

# Beliefs and Perceptions About Parenteral Nutrition and Hydration By Advanced Cancer Patients

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## Research Article

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# Abstract

## Purpose

Objectives of this study are to clarify the beliefs and perceptions of parenteral nutrition and hydration (PNH) by patients with advanced cancer and to examine the relationships between their beliefs and perceptions and cachexia stages.

## Methods

We conducted a questionnaire survey. We asked about patient characteristics and anthropometric measurements. We subsequently asked patients to answer 15 items regarding their beliefs and perceptions. The proportions of patients were calculated. Comparisons were performed using the Mann-Whitney U test. We conducted an explanatory factor analysis and calculated Cronbach's alpha coefficients to assess the internal consistency. A multiple logistic regression analysis was performed to identify the independent factors affecting cancer cachexia stages.

## Results

Among 495 patients, 378 responded. Due to missing data, 357 remained in the frequency distribution analysis and explanatory factor analysis, and 344 were classified into the non-cachexia group (n = 174) and cachexia group (n = 170). Approximately 60% of patients thought that PNH were beneficial. Approximately 70% considered PNH as a standard medical practice. Approximately 70% did not feel that they received a sufficient explanation. There were no significant differences in any items between the two groups. We extracted four conceptual groups and Cronbach's alpha coefficients were 0.87, 0.73, 0.71, and 0.48, respectively. The concept of 'Belief that PNH are harmful' was identified as an independent factor [odds ratio 2.57 (95% confidence interval 1.10-6.01), P = 0.030].

## Conclusions

This study revealed that patients had a strong preference for receiving PNH with or without cancer cachexia.

## Introduction

Routine screening for nutritional risks and optimal nutritional support are needed for all cancer patients [1]. The initiation of parenteral nutrition and hydration (PNH) needs to be considered for patients with an inadequate dietary intake [1]. However, the provision of PNH to patients with advanced cancer is controversial, and there is a growing consensus that PNH are to be forgone in this population because it is unlikely to provide any benefits [1–4]. A recent randomized controlled trial conducted in France demonstrated that PNH did not improve the quality of life or survival of cancer patients with a median survival of 2.5 months [5]. In contrast, a recent prospective multicenter cohort study performed in Japan showed the potentially beneficial effects of PNH on survival among cancer patients with a mean survival

of 5 weeks [6]. Therefore, there is currently no consistency in findings and a paucity of evidence on the beneficial effects of PNH in advanced cancer, which has led to diversity in daily clinical practice [1–4].

In decisions regarding the use of PNH in advanced cancer, beliefs and perceptions about PNH by patients and family members cannot be ignored. Previous studies conducted in Japanese palliative care settings reported that the majority of cancer patients and family members wanted nutritional support to be initiated when patients became unable to intake a sufficient amount of food orally and the negative impact of cachexia, including a lack of appetite, reduced dietary intake, and weight loss, became apparent [7–11]. Furthermore, a large number of patients and family members wished to receive PNH rather than enteral tube feeding under these conditions [9, 11]. An unmet need for PNH may be connected with eating-related distress experienced by patients and family members, which needs to be alleviated by integrated palliative, supportive, and nutritional care [12]. However, it is unclear whether patients and family members were able to distinguish between parenteral nutrition (PN) and parenteral hydration (PH) [9, 11].

On the basis of the above, patients with advanced cancer cachexia seem to have a strong preference for receiving PNH. To the best of our knowledge, the beliefs and perceptions of PNH, PN, and PH by patients who are unable to intake a sufficient amount of food orally have not yet been elucidated. Therefore, we conducted a questionnaire survey of patients with advanced cancer in palliative care settings across Japan to clarify their beliefs and perceptions about PNH, clearly distinguishing between PN and PH, and to examine the relationships between their beliefs and perceptions and cachexia stages, namely, non-cachexia and cachexia, based on criteria from the international consensus [13].

## Methods

The present study was performed as part of a multicenter self-report questionnaire survey to develop measurements for evaluating eating-related distress experienced by patients with advanced cancer and their family members. The survey consisted of a development phase and validation phase. The development phase was conducted at 5 hospitals between July and September in 2020, and the validation phase at 11 hospitals between January and July in 2021. All participating hospitals were required to obtain data up to the designated number of subjects according to the size of the institution. The same dataset was used in this analysis.

