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Perceptions and experiences of nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period: A qualitative study



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ABSTRACT

Objective: Malnutrition in patients with esophageal cancer is a major health problem. However, the information about the perceptions and experiences of nutritional management needs during the peri-radiotherapy period is lacking. This study aimed to understand the experiences of, and perspectives on, nutritional management needs of patients with esophageal cancer, family caregivers, doctors, and nurses so as to explore the influencing factors and coping strategies to meet nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period.

Methods: A qualitative study with purposive and theoretical sampling was used in this study. One-to-one and focus group interviews were held among patients, main family caregivers, doctors, and nurses in a tertiary general hospital and a tertiary cancer hospital in Shantou, south of China, from August to September in 2020. Data were analyzed using grounded theory by a three-level coding method. The reporting of this study adhered to the COREQ guidelines.

Results: A total of 12 patients, 10 main family caregivers, 6 doctors, and 9 nurses were interviewed. According to the participants, the three main categories, "personal cognition," "family and social factors," and "nutritional management environment and system," were the main factors influencing nutritional management needs. "Lack of nutrition-related cognition," "effects of feeding-related symptom clusters," and "motivation" were the three major factors that constituted participants' personal cognition on nutritional management. "Dietary conditions in medical institutions," "nutritional management system in medical institutions," and "home nutritional care" were the main components of the nutritional management environment and system. The coping strategies included standardized nutritional training for staff, patients and caregivers, social support system, discharge preparation services, multidisciplinary nutritional management, and construction of the organization and management system.

Conclusions: Malnutrition in patients with esophageal cancer who suffer from great diet pain during the periradiotherapy period has become a concerning health issue. It is still challenging and needs more nutritional research. The full identification of influencing factors for nutritional management needs and the proposal of coping strategies may help provide theoretical support and a practical basis for constructing a tumor nutritional management scheme to meet the needs of patients with esophageal cancer.

Introduction

Esophageal cancer is one of the most common cancers in China and even worldwide. Its incidence and mortality in China account for about

50% across the world, which is one of the highest prevalences of malnutrition among all other malignant tumor groups. ^{1,2} As one of the most important means in the comprehensive treatment for esophageal cancer, radiotherapy leads to a higher incidence of malnutrition in

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patients due to dysphasia caused by cancer and radiotherapy-related toxicity (i.e, reduced taste acuity, odynophagia, radioactive oral mucositis, radioactive xerostomia, radioactive tracheitis, tracheoesophageal fistula, and so on), which affects the whole process of nutrient intake, digestion, absorption, and metabolism.^{3,4} This leads to the occurrence of malnutrition or the deterioration of the nutritional status, which seriously affects the therapeutic effect, prognosis, and quality of life in patients with esophageal cancer.^{3,4} One retrospective study also showed that patients commonly presented with significant weight loss, and this continued during the course of their anticancer treatment.⁵ Therefore, maintaining optimal nutritional status is essential for improving outcomes, treatment tolerance, and quality of life for patients with esophageal cancer during the peri-radiotherapy period.

Studies have shown that the nutritional support during the periradiotherapy period can prevent the weight loss of patients with esophageal cancer, maintain the quality and function of skeletal muscle, improve the sensitivity to radiotherapy, reduce the toxicity of radiotherapy and treatment interruption rate of patients, and improve the completion rate of radiotherapy and the curative effect of patients.⁶ Active nutritional therapy is of great significance for the treatment and prognosis of patients with esophageal cancer treated with radiotherapy. It has become an indispensable part of comprehensive cancer therapy. Whole-course nutrition management refers to a systematic, standardized, and individualized quantitative nutrition management model, which dynamically adjusts nutrition intervention methods, dietary structure, and dosage according to patient's nutritional status, dietary intake, and eating status during admission and discharge.⁸ The guidelines of the European Society of Enteral Nutrition recommend that all patients with cancer should undergo whole-course nutrition management. The guidelines of the Branch of Radiation Oncology of Chinese Medical Association recommend that the patients with malignant tumors receiving radiotherapy need standardized and whole-course nutrition management during the peri-radiotherapy period. 10

