Psychosocial Support and Nutrition Counselling Among Patients with Cancer Receiving Chemotherapy: A Mixed-Methods Study

Saori Koshimoto (s_koshi@kasei-gakuin.ac.jp)
Tokyo Kasei Gakuin Daigaku - Chiyoda Sanbancho Campus: Tokyo Kasei Gakuin Daigaku
https://orcid.org/0000-0002-6784-8706

Tomoko Yamazaki
Tokyo Medical and Dental University: Tokyo Ika Shika Daigaku

Koji Amano
National Cancer Center Hospital: Kokuritsu Gan Kenkyu Center Chuo Byoin

Jun Kako
Hyogo Kenritsu Daigaku

Masako Arimoto
Tokyo Ika Shika Daigaku Igakubu Fuzoku Byoin

Keiko Saitou
Tokyo Ika Shika Daigaku Igakubu Fuzoku Byoin

Akiko Hashizume
Tokyo Ika Shika Daigaku Igakubu Fuzoku Byoin

Takashi Takeuchi
Tokyo Medical and Dental University Graduate School of Medical and Dental Sciences: Tokyo Ika Shika Daigaku Daigakin Ishigaku Sogo Kenkyuka

Eisuke Matsushima
Tokyo Medical and Dental University Graduate School of Medical and Dental Sciences: Tokyo Ika Shika Daigaku Daigakin Ishigaku Sogo Kenkyuka

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Abstract

Purpose

Cancer chemotherapy causes nutrition impact symptoms (NIS) that affect patient diet and nutrition. Such patients, therefore, require nutrition counselling. In this study, we aimed to 1) identify the psychosocial factors of patients who require nutrition counselling and 2) articulate the specific details of the issues for which patients desire advice.

Methods

We conducted anthropometric measurements, surveys using questionnaires, and interviews with patients receiving outpatient chemotherapy for head and neck, oesophageal, gastric, colorectal, and lung cancers. The questionnaire included items on NIS, patients' experience of eating-related distress (ERD), and quality of life (QOL). Interviews were conducted with patients who required nutrition counselling regarding specific issues. We provided nutrition counselling in two sessions.

Results

Of the 151 patients, 42 required nutrition counselling. The psychosocial factors affecting the required nutrition counselling were the number of people in the household, employment status, QOL, and ERD. The contexts of the specific issues patients wanted to discuss included self-management, distress, understanding and sympathy, anxiety, and confusion.

Conclusion

Nutrition counselling for patients receiving cancer chemotherapy needs to involve multidisciplinary support that considers psychological (anxiety, confusion) and social (family structure, employment situation) aspects as additional means to address NIS.

Introduction

Cancer chemotherapy causes nutrition impact symptoms (NIS) such as taste disorder, olfactory disorder, and constipation, and aggravates patients' nutritional issues [1, 2]. Studies have shown that 50–80% of patients with advanced cancer experience cachexia, a nutritional metabolic disorder characterised by weight loss, which affects their quality of life (QOL) and for which nutritional support is required [3-5]. Approximately 80% of patients with cancer experience anorexia and weight loss [4]. Moreover, numerous patients with advanced cancer, as well as their family members, suffer from eating-related distress (ERD) [6]. In a previous research, it was found that 77.5% of the outpatients receiving chemotherapy needed nutrition counselling, and the need for nutrition counselling was also found to be associated with ERD [7].

The European Society for Clinical Nutrition and Metabolism practical guideline states: ‘We recommend nutritional intervention to increase oral intake in cancer patients who are able to eat but are malnourished or at risk of malnutrition. This includes dietary advice, the treatment of symptoms and derangements impairing food intake (NIS), and offering oral nutritional supplements (ONS)’ [8]. However, it does not mention any psychosocial aspects.