Consecutive eligible patients were enrolled during the study period. Inclusion criteria were (1) patients newly referred to palliative care, (2) adult patients ( $\geq 20$  years old), (3) patients with locally advanced or metastatic cancer (hematological neoplasms were included), (4) patients with awareness of the diagnosis of malignancy, and (5) patients with the ability to reply to a self-reported questionnaire. Exclusion criteria were (1) patients forbidden to eat by the physician for medical reasons, e.g., dysphagia or malignant bowel obstruction, and (2) psychological issues recognized in an interview with the primary or palliative care physician. If subjects did not want to participate, we requested them to return the questionnaire with 'no participation' indicated. The completion and return of the questionnaire were

regarded as consent to participate in this study. Ethical approval for the present study was granted by the Institutional Review Board of each hospital.

## Questionnaires

The questionnaire for the present study was developed by the authors based on a previous survey of bereaved family members [11] and discussions among the authors. The face validity of the questionnaire was confirmed by a pilot test with five medical personnel, five palliative care physicians, and three palliative care nurses.

We initially asked about patient characteristics, such as sex, age, the primary cancer site, Eastern Cooperative Oncology Group Performance Status (ECOG PS), setting of care, and treatment status. We also asked patients to report on dietary intakes with the ingesta-Verbal/Visual Analogue Scale (ingesta-VVAS), using 10-point analogue scales to estimate dietary intake in patients with cancer (high scores indicate better dietary intakes) [14].

We subsequently requested patients to report anthropometric measurements, i.e., height, current body weight, and previous body weight, to calculate body mass index (BMI) and % weight loss (WL) in 6 months.

We finally asked patients to answer 15 items regarding their beliefs and perceptions about PNH using the following seven-point Likert scale: (1) absolutely agree, (2) agree, (3) somewhat agree, (4) not either, (5) somewhat disagree, (6) disagree, and (7) absolutely disagree. In the questionnaire, we explained PNH as 'supplying nutrition and hydration through an intravenous drip' in easy Japanese.

## Statistical Analyses

Patient characteristics were presented as n (%) or medians (interquartile ranges) where appropriate.

BMI was calculated by dividing current body weight (kg) by height (m)<sup>2</sup>. %WL was calculated as follows: (current body weight [kg] - previous body weight [kg]) / previous body weight (kg) × 100. Cachexia was %WL in 6 months ≥5% or BMI <20 kg/m<sup>2</sup> + %WL in 6 months ≥2%. Patients above or below these cut-off values were grouped as follows: the non-cachexia group and cachexia group [13].

The proportions of patients with 'absolutely agree', 'agree', or 'somewhat agree' were calculated with a 95% confidence interval (CI) regarding the 15 items about their beliefs and perceptions of PNH. Comparisons of the scores for the 15 items between the non-cachexia and cachexia groups were also performed using the Mann-Whitney U test.

We then conducted an explanatory factor analysis using the principle method with a promax rotation. Based on the results of the factor analysis, attributes with factor loadings less than 0.4 (standardized

regression coefficient) were not excluded. We also calculated Cronbach's alpha coefficients to assess the internal consistency of a set of items in each of the conceptual groups extracted.

A multiple logistic regression analysis was performed to identify the independent factors affecting cancer cachexia stages using patient characteristics and the mean scores for items in each concept of patients' beliefs and perceptions, which were dichotomized with  $<4$  (absolutely agree, agree, and somewhat agree) or  $\geq 4$  (not either, somewhat disagree, disagree, and absolutely disagree). A multivariate model was adjusted for sex, age, the primary cancer site, and ECOG performance status.

All results were considered to be significant when the p-value was less than 0.05. All analyses were performed using SPSS software version 27.0.

## Results

A total of 495 patients were asked to take part in the questionnaire survey, and 378 responded (response rate, 76.4%). None of these patients refused to participate. Twenty-one patients were excluded due to missing data on beliefs and perceptions about PNH, and, thus, 357 remained in the frequency distribution analysis and explanatory factor analysis. Following the exclusion of 13 patients due to missing data on the classification of cachexia stages, 344 were classified into the non-cachexia group ( $n = 174$ ) and cachexia group ( $n = 170$ ).