During the treatment, the ability of patients to care for themselves is limited. Their main family caregivers play a vital role in promoting patient recovery through nutritional care. 11 Furthermore, many studies about the nutritional management of patients with esophageal cancer have been reviewed. However, only a few studies have focused on the experience of nutritional support in patients with gastric cancer and those with head and neck cancer. 12,13 A previous qualitative study attempted to understand caregivers regarding the nutritional status of patients with esophageal cancer after the surgery. ¹⁴ Further, a systematic qualitative review investigated patients' and caregivers' experience of nutritional care throughout and beyond head and neck cancer treatment. 15 Yet, the qualitative research worldwide about the experiences of nutritional management needs on patients with cancer is limited. No study has been undertaken to gain a deeper understanding of experiences of nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period following an esophageal cancer diagnosis. To date, key insights from the experiences of nutritional support of patients with cancer have been predominantly from the viewpoint of patients and caregivers. Doctors and nurses, as the top members of the nutrition support team, are highly responsible for nutritional management.¹⁶ Doubtlessly, doctors and nurses play a vital role in cancer nutritional support and care. However, few studies have examined doctors' and nurses' perceptions and experiences about nutritional support for patients with cancer. Thus, this study was performed to reveal the essence of the phenomenon more comprehensively from the perspective of relevant stakeholders. A more thorough understanding of the subjective perceptions and experiences of the nutritional management needs of patients with esophageal cancer, family caregivers, doctors, and nurses is crucial to ensure a more patient-centered nutritional management that meets the patients' individual needs and preferences. Further identification of the influencing factors of nutritional management needs and proposing coping strategies to meet nutritional management needs may contribute to the construction of a standardized and individualized

nutritional management scheme for patients with esophageal cancer during the peri-radiotherapy period.

Therefore, this study took into consideration the perspective of patients, main family caregivers, doctors, and nurses. It involved a deeper description of participants' perceptions and experiences to analyze the influencing factors for nutritional management needs and coping strategies for patients with esophageal cancer during the peri-radiotherapy period.

Methods

Study design

Various methods of analyzing the nutritional management of patients with esophageal cancer have been reviewed. However, they are mostly technical and not suitable for answering the questions and objectives of this research. Therefore, a general qualitative method that would be able to disclose the perceptions and experiences of nutritional management needs from the relevant stakeholders (patients, family caregivers, doctors, and nurses) is required. The grounded theory was applied as the research method considering the lack of a comprehensive theory of nutritional management needs, observing the subject from the perceptions and experiences of relevant stakeholders, and achieving discoveries in this area. The essence of grounded theory is inductive reasoning, which directly summarizes concepts and propositions from the original data according to the research questions, and then forms the theory of substance to reveal the specific phenomena and their internal connections. This theory is different from the empty and abstract theories obtained by deductive reasoning and from the excessive emphasis on factual description and lack of theoretical depth in some qualitative studies.¹⁷ A qualitative design with a grounded theory approach was employed to describe the experiences and perceptions of patients' nutritional management needs, perceived by relevant stakeholders, thus exploring the influencing factors and coping strategies to meet nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period.

Participants

The study was carried out in a tertiary general hospital and a tertiary cancer hospital in Shantou, south of China, from August to September in 2020. The selection of the participants with a variety of characteristics and experiences to determine findings was initiated using purposive sampling and continued through theoretical sampling until saturation was achieved.¹⁷ The inclusion criteria for patients were as follows: (1) pathologically confirmed to have esophageal cancer without any other cancer, diagnosed with stages I-IV; (2) aged more than 18 years; (3) examined during the peri-radiotherapy period; and (4) capable of normal cognition and communication ability. The inclusion criteria for main family caregivers were as follows: (1) with the longest daily care; (2) aged between 18 and 70 years; and (3) with normal cognition and communication ability. Doctors and nurses should hold a doctor or nurse qualification certificate and should have been engaged in esophageal cancer radiotherapy or nursing work for more than 5 years. All participants provided signed informed consent.