Nevertheless, patients may require nutrition counselling, the objective of which is not limited to ensuring adequate caloric and protein intake. Diet is related to various contextual factors that affect patients, such as anxiety regarding weight loss, building physical strength to fight the disease, and the desire to maintain pre-illness lifestyles as much as possible. Therefore, in addition to providing support according to each patient’s pathophysiology, nutrition counselling must use a holistic approach. While some studies have explored the views of patients with cancer in relation to nutrition support using mixed-methods study approaches [9, 10], no studies have investigated psychosocial factors related to nutrition counselling, and few studies have examined the specific circumstances in which patients require counselling. Therefore, it is necessary to investigate the psychosocial factors that cause patients to feel anxious and irritable regarding diet and nutrition issues.

Thus, in this secondary analysis, we aimed to identify the psychosocial factors of patients who require nutrition counselling and qualitatively refine the specific issues that patients discuss during nutrition counselling. We believe that this study will help provide improved holistic support, tailored to patients’ needs.

Objectives

1) To elucidate psychosocial factors of patients who require nutrition counselling.

2) To elucidate specific issues that patients who require nutrition counselling wish to discuss.

Materials And Methods

Participants

A survey was conducted between August 2016 and November 2017 in an urban university hospital in Japan. Participants were patients receiving outpatient chemotherapy for head and neck, oesophageal, gastric, colorectal, and lung cancers. The inclusion criteria comprised individuals aged 20–80 years with a cancer diagnosis, who had undergone chemotherapy, had never received nutrition counselling on chemotherapy, were able to understand Japanese, and had provided written informed consent. Patients with severe dementia/mental disorders, those deemed unable to participate by a doctor owing to psychological/physical reasons, and those unavailable on the survey day were excluded.

Study design

This study involved a secondary analysis that combined qualitative assessments of patients' subjective feelings with quantitative analysis [7]. A survey description was provided to patients expressing interest in participating. Those who provided written consent underwent anthropometric measurements and completed the questionnaire. After confirming that they required nutrition counselling, they were asked what specific issues they desired to discuss. Two individual nutrition counselling sessions were scheduled to be run by registered dieticians specialising in cancer, as twice-monthly nutrition counselling is covered by medical insurance according to a general implementation schedule in Japan. The first nutrition consultation was conducted for 40 minutes, and the second was performed after a period of approximately 1 month to verify the intervention effects. Before and after the sessions, the patients' body mass index (BMI), C-reactive protein (CRP) and serum albumin (Alb) levels, modified Glasgow Prognostic Score (mGPS, a measure used in the assessment of cachexia from the combined Alb and CRP scores), NIS, QOL, and ERD were measured. Anthropometric measurements comprised BMI, muscle mass, body fat percentage, estimated bone mass, and body water content; these were performed using a bioelectrical impedance analysis (TANITA BC308). All surveys, sessions, measurements, and nutritional guidance were scheduled for outpatient chemotherapy practice days.

Questionnaires

The Patient-Generated Subjective Global Assessment-Short Form (PG-SGA-SF) was used to investigate NIS [11]. The items included weight history, anorexia, nausea, constipation, diarrhoea, thirst, dysgeusia, olfactory disorder, vomiting, dysphagia, early satiety, fatigue, and pain. Patients' experience of ERD was assessed using the ERD questionnaire [12], which comprises 19 items in relation to distress concerning ERD treatment, patients' feelings about ERD, and strained relationships with family members because of ERD. Further, QOL assessments were conducted using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0 (EORTC-QLQ-C30) [13]. The questions included those on the global health domain and physical functioning domain; items included role-, emotional-, cognitive-, and social functioning and symptom scales. The social factors survey included questions on the number of people in the household, employment status, monthly food expenses, and who prepares meals.

Interviews

Semi-structured interviews were conducted with patients who required nutrition counselling. Patients were asked: 1) Do you think nutrition counselling is necessary for chemotherapy treatment? 2) Do you require nutrition counselling from a dietician now? 3) What do you desire to discuss in this nutrition counselling? The interview questions were designed to elicit descriptive responses from the patients. Following the attending physician's instructions, a registered dietician specialising in cancer conducted two individual nutrition counselling sessions in response to the patients' requirements. The interviewer asked 42 patients who required nutrition counselling about the specific issues they discussed and recorded their responses on a survey form. These were then encoded and categorised using content analysis [14].