### Patient characteristics

Patient characteristics are shown in Table 1. Males accounted for 50.8% of patients and median age was 63.0 years old. The lungs (22.0%) were the most common primary cancer site, followed by the liver, biliary system, and pancreas (15.7%), and the upper and lower gastrointestinal tract (13.1%). The proportions of ECOG PS 0-1, 2, and 3-4 were 45.7, 19.2, and 27.5%, respectively. The proportion of outpatient service was 67.9%, followed by a hospital palliative care team (22.5%) and palliative care unit (3.3%). The proportion of chemotherapy was 60.4%, followed by never treated/previous treatment (26.0%).

Table 1  
Patient characteristics (n = 378)

<b>Sex</b>	
Male	192 (50.8)
Female	181 (47.9)
Age in years	63.0 (53.0-72.0)
Age	
<65	201 (50.8)
65-74	111 (28.0)
≥75	61 (15.4)
Primary cancer site	
Upper and lower gastrointestinal tract	52 (13.1)
Liver, biliary system, and pancreas	62 (15.7)
Lungs	87 (22.0)
Others	167 (42.2)
ECOG performance status	
0-1	181 (45.7)
2	76 (19.2)
3-4	109 (27.5)
Setting of care	
Outpatient service	269 (67.9)
Hospital palliative care team	89 (22.5)
Palliative care unit	13 (3.3)
Treatment status	
Pre-chemotherapy	24 (6.1)
Chemotherapy	239 (60.4)
Never treated/previous treatment	103 (26.0)
Dietary intake	6.0 (4.0-8.0)
Body mass index (kg/m <sup>2</sup> )	20.8 (18.5-23.5)

<b>Sex</b>	
Weight loss in 1 month, yes	158 (48.8)
Cachexia, yes	170 (45.0)
Symptomatic fluid retention, yes	80 (21.2)
<p>Values represent n (%) or medians (interquartile ranges) where appropriate. The sums of some percentages do not add up to 100% due to missing values. Dietary intakes were measured with the ingesta-Verbal/Visual Analogue Scale using 10-point analogue scales. Cachexia was based on criteria from the international consensus.</p> <p>ECOG, Eastern Cooperative Oncology Group.</p>	

### **Prevalence of beliefs and perceptions about PNH**

The prevalence of beliefs and perceptions about PNH is shown in Table 2.

Table 2  
Prevalence of beliefs and perceptions about parenteral nutrition and hydration

Items	Absolutely agree, agree, and somewhat agree; n (%), 95% CI	N
Q1. Parenteral nutrition serves as a substitute for oral nutrition.	203 (56.9), 49-59	357
Q2. Parenteral hydration serves as a substitute for oral hydration.	247 (69.2), 64-74	357
Q3. When I cannot eat enough, parenteral nutrition is needed.	238 (66.9), 62-72	356
Q4. When I cannot eat enough, parenteral hydration is needed.	252 (70.8), 66-75	356
Q5. If my family member were a patient and could not eat enough, parenteral nutrition would be needed.	275 (77.5), 73-82	355
Q6. If my family member were a patient and could not eat enough, parenteral hydration would be needed.	289 (81.4), 77-85	355
Q7. When a patient cannot eat enough, the administration of parenteral nutrition and hydration is naturally required.	242 (68.4), 63-73	354
Q8. Parenteral nutrition and hydration help a patient live longer.	214 (61.0), 64-74	351
Q9. Parenteral nutrition and hydration contribute to cancer progression.	22 (6.3), 4-9	347
Q10. Parenteral nutrition and hydration alleviate some symptoms, such as fatigue and dry mouth.	196 (57.1), 52-62	343
Q11. Parenteral nutrition and hydration worsen some symptoms, such as edema and ascites.	67 (19.5), 16-24	343
Q12. Parenteral nutrition and hydration improve the condition of a patient.	194 (55.9), 51-61	347
Q13. I have received a full explanation on the benefits and risks of parenteral nutrition and hydration.	97 (28.7), 24-34	338
Q14. I have sufficient information on parenteral nutrition and hydration.	52 (15.1), 12-19	345
Q15. The opinions of medical staff are important in the issue of parenteral nutrition and hydration.	278 (79.4), 75-83	350
CI, confidence interval.		

