese patients. However, we excluded patients with marked fluid retention and there were only 2 overweight or obese patients, i.e., BMI greater than 30, in the present study. Finally, there may have been heterogeneity in primary cancer sites, the treatment status, and age in nutrition impact symptoms and eating-related distress.

Conclusion

Advanced cancer patients with or without cachexia appear to have nutrition impact symptoms to some degree, and these symptoms are stronger in patients with than in those without cachexia. Furthermore, patients with cachexia and their family members have greater eating-related distress than those without cachexia. Further prospective and comparative surveys are needed in order to establish indicators and outcomes of interventions, e.g., nutritional support, for nutrition impact symptoms and eating-related distress among advanced cancer patients and their family members in palliative and supportive care settings.

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Compliance with ethical standards

The completion and return of the questionnaire was regarded as consent to participate in this study. The Institutional Review Board approved this study (No. 1804008).

Conflict of interest The authors declare that they have no conflict of interest.

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