Statistical analysis

The factors influencing nutrition counselling were studied using logistic regression analysis (maximum likelihood estimation). A Wilcoxon signed-rank test was performed to compare changes occurring after nutrition counselling. SPSS version 25 (IBM, Armonk, NY, USA) was used, with statistical significance set at 5% (both sides); missing values were excluded from each item.

Content analysis based on Krippendorff's guidelines [14] was performed on the specific issues the patients discussed during nutrition counselling. The contents of the records were encoded, and those with similar meanings were placed into sub-categories, which were then organised into conceptual categories. The content analysis was performed independently by two researchers, under the supervision of two palliative care specialists who had experience in content research and clinical experience in the field of palliative care, to ensure its reliability. A common concept emerged from the content analysis and from logistic regression analysis of NIS, QOL, and ERD. Therefore, as part of the mixed-methods approach, the qualitative analysis results were integrated with the quantitative data [9, 12].

Results

Patient characteristics

We recruited 174 patients, of whom 23 were excluded. Figure 1 illustrates the research plan, and Table 1 illustrates patients' characteristics. Of the 151 patients, 42 (27.8%) required nutrition counselling, and eight (19.0%) completed individual counselling.

Table 1
Characteristics of patients who required nutrition counselling (n=42)

	n(%)
Female	11(26.2)
Male	31(73.8)
Cancer site/type	
Head and neck	2(4.8)
Oesophageal	5(11.9)
Gastric	4(9.5)
Colorectal	17(40.5)
Lung	14(33.3)
Symptoms	
Anorexia	19(45.2)
Weight loss of 2% or more	9(21.4)
Constipation	16(38.1)
Diarrhoea	7(16.7)
Thirst	9(24.4)
Dysgeusia	20(47.6)
Olfactory disorder	11(26.2)
Vomiting	10(23.8)
Dysphagia	8(19.0)
Early satiety	9(21.4)
Fatigue	22(52.4)
Pain	15(35.7)
	Mean±standard deviation
Age (years)	65.5±9.1
Disease stage	3.2±0.8
Body mass index kg/(cm)^2	21.7±3.6

Note. EORTC-QLQ C30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0

	n(%)
Serum albumin g/dL	3.8±0.4
C-reactive protein mg/dL	0.8±1.2
Modified Glasgow Prognostic Score	1.7±0.1
Patient-Generated Subjective Global Assessment-Short Form score	8.6±5.0
Quality of life score (EORTC-QLQ-C30)	
Global health status	52.8±16.0
Physical functioning	75.4±22.7
Role functioning	76.6±24.7
Emotional functioning	80.2±18.1
Cognitive functioning	82.5±19.6
Social functioning	72.4±26.0
Note. EORTC-QLQ C30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0	

Psychosocial factors that influenced patients' nutrition counselling requirements

Table 2 illustrates the psychosocial factors that influenced nutrition counselling requirements, which comprised the dependent variable. The independent variables were age, QOL, SGA-SF score, employment status (yes vs. no), number of people in the household (two or fewer vs. three or more), meal preparation (self vs. someone else), food expenses (25,000 yen/month or more vs. under 25,000 yen/month; in Japan, the mean cost of food per person is approximately 25,000 yen/month), and ERD (distress from ERD treatment, from patients' feelings about ERD, and from strained relationships with family members because of ERD). The factors that influenced counselling requirements included the number of people in the household (p=0.014), employment status (p=0.015), QOL (p=0.023), and distress from ERD treatment (p=0.036). Thirty-three (80.5%) patients who required nutrition counselling lived alone or with another person. Patients who were being treated while working and who had low QOL, and those who experienced ERD with treatment, tended to require nutrition counselling.

Table 2
Psychosocial factors that influenced nutrition counselling requirements.