Q1-6: Items regarding preferences for PN and PH, which were clearly distinguished

- 56.9 and 69.2% of patients thought that PN and PH were substitutes for oral nutrition and hydration, respectively.
- 66.9 and 70.8% of patients preferred to receive PN and PH, respectively.
- 77.5 and 81.4% of patients needed PN and PH for their family members, respectively.
- The preference for PH was consistently higher than that for PN.

#### Q7-12: Items regarding perceptions of PNH

- 68.4% of patients thought that PNH need to be a standard medical practice.
- 55.9-61.0% of patients thought that PNH were beneficial and favorable, while they rarely considered PNH to be harmful or unfavorable (6.3-19.5%).

#### Q13-15: Items regarding the explanation of and information on PNH

- Patients rarely thought that they received a full explanation or received sufficient information (15.1-28.7%).
- 79.4% of patients depended on medical staff to make a decision on PNH.

#### Comparison of beliefs and perceptions about PNH between the non-cachexia group and cachexia group

Differences in beliefs and perceptions about PNH between the two groups are shown in Table 3. There were no significant differences in any items between the two groups.

Table 3

Comparison of beliefs and perceptions about parenteral nutrition and hydration between the non-cachexia group and cachexia group (n = 344)

Items	Non-cachexia	Cachexia	P value
Q1. Parenteral nutrition serves as a substitute for oral nutrition.	3.5 ± 1.7, 3.0	3.5 ± 1.8, 3.0	0.75
Q2. Parenteral hydration serves as a substitute for oral hydration.	3.0 ± 1.5, 3.0	3.0 ± 1.5, 3.0	0.66
Q3. When I cannot eat enough, parenteral nutrition is needed.	3.2 ± 1.6, 3.0	3.0 ± 1.6, 3.0	0.31
Q4. When I cannot eat enough, parenteral hydration is needed.	3.1 ± 1.6, 3.0	2.8 ± 1.5, 2.0	0.10
Q5. If my family member were a patient and could not eat enough, parenteral nutrition would be needed.	2.7 ± 1.4, 2.0	2.6 ± 1.5, 2.0	0.32
Q6. If my family member were a patient and could not eat enough, parenteral hydration would be needed.	2.5 ± 1.3, 2.0	2.4 ± 1.3, 2.0	0.10
Q7. When a patient cannot eat enough, the administration of parenteral nutrition and hydration is naturally required.	2.8 ± 1.3, 3.0	3.0 ± 1.5, 3.0	0.44
Q8. Parenteral nutrition and hydration help a patient live longer.	3.1 ± 1.3, 3.0	3.3 ± 1.5, 3.0	0.56
Q9. Parenteral nutrition and hydration contribute to cancer progression.	5.1 ± 1.3, 5.0	5.2 ± 1.3, 5.0	0.32
Q10. Parenteral nutrition and hydration alleviate some symptoms, such as fatigue and dry mouth.	3.5 ± 1.4, 3.0	3.3 ± 1.3, 3.0	0.14
Q11. Parenteral nutrition and hydration worsen some symptoms, such as edema and ascites.	4.3 ± 1.2, 4.0	4.5 ± 1.3, 4.0	0.10
Q12. Parenteral nutrition and hydration improve the condition of a patient.	3.4 ± 1.2, 3.0	3.3 ± 1.2, 3.0	0.51
Q13. I have received a full explanation on the benefits and risks of parenteral nutrition and hydration.	4.1 ± 1.5, 4.0	4.1 ± 1.5, 4.0	0.89
Q14. I have sufficient information on parenteral nutrition and hydration.	4.9 ± 1.6, 5.0	4.8 ± 1.5, 5.0	0.30
Q15. The opinions of medical staff are important in the issue of parenteral nutrition and hydration.	2.6 ± 1.4, 2.0	2.5 ± 1.4, 2.0	0.50
Values represent means ± standard deviations and medians.			

### Explanatory factor analysis and internal consistency of a set of items

We extracted four conceptual groups as follows: 'Belief that PNH are a standard medical practice I want' from 5 items, 'Belief that PNH are beneficial' from 6 items, 'Perception that knowledge about PNH is enough' from 2 items, and 'Belief that PNH are harmful' from 2 items. Cronbach's alpha coefficients were 0.87, 0.73, 0.71, and 0.48, respectively (Table 4).