Data collection

In this study, the grounded theory method of qualitative research was adopted. Data collection was carried out by combining one-on-one interviews with focus group interviews. Some interview techniques, such as questioning, listening, responding, and repeating, were used to observe and record the interviewees' tone, body language, and other nonverbal behaviors. The semi-structured interview was used to conduct one-on-one, in-depth interviews with doctors and nurses. The interview ended when the interview data reached saturation, and no new findings

appeared. Finally, six doctors and nine nurses were interviewed. The focus group interview, which was easy for full discussion, mutual inspiration, and interactive stimulation, 17 was used to conduct a face-to-face, semi-structured interview with the patients and their main family caregivers. Each focus group interview was limited to 10–12 people. ¹⁷ In two focus group interviews, the patients and main family caregivers were interviewed separately. The main interview questions for patients were as follows: (1) What problems and difficulties did you encounter with nutrition during the peri-radiotherapy period? How did you solve it? (2) What nutritional care do you wish to receive during the peri-radiotherapy? The interview questions for the main family caregivers were as follows: (1) What problems and difficulties did you encounter with nutritional care for patients during the peri-radiotherapy period? How did you solve it? (2) What needs did you perceive when taking nutritional care of patients during the peri-radiotherapy period? (3) What guidance and assistance are you eager to receive in nutritional care for patients? The questions for the doctors and nurses were as follows: (1) What are your views on nutritional management in patients with esophageal cancer during the peri-radiotherapy period? (2)What problems do you encounter with nutritional management during the peri-radiotherapy period? How to solve and how to interact with patients and family members? (3) How did you manage the nutrition for patients with esophageal cancer during the peri-radiotherapy period? (4) What else do you think should be included in the nutrition management of esophageal cancer, or what do you think should be done during the peri-radiotherapy period?

All transcripts of the recordings were transcribed within 24 h after each interview. The recordings and texts were verified and analyzed by two other researchers. Then the theory was preliminarily generated and used as the criteria to determine the interview direction of the next interviewees.

Data analysis

NVivo software (Version 11, QRS International) was used to collate and analyze data. A three-level coding method, adhering to Strauss and Corbin's grounded theory, was used for open coding, axial coding, and selective coding. ¹⁸ The concept was formed and classified through three-level coding, and the core category was formed through constant analysis and comparison.

Ethical considerations

This study was approved by the ethics committee of the Cancer Hospital of Shantou University Medical College (reference 2019041) in November 2019. Before the interview, the interviewer explained the purpose, meaning, and confidentiality principle of the study to the interviewees, and a signed informed consent form was obtained from each of them.

Results

Demographic characteristics

In two focus group interviews, 12 patients and 10 main family caregivers were interviewed respectively. Each group interview lasted between 1.5 and 2 h. The average duration of each one-to-one interview was 30 min. Patients were coded as P1–P12, main family caregivers as C1–C10, doctors as D1–D6, and nurses as N1–N9. All patients were given linear accelerator intensity-modulated radiotherapy and were treated with 6 MV X-rays, 2.0–2.2 Gy/time, five times per week, with a total of 50–66Gy. The demographic characteristics of participants as shown in Table 1.

Demographic characteristics of participants.

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Participant	No. of cases	No. of cases Age (years) Gender	Gender		Education					Professional rank	al rank		Years of working on cancer radiotherapy or nursing
			Male	Male Female Illiterate	Illiterate	Primary school Bachelor Master Doctor	Bachelor	Master	Doctor	Junior	Junior Intermediate Senior	Senior	
Patients	12	66 (SD, 9)	6	3	8	4	0	0	0	1	1	1	1
Family caregivers	10	50 (SD,11)	8	2	9	2	2	0	0	1	1	1	1
Doctors	9	37 (SD,6)	3	3	0	0	0	2	4	0	4	2	12 (SD, 7)
Nurses	6	43 (SD, 8)	0	6	0	0	8	1	0	1	2	3	23 (SD, 10)

Coding of the collected data

After data collection, the researchers transcribed the recorded content in the interviews, and the terms, concepts, and phrases that the participants provided about the perceptions and experiences of nutritional management needs were extracted. These terms had the same open coding conceptualized and regulated by the researchers. 18 Data coding continued until reaching the repeated and reusable ones. 19 Then, the component was investigated and categorized using the detailed content analysis method, and the axial codes (a class of categories at a higher level) were determined based on similarities and common characteristics between these concepts.¹⁸ Finally, selective coding was identified methodically. Then, participants' perceptions and experiences were classified into eight axial categories (personal cognition, family and social factors, nutritional management environment and system, standardized nutritional training for staff, patients and caregivers, social support system, discharge preparation services, multidisciplinary nutritional management, and construction of the organization and management system) and two selective or core categories (the influencing factors and coping strategies of to meet nutritional management needs for patients with esophageal cancer).