	Required nutritional counselling (n=42)		**Did not require nutritional counselling (n=109)**		**P value[a]**
Number of people in the household (one or two) n(%)	33(80.5)		62(57.4)		0.009
Employment status (working) n(%)	18(42.9)		34(31.8)		0.203
Global health status on QOL [c] Mean±standard deviation (SD)	52.8±16.0		60.3±18.8		0.028
Distress from ERD treatment [d] Mean±SD	2.4±0.6		2.1±0.5		0.002
	Partial regression coefficient	Odds ratio	95% confidence interval		P value[b]
			Min.	Max.	
Number of people in the household	1.39	4.00	1.33	12.02	0.014*
Employment status	-1.14	0.32	0.13	0.80	0.015*
Global health status on QOL [c]	-0.03	0.97	0.95	1.00	0.023*
Distress from ERD treatment [d]	0.93	2.52	1.06	6.00	0.036*

[a] Mann-Whitney's U-test

[b] Logistic regression analysis (maximum likelihood estimation), Dependent variable: Require nutrition counselling, model coefficient omnibus test model <0.0001, Hosmer–Lemeshow test significance 0.178, Proportion of correctness 78.7%

[c] Quality of life (QOL) scored using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0

[d] Eating-related distress (ERD) calculated by the mean score for all ERD assessment items (response options: 1=strongly disagree, 2=disagree, 3=agree, 4=strongly agree)

*<0.05

Specific issues that led to a desire for nutrition counselling

Table 3 illustrates the results of the content analysis of the specific issues patients discussed during nutrition counselling.

Table 3
Issues patients desired to discuss during nutrition counselling

Category	Sub-categories (n)	Codes (n)
Motivation for self-management	Information regarding nutritional balance (11)	I want to know about the absorption of fats and nutrients, and meal combinations. (2)
		I want advice about specific foods. (3)
		I want to know more about nutrients. (1)
		I want to know more about quality/quantity and nutrition. (2)
		I want informational materials about the classification of nutrients. (1)
		What meals have a high nutrient content and provide a good nutritional balance? (1)
		Are my portion sizes large enough? (1)
	Information on how to adjust diet to improve physical condition (6)	Which foods are easy to digest? (2)
		Which foods increase physical strength? (1)
		How can I increase my weight? No matter what I do, my weight doesn't seem to increase. (1)
		What can I eat and is easy for me to eat? (1)
		I have heard that salivary gland massaging is good. Please teach me how to do it. (1)
	Information regarding foods beneficial for treatment (7)	What foods can I eat despite cancer? (2)
		What foods shouldn't I eat due to cancer? (1)
		Which foods are effective against cancer? (2)
		How can I adjust my foods, nutrition, and meals according to my type of cancer? (1)
		Which foods can help with the treatment without supplements? (1)
Distress from symptoms	Distress from nutrition impact symptoms and side effects (12)	I do not know about suitable menus during chemotherapy. (1)
		I do not know how to manage medication with food (ingredients). (1)
		Which cooking methods are suitable for my symptoms? (1)
		How can I deal with the smell of certain foods? (1)

Category	Sub-categories (n)	Codes (n)
		It is difficult to improve my anaemia. (1)
		I worry that chemotherapy will harm the function of my kidney and liver. What should I eat to prevent this? (1)
		How can I supplement my nutrition when I cannot eat owing to mouth ulcers? (1)
		How can I deal with taste disorders? (1)
		It is difficult to control constipation. (1)
		What can I eat when my condition worsens due to side effects? (1)
		It is difficult to control the timing around medication when I cannot eat owing to side effects. (2)
	Difficulty in handling multiple complications (6)	It is difficult to coordinate diabetes and cancer treatments. (4)
		I have both hypertension and diabetes; therefore, I am confused over which treatment to prioritise. (1)
		What can I eat when I have intestinal obstruction? (1)