Table 4

Factor validity of beliefs and perceptions about parenteral nutrition and hydration: four core domains (n = 357)

	Standardized regression coefficients				Communality
	F1	F2	F3	F4	
F1: Belief that parenteral nutrition and hydration are a standard medical practice I want (mean = 2.79, SD = 1.48., Cronbach's $\alpha$ = 0.87)					
Q5. If my family member were a patient and could not eat enough, parenteral nutrition would be needed.	<b>0.993</b>	-0.209	0.068	-0.035	0.817
Q6. If my family member were a patient and could not eat enough, parenteral hydration would be needed.	<b>0.918</b>	-0.161	0.036	-0.054	0.715
Q3. When I cannot eat enough, parenteral nutrition is needed.	<b>0.712</b>	0.183	-0.034	0.031	0.678
Q4. When I cannot eat enough, parenteral hydration is needed.	<b>0.650</b>	0.238	-0.049	-0.013	0.640
Q7. When a patient cannot eat enough, the administration of parenteral nutrition and hydration is naturally required.	<b>0.469</b>	0.125	-0.021	0.017	0.298
F2: Belief that parenteral nutrition and hydration are beneficial (mean = 3.15, SD = 1.47, Cronbach's $\alpha$ = 0.73)					
Q12. Parenteral nutrition and hydration improve the condition of a patient.	-0.101	<b>0.872</b>	0.076	-0.076	0.695
Q10. Parenteral nutrition and hydration alleviate some symptoms, such as fatigue and dry mouth.	-0.071	<b>0.658</b>	-0.005	0.029	0.390
Q2. Parenteral hydration serves as a substitute for oral hydration.	0.347	<b>0.456</b>	-0.077	0.000	0.491
Q8. Parenteral nutrition and hydration help a patient live longer.	0.208	<b>0.350</b>	-0.004	0.123	0.265
Q1. Parenteral nutrition serves as a substitute for oral nutrition.	0.320	<b>0.343</b>	-0.018	0.105	0.352
Q15. The opinions of medical staff are important in the issue of parenteral nutrition and hydration.	0.066	<b>0.255</b>	0.138	-0.116	0.122

	Standardized regression coefficients				
F3: Perception that knowledge about parenteral nutrition and hydration is enough (mean = 4.47, SD = 1.57, Cronbach's $\alpha$ = 0.71)					
Q14. I have sufficient information on parenteral nutrition and hydration.	-0.021	0.054	<b>0.735</b>	0.013	0.552
Q13. I have received a full explanation on the benefits and risks of parenteral nutrition and hydration.	0.046	0.040	<b>0.709</b>	0.019	0.523
F4: Belief that parenteral nutrition and hydration are harmful (mean = 4.76, SD = 1.35, Cronbach's $\alpha$ = 0.48)					
Q9. Parenteral nutrition and hydration contribute to cancer progression.	-0.011	-0.091	0.042	<b>0.776</b>	0.612
Q11. Parenteral nutrition and hydration worsen some symptoms, such as edema and ascites.	-0.026	0.069	-0.012	<b>0.459</b>	0.216
Cumulative proportion, 49.1%					
F#, Factors 1 to 4; SD, standard deviation; Cronbach's $\alpha$ , Cronbach's alpha coefficients. Boldfaced numbers indicate attributes belonging to each domain.					

### Multiple logistic regression analysis

The results of a multiple logistic regression analysis performed to identify the independent factors affecting cancer cachexia stages using patient characteristics and the four concepts of beliefs and perceptions about PNH are shown in Table 5. The concept of 'Belief that PNH are harmful' was identified as an independent factor [odds ratio (OR) 2.57 (95% CI 1.10-6.01), P = 0.030].