Seeking understanding and sympathy	Eagerness for others to understand their inability to eat (10)	I am doing my best but cannot eat because my throat hurts. (1)
		I want you to know that it is difficult to prepare meals because of severe numbness. (1)
		You may not realise it, but I cannot eat because of my mouth ulcers. (1)
		I know I must eat, but it is difficult due to perleche and taste disorder. (1)
		I want to eat, but when I do, the food gets stuck in my throat, and I cannot eat enough. (1)
		I had nutrition counselling in the past, but I could not do all the things I was advised. (1)
		I understand that I should eat what I can when I want to eat, but I cannot eat. (2)
	Desire for others to understand their symptoms (3)	I am worried about having diarrhoea at work. (2)
		I want my spouse to understand changes in my sense of taste and provide foods that are easy to eat. (1)
Anxiety and confusion	Anxiety about being unable to eat in the future (8)	What should I do if I cannot eat? (4)
		What will happen in the future? (2)
		I would like advice regarding losing weight if the need arises. (2)
	The burden of changing dietary habit (5)	I always eat the same things. (1)
		I have no appetite, but I can drink alcoholic beverages. (1)
		It is difficult to find foods I can and should eat. (1)
		I am struggling with my dislike of vegetables. (1)
		I am struggling with being a picky eater. (1)
	Swayed by uncertain information about foods (6)	Can I eat meat, eel, or purified rice? I heard these foods are bad. (1)
		Are carrots, *aojiru* (juice made of green leafy vegetables), and hydrogen water effective? Is there any scientific basis for this? (1)
		I cannot eat vegetables, but is it ok to drink *aojiru*? (1)
		I read a cookbook by Dr. A of a certain university, which said that I should prepare meals with brown rice, vegetables, and fish. However, I lost weight when I followed that advice. (1)
		I heard that unpolished rice is good against cancer, but I lost weight when I followed this advice. (1)

		Does a low-carbohydrate diet inhibit the growth of cancer cells? (1)
	Fixated on dietary rules (5)	I am worried about getting an infection when I take off my mask to eat. (1)
		I was told to avoid raw foods in post-operative counselling, so I have avoided them for years. (1)
		I was told to avoid brown rice and seaweed in post-operative counselling, so I have avoided them for years. (1)
		I use steroids to improve my appetite; can I take them with milk to protect my stomach? (1)
		I suck on candy to reduce the side effects, but my family says that I have no appetite because of this. Does candy suppress one's appetite? (1)

Discussion

Our research findings indicated that nutrition counselling for patients with cancer undergoing outpatient chemotherapy should include multidisciplinary team support in relation to nutrition symptoms and psychosocial factors.

Nutrition support affects patients' symptoms

The patients desired another perspective on their diet management. Additionally, diet could possibly motivate patients to seek treatment, especially those with a positive attitude towards diet self-management and those willing to use dietary measures to manage their illness. However, patients appeared to experience distress from eating problems due to NIS, side effects, or multiple complications. Furthermore, they seemed to confuse less relevant information to be less scientifically rigorous guidelines or dietary rules. Therefore, distress and confusion stemming from NIS need to be managed by providing individual nutrition counselling and information on enriching foods, oral nutritional supplements, enteral and parenteral nutrition, exercise training, and supportive care to enable and improve food intake [15]. There is potential to reduce nutritional risk during cancer treatment and address eating problems, and optimal management could improve treatment tolerance and decrease treatment interruptions [16].

Psychosocial support for patients

Patients who required nutrition counselling either lived alone or with another person, and continued working while undergoing chemotherapy treatment, and had low QOL. Patients wanted their colleagues and nutritionists to understand their symptoms and empathise with their efforts. Healthy eating plays an important role in maintaining a psychological balance that contributes to overall QOL and is closely associated with social contact. Additionally, studies have reported a link between poor appetite following cancer therapy and anxiety, depression, and loneliness [17, 18]. Therefore, there is a need to provide nutrition counselling in terms of psychosocial support. For example, if a patient is unable to eat because

of anxiety over future events, support should be provided to sustain feelings of hope and well-being [19]. Additionally, patients with cancer undergoing chemotherapy should be encouraged to share valuable moments with friends and family [20] to reduce diet-associated psychosocial distress [21].

Nutritional support from a multidisciplinary team

The need for nutrition counselling is related to social factors, such as family structure and employment status, and psychosocial outcomes (anxiety and confusion) can arise from NIS treatment. A multidimensional perspective on food and eating is therefore recommended to support individuals' ways of experiencing and dealing with eating issues [15]. Figure 2 presents themes of psychosocial and physical support related to ERD. Based on this study's results, it is recommended that nutritional screening and assessment include psychosocial assessment for ERD and other eating issues in addition to conventional assessments involving nutritional status, symptoms, and blood test findings. Generally, nutrition counselling is conducted on a one-on-one basis; however, if psychosocial problems are identified, counselling sessions should be set up with a psychologist, a nurse specialising in cancer care, or a psycho-oncologist in addition to the dietician, so that the patient can be appropriately treated. Furthermore, it is important that dietitians themselves develop skills related to cognitive behavioural therapy, in addition to their knowledge of nutrients. Thus, combination therapy and multimodal care are likely to be critical in nutrition counselling [16, 22-24]. Additionally, many patients with advanced cancer undergoing chemotherapy are anxious about their future. Therefore, as part of a holistic treatment approach, dieticians should collaborate with specialists in relevant fields to develop multidisciplinary interventions [7]. Furthermore, rather than simply insisting that patients follow their instructions, medical professionals should take into consideration both the symptoms and emotions of patients. Patients need to be involved in decision-making processes regarding what treatment to choose and how they can adhere to such treatment. A patient may want to adhere to treatment but is unable to because of their debilitating condition. Given such eventualities, medical staff need to ensure that interventions consider such information regarding patients, and support and encourage them accordingly. In nutrition counselling, dieticians help patients determine what they can eat and when they can eat it. Health professionals, however, also need to understand that patients can experience anxiety and desperation about not being able to eat.

Based on objective assessments combining NIS, nutritional status, and other relevant data, our qualitative summary of patients' statements helped identify what these patients were experiencing and in what circumstances. Thus, to develop realistic nutritional support, assessments as part of nutrition counselling should be performed by dieticians from a multifaceted perspective. Furthermore, it is useful to use a mixed-method design [25] that combines qualitative assessments of patients' subjective feelings and quantitative analysis to evaluate patients' conditions objectively.

Limitations

This study has several limitations. Many patients dropped out owing to worsening symptoms. Further, 80% of patients who required nutrition counselling did not undergo the counselling because of worsening

symptoms, hospital transfer, inability to be contacted, or scheduling problems. The problem of high dropout rates of patients with advanced cancer has been noted in other studies [26, 27]. However, this issue underscores the importance of compiling whatever little data can be obtained. For continuous nutrition counselling, a system that allows for flexible handling of patients by telephone, e-mail, and web-based contact needs to be created.

It is insufficient to provide nutrition counselling only after nutritional issues worsen or after chemotherapy has begun and symptoms have appeared. Distress, anxiety, and confusion can be reduced if patients and family members know they can consult a dietician when encountering problems. Therefore, dieticians should collaborate with attending physicians and other medical staff members, and intervene early in the treatment of patients.

Conclusions

This study used a mixed-methods design to analyse psychosocial factors affecting patients receiving chemotherapy, specifically, those issues patients identified as wanting to discuss during nutrition counselling, and to better understand the requirements of patients when conducting interventions in relation to nutrition counselling. This study makes an important contribution to the field because it shows that elucidating patients' specific nutrition-related issues provides key relevant information, whereas dieticians often conduct patient assessments based only on biochemical data and objective pathology. However, it is important to determine the concerns of patients more comprehensively to ensure effective help is provided.

Nutrition counselling for patients receiving cancer chemotherapy needs to include methods of handling NIS and provide multidisciplinary support that considers social and psychosocial factors. Although ensuring continuous nutrition counselling for outpatients is challenging, it is important to address patient concerns promptly and create an individually tailored system that facilitates early interactions with patients and maintains nutrition counselling at home or in hospitals.

Declarations

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Conflicts of interest

The authors declare no conflicts of interest.

Availability of data and material

Data can be made available upon request to the corresponding author.

Code availability

Not applicable.

Data transparency

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with STROBE guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

Authors' contributions

SK, KA, and EM contributed to the conception and design of the study. SK, MA, KS and AH were responsible for data collection. SK, TY, JK and TT performed the analyses. SK and EM wrote the original draft. All authors critically reviewed the manuscript and approved the final version submitted for publication.

Ethical approval

The Institutional Review Board of the Medical Research Ethics Committee of Tokyo Medical and Dental University (no. M2015-578) approved this study. The survey began after registering this study as a clinical trial (UMIN registration no.000021540).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publish

Consent was obtained from all participants to publish the collected research data in a professional journal, provided that no individual was identified.