Table 5

Estimated crude and adjusted odds ratios for a logistic regression model assessing the effect of beliefs and perceptions about parenteral nutrition and hydration on cachexia stages (N = 344)

	Crude OR (95% CI)	<i>p</i>	Adjusted OR (95% CI)	<i>p</i>
Sex				
Male	1.00 (reference)		1.00 (reference)	
Female	0.81 (0.53- 1.24)	0.32	1.02 (0.62- 1.68)	0.94
Age				
<65	1.00 (reference)		1.00 (reference)	
65-74	1.99 (1.21- 3.27)	0.007	2.08 (1.15- 3.76)	0.015
≥75	0.83 (0.45- 1.53)	0.55	1.10 (0.53- 2.27)	0.80
Primary cancer site				
Upper and lower gastrointestinal tract	1.00 (reference)		1.00 (reference)	
Liver, biliary system, and pancreas	1.28 (0.60- 2.73)	0.52	1.16 (0.50- 2.73)	0.73
Lungs	1.39 (0.69- 2.83)	0.36	1.11 (0.50- 2.47)	0.79
Others	0.84 (0.44- 1.60)	0.60	0.72 (0.35- 1.49)	0.37
ECOG performance status				
0-1	1.00 (reference)		1.00 (reference)	
2	1.23 (0.71- 2.13)	0.47	1.15 (0.61- 2.16)	0.66
3-4	2.03 (1.23- 3.36)	0.006	1.96 (1.09- 3.54)	0.025
Factor 1				
Absolutely agree, agree, and somewhat agree (mean scores <4)	1.00 (reference)		1.00 (reference)	

	Crude OR (95% CI)	<i>p</i>	Adjusted OR (95% CI)	<i>p</i>
Not either, somewhat disagree, disagree, and absolutely disagree (mean scores $\geq 4$ )	0.61 (0.34-1.10)	0.10	0.79 (0.39-1.63)	0.53
Factor 2				
Absolutely agree, agree, and somewhat agree (mean scores $< 4$ )	1.00 (reference)		1.00 (reference)	
Not either, somewhat disagree, disagree, and absolutely disagree (mean scores $\geq 4$ )	0.72 (0.41-1.27)	0.26	0.84 (0.41-1.69)	0.62
Factor 3				
Absolutely agree, agree, and somewhat agree (mean scores $< 4$ )	1.00 (reference)		1.00 (reference)	
Not either, somewhat disagree, disagree, and absolutely disagree (mean scores $\geq 4$ )	0.79 (0.48-1.31)	0.36	0.74 (0.42-1.31)	0.30
Factor 4				
Absolutely agree, agree, and somewhat agree (mean scores $< 4$ )	1.00 (reference)		1.00 (reference)	
Not either, somewhat disagree, disagree, and absolutely disagree (mean scores $\geq 4$ )	1.64 (0.79-3.43)	0.19	2.57 (1.10-6.01)	0.030
Thirty-four subjects were excluded due to missing data: beliefs and perceptions about parenteral nutrition and hydration ( $n = 21$ ) and cachexia stages ( $n = 13$ ). A multivariate model adjusted for sex, age, the primary cancer site, and ECOG performance status.				
ECOG, Eastern Cooperative Oncology Group; OR, odds ratio; CI, confidence interval.				

## Discussion

To the best of our knowledge, this is the first study to conduct a questionnaire survey of patients with advanced cancer receiving palliative care to clarify their beliefs and perceptions about PNH, clearly distinguishing between PN and PH. The relationships between their beliefs and perceptions and cachexia stages were also examined.

Regarding the perceived value of PNH, approximately 60% of patients thought that PNH were beneficial and they rarely assumed that PNH were harmful. Therefore, approximately 70% of patients thought that PNH needed to be a standard medical practice when their intake of food was insufficient. However, more than 70-80% of patients did not feel that they received a sufficient explanation and information or that they had adequate knowledge. Therefore, a large number of patients were dependent on their primary physicians and followed the decisions made by medical staff.

The previous survey of the bereaved family members of patients with advanced cancer reported that 60-80% of family members believed that PNH were beneficial and that 80-90% expressed a need for PNH when the patient was unable to intake a sufficient amount of food [11]. In addition, more than 70% of family members had insufficient information on PNH and more than 50% did not receive a full explanation about PNH [11]. Family members were also likely to depend on medical staff when they had to make a decision regarding PNH for their loved one [11].

Patients and family members both appeared to be able to distinguish between PN and PH based on the present results and our previous findings because both showed that a preference for PH that was consistently higher than that for PN [11]. Patients/family members were more likely to request to receive/supply water at least through an intravenous drip to prevent dehydration when the patient was unable to drink a sufficient amount of water. Furthermore, a study conducted on patients and family members receiving hospice care indicated the attachment of significant meaning, such as hope and dignity, to PH, which may increase the difficulties associated with the discontinuation of this treatment [15]. On the other hand, the findings of 2 nationwide surveys on physician and nurse attitudes toward PH for terminally ill cancer patients reported that the majority of palliative care unit physicians and nurses had a perception that withholding PH alleviated several physical symptoms [16].