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Figures

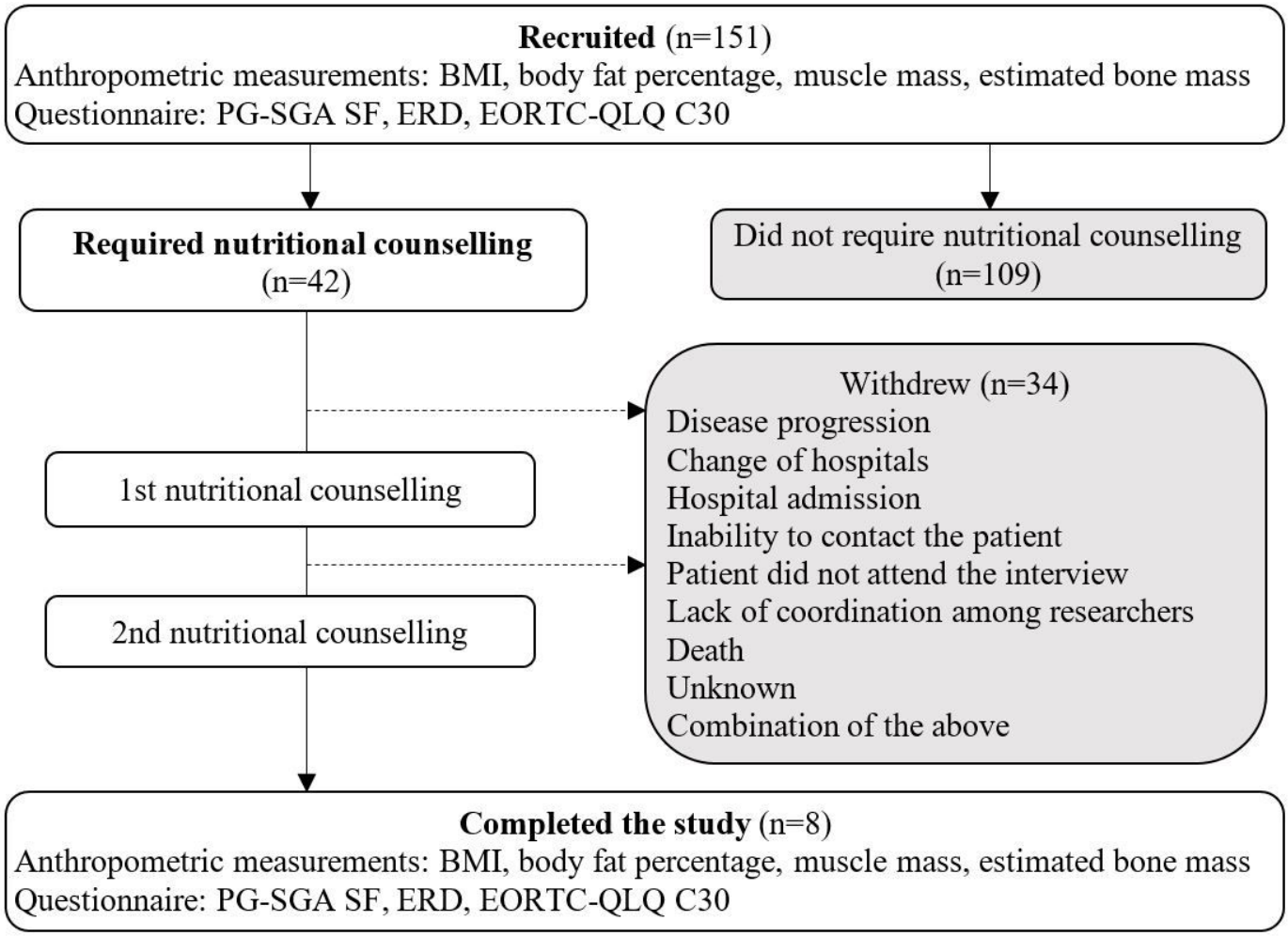

Figure 1

Research plan and flow of the survey conducted with the study participants BMI: body mass index; PG-SGA SF: Patient-Generated Subjective Global Assessment-Short Form; ERD: eating-related distress; EORTC-QLQ C30: European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Version 3.0