Based on these findings, the decision to withhold or withdraw PNH made by medical staff without an appropriate process may upset patients and their family members if they believe that PNH are a standard medical practice when the patient becomes unable to intake sufficient amounts of food and water orally. Patients and family members had similar preferences regarding PNH; however, family members were reluctant to withhold PNH for their loved one even if the patient confidently decided to forgo PNH [17]. On the other hand, the majority of patients considered their family members' opinions to be crucial for making decisions regarding PNH [17]. Differences in the perception of this matter between patients, family members, and medical staff may generate conflict, leading to eating-related distress experienced by patients and family members. Additionally, cancer cachexia appears to be more distressing for family members than for patients [10].

A review proposed that the initiation or discontinuation of PNH must be accompanied by an acceptable clinical explanation of the associated benefits and risks to patients and family members despite limited evidence, which may remove their misconceptions resulting from a lack of information and knowledge [12]. Other reviews suggested that PNH were more significant in their symbolic value, such as a feeling of non-abandonment and a relationship of mutual trust between patients/family members and medical staff, rather than their clinical effectiveness [18–20]. According to the ESPEN guidelines on the ethical aspects of artificial nutrition and hydration, decisions have to be made in consideration of social, cultural, emotional, and existential aspects as well as patients' spiritual and ethnic backgrounds [21]. Expert opinion/guidance on the use of clinically assisted nutrition in patients with advanced cancer edited by the Multinational Association of Supportive Care in Cancer (MASCC) concluded that PNH are not indicated for the management of cachexia-related symptoms, but that every patient needs individualized management and patient-centered care [22]. Therefore, medical staff have to provide a full explanation

and educate patients and family members as much as possible, and medical staff also need to recognize the perceived value of PNH to patients and family members in end-of-life discussions.

Regarding the relationships between patients' beliefs and perceptions about PNH and cachexia stages, no significant differences were observed between the non-cachexia and cachexia groups. The results obtained also identified the concept of 'Belief that PNH are harmful' as an independent factor. However, a correlation was not observed between cachexia stages and the following three concepts: 'Belief that PNH are a standard medical practice I want', 'Belief that PNH are beneficial', and 'Perception that knowledge about PNH is enough'. Several reasons need to be considered as follows. Patients are likely to think that PNH are a standard medical practice, that PNH are beneficial, and that knowledge about PNH is not sufficient with or without cancer cachexia. In contrast, they rarely feel that PNH are harmful with or without cancer cachexia; however, the negative perception of PNH may decrease if cachexia-related symptoms become more apparent. The previous surveys, which demonstrated that patients with cachexia had more severe cachexia-related symptoms and greater eating-related distress than those without cachexia [10] and that patients with cachexia expressed a greater need for nutritional support [9], appear to support this result. Further studies are warranted.

The strength of the present study is its methodology, the high response rate to the questionnaire, and all respondents agreeing to participate. Despite these strengths, this study has several limitations that need to be addressed. Since non-responding subjects were not included in the analysis, the results of the present study cannot be generalized. Moreover, since this study employed a cross-sectional analysis of a questionnaire survey, survival data were not obtained. Furthermore, the questionnaire for the present study, which has not been validated, may have led confirmation bias. However, there is currently no validated tool to investigate beliefs and perceptions about PNH by patients with advanced cancer.

## **Conclusion**

The present study showed that patients with advanced cancer prefer receiving PNH when they are unable to intake a sufficient amount of food orally. Every patient requires individualized management and nutritional support, which needs to be considered along with the intention of patients and family members as much as possible. However, medical staff need to address the imbalance between the hope of patients and family members and reality with the provision of correct information and education when PNH appear to be disproportionate care. The primary goal of palliative care is to help patients live as well as possible for as long as possible with their loved ones.

## **Declarations**

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## Conflict of interest

The authors have read and understood the journal's policy on the declaration of interest and declare that there is no conflict of interest.

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The authors of this manuscript certify that they comply with the ethical guidelines for editorship and publishing in the Journal.

## Author contributions

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