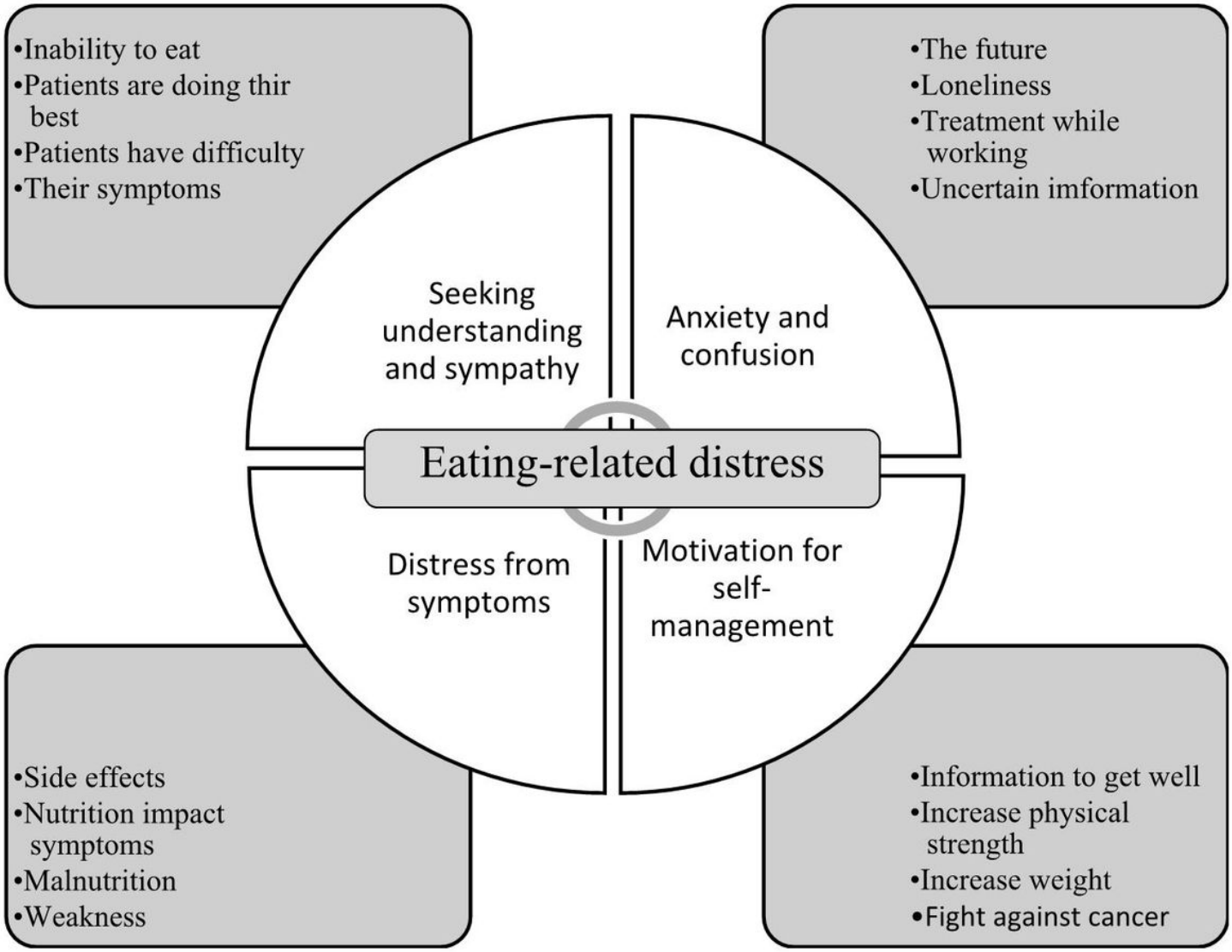

Figure 2

Themes of psychosocial and physical support related to eating-related distress