Themes of findings

The factors influencing nutritional management needs of patients with esophageal cancer during the peri-radiotherapy period included personal cognition, family and social factors, and nutritional management environment and system. The coping strategies included standardized nutritional training for staff, patients and caregivers, social support system, discharge preparation services, multidisciplinary nutritional management, and construction of the organization and management system.

Personal cognition

Cognition refers to the process of acquiring or applying knowledge, or the process of information processing, which is the most basic psychological process of people. ²⁰ The personal cognition of this study mainly reflected three aspects of the lack of nutrition-related cognition, effects of feeding-related symptom clusters, and motivation.

Lack of nutrition-related cognition

Almost all patients and caregivers interviewed lacked nutritionrelated cognition and had low nutritional literacy, little or incorrect nutrition knowledge, inconsistent knowledge and practice, and poor compliance with nutritional management. As one patient said:

"I do not know what is more nutritious to eat ... I like to eat meat and seldom eat fruit and vegetables. I am often constipated." (P7)

A nurse said:

"Many patients and caregivers do not have the concept of nutrition; they think that cancer is toxic, and basically only eat porridge ... Some patients say the more you eat, the better the nutrition, so the faster the tumor grows ... The patients or the caregivers often consult that the healthcare products or supplements can be used or not." (N1)

Another nurse said:

"Keep urging patients to eat and drink more, and diversify their food ... Use enteral nutrition powder and eat regularly. If they are not constantly urged, they will be lazy." (N3)

Effects of feeding-related symptom clusters

Patients with esophageal cancer had different symptom clusters while undergoing radiotherapy. The most serious symptom clusters were the feeding-related symptom clusters, including dysphagia, eating pain, xerostomia, anorexia, fatigue, distress, and dyssomnia, which severely reduced the tolerance to anti-tumor therapy and affected the effectiveness of radiotherapy. ²¹ The patients, affected by the feeding-related symptom clusters, had high requirements for food, bore great diet pain, and had risks of unsafe eating. As one patient said:

"I have undergone radiotherapy 11 times, but I still suffer dysphagia and cannot swallow food, and hence I need water to help me swallow it slowly." (P5)

Another patient said:

"After having undergone radiotherapy 20 times, my throat was so sore that I could not eat anything, and always had hiccups, cough, difficulty speaking. I have lost 2.5–3 kg in less than a month." (P10)

A doctor said:

"Dysphagia is the most dreaded complications for patients with esophageal cancer; most of them said they had dysphagia so that their nutrient intake was significantly lower than normal, leading to nutritional problems. During or after radiotherapy, although the impact on symptoms might be improved, all patients with esophageal cancer could develop radiation esophagitis, which caused painful swallowing that seriously affected eating." (D5)

Motivation

Nutritional motivation is the internal driving force that affects the initiation, purpose, and continuity of nutritional management behaviors in patients. ²² However, in this study, patients' motivation for nutritional management might be influenced by education, age, dietary habits, disease severity, and psychological status.

- (1) Education, age, and dietary habits: A nurse said: "if we provide nutritional education to families with a high education level or young family members, the acceptance level is high. On the contrary, patients with low education level or older have poor acceptance of nutritional education." (N1)Another nurse said: "Dietary habits will affect the diet structure. In particular, when we asked older patients what they ate, their answers were 'porridge'." (N3) A patient said: "I just like meat, not vegetables." (P7)
- (2) Disease severity: A patient said: "I have a sore throat and am constipated so that I cannot eat anything." (P10) A family caregiver said: "Patients cannot eat and throw up, and they are so tired that they do not exercise much." (C10)
- (3) Influence of psychological status: A family caregiver said: "After my husband was ill, his temper became very cranky, leading to trouble communicating with each other." (C11)

Family and social factors

The doctors and nurses interviewed emphasized that family and social support provided patients with material, mental, and emotional support. On the contrary, insufficient support weakened the behavior of patients' nutritional rehabilitation. As a nurse said:

"The family relationship will also affect the patient's nutritional status. If the family is harmonious, the patient will be in a good mood, patients will be more motivated to receive treatment ... Sometimes, when the patient's family does not take good care of him, he will not eat and

becomes very thin, as if the family caregivers have just finished the task by getting patients to the hospital for treatment." (N3)

Another nurse said:

"The communication and encouragement between patients and cancer survivors are far more effective and convincing than the nutritional guidance of our medical staff and family members ... Our hospital will regularly hold public welfare group activities to provide a platform for patients to communicate." (N8)

Nutritional management environment and system

Dietary conditions in medical institutions

In terms of perceptions and experiences of participants, the medical institutions were not fully equipped with dietary resources to meet the nutritional needs of patients during hospitalization. As a family caregiver complained:

"The hospital did not provide a proper cooking environment for the family caregiver. And the patient had severe dysphagia and dentures, so the doctor ordered the patient to eat liquid or soft food ... It was difficult to buy him anything to eat." (C5)

Nutritional management system in medical institutions

A serious shortage of nutrition professionals existed, and the setting of full-time personnel was unreasonable. As a nurse said:

"Our nurses still lack nutritional knowledge and need further improvement to provide more professional guidance to patients and caregivers." (N1)

Another nurse said:

"How to match specific nutrition disposition? How to assess the extent of malnutrition? How to do dietary guidance? There had been short of full-time personnel allocation." (N8)

A doctor said:

"Due to the busy workload every day, and the lack of both a comprehensive understanding of nutritional risk screening and the assistance of a nutrition specialist medical team, radiotherapy doctors can only roughly guide patients to supplement enteral or parenteral nutrition according to the biochemical examination results of the patient's physical status, without scientific and quantitative treatment. For patients with esophageal cancer complicated with metabolic diseases, such as diabetes and hyperlipidemia, it is even more difficult to assess and provide guidance for nutrition, which is far from enough in the era of precise and individual treatment." (D1)

The standardized nutritional training programs were lacking. A nurse said:

"Nutrition-related knowledge and training for nurses can only be acquired by self-study. Sometimes the nutritional specialist nurse is invited to teach us. Our hospital does not give us any training in nutrition-related knowledge." (N4)

A doctor said:

"Patients often consult their doctors about nutrition-related knowledge during radiotherapy, but clinicians certainly have less nutrition-related knowledge than dietitians." (D6)

The follow-up supervision for nutritional management after discharge was inadequate. A nurse said:

"Follow-up is usually done by doctors who simply call the patient for a routine checkup, but there is no follow-up on nutritional status." (N2)

Home nutritional care

A serious shortage of home nutritional care existed, and the participants expressed their strong desires for home nutritional care to patients. A caregiver worried:

"The nutritional status of patients is so poor. I do not know how to take home nutritional care after discharge." (C6)

A nurse said:

"Home care has become the main care pattern for patients with cancer, and plays an important role in the recovery process. However, the family caregivers often complained to me that they did not know how to take nutritional care of patients, and lacked nutrition-related knowledge ... Home nutritional care would promote the rehabilitation of patients." (N8)

Coping strategies to meet nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period

Standardized nutrition training for staff, patients and caregivers.

Standardized nutrition training for staff, patients, and caregivers would effectively reduce the incidence of complications, improve patients' nutritional status and quality of life, as well as improve the nutritional management practices of healthcare staff.

(1) Training of healthcare staff in nutrition: The doctors and nurses interviewed appealed to comprehensively strengthen the training of healthcare staff in nutrition, improve nutrition management awareness, and standardize diagnosis and treatment behavior. A nurse said:

"Training of specialized nurses in nutrition would be strengthened...I think the nutritional training system is very vital. We must be trained and provide the patients' caregivers better education about nutrition." (N4)

A doctor said:

"For the nutrition management of our whole ward, first of all, I think doctors and nurses, patients, and caregivers should have a full understanding of the importance of nutrition. Doctors and nurses should learn about nutrition as actively as possible." (D5)

(2) Nutrition education: A nurse said:

"I think nutrition education is the most important and the first step of nutritional therapy. Patients need to get rid of the old concepts and correct nutritional knowledge errors and bad eating habits. Dietary guidance and nutritional education are absolutely necessary." (N1)

A doctor said:

"We should give patients regular nutritional education and guidance." (D2)

(3) Fostering nutritional care skill: Improving the nutritional care skill of primary family caregivers would help reduce the burden of nutritional care and improve the nutritional care training system. A nurse said:

"It is better for the family caregivers to work together to increase the variety of food and calories, in order to improve the patient's nutritional status...Family is very important in improving nutritional status of patients. Some family members feel that they cannot do anything, while others will look for solutions to the problem and do a good job of providing balanced nutrition." (N1)

Another nurse said:

"Nutrition knowledge of the family caregivers is really important. A lot of patients with esophageal cancer have a serious problem of dysphagia, but the family does not know what to do in terms of diet. They say they want the patient to eat well, but they cannot do it in a proper way." (N2)

Social support system

Whether it is family support, interaction with friends, or community activities, any kind of social support can reduce the risk of disease recurrence and death.

(1) A good social support network is conducive for patients and their families to correct knowledge – attitude - practice about nutrition; integrate knowledge, attitude, and practice; access substantive help; channel bad emotions; and improve the psychological control of the disease. A patient said:

"The patients told me that I could make food into a paste which would be easier to eat. After that, I made food into a paste every day, and I could eat many meals every day. I never became too hungry and I did not feel weak and fatigued throughout the day." (P8)

(2) A good social support network provides substantial social assistance and emotional support to patients and their caregivers from a multi-dimensional perspective. A nurse said unhappily:

"Some patients have a large economic burden, so we help them apply for the financial aid from the hospital, as far as possible to help reduce the economic burden." (N7)

A nurse said:

"For example, the non-profit social organizations in our hospital offer a platform for patients to communicate with each other. It is more effective to exchange experiences and giving their own opinions and it also helps patients gain a healthy sense of social belonging." (N8)

Discharge preparation service

As an extension of in-patient care, extending the hospital discharge preparation to the patient's family has good social and economic benefits. A caregiver said:

"As I was getting ready to leave the hospital, I just wanted to know what is the best food for the patient to eat. I wish someone could call us." (C7)

Another caregiver said:

"I wanted to know how the patient should improve nutritional status at home after discharge." (C9)

A nurse said:

"I thought it was necessary to follow up after discharge and make regular nutritional assessments. However, it is impossible to do home nutritional care and it is necessary to provide discharge preparation service during hospitalization." (N7)

Multidisciplinary nutrition management

(1) Professional nutritionist resources: A nurse said: "In fact, every department should have nutritionist in the hospital." (N5)A doctor also said: "I hope the ward can be equipped with a professional nutritionist." (D5)Another doctor said: "The nutritionist kept track

- of our nutritional support in real time, such as monitoring the patient's weight regularly, keeping track of their daily intake, and calculating how much energy they were taking in and how much they were consuming." (D3)
- (2) Nutritional management team building: Nutritional management requires the cooperation of doctors, nutritionists, pharmacists, nurses, and other disciplines to implement the entire process involving a three-level diagnosis of malnutrition, nutritional screening, nutritional therapy, and nutritional monitoring followup. A doctor said:

"For the nutrition management of esophageal cancer during the periradiotherapy period, I thought a nutrition specialist team should be established that included doctors, nurses, dietitians, and endocrinologists. A systematic and complete nutritional risk screening and assessment scale should be established to guide the nutrition intake of patients." (D1)

A nurse said:

"In my opinion, the management personnel should include not only nurses, doctors, nutritionists and patients, but also the patients' family members and cooking instructors." (N6)

Construction of the organization and management system

The construction of the organization and management system would promote the establishment of a standardized model of nutritional management.

(1) Construction of public facilities that promote nutrition in hospitals. A nurse thought about:

"In fact, guiding the patient's diet is related to guiding the way, such as popularization of science videos, brochures, or food mold of nutrition tower." (N7)

A nurse suggested:

"After admission, each patient should be given a diet booklet...and an official account for dietary publicity should be set up in hospitals." (N3)

Another nurse suggested:

"Put a scrolling screen at the door of office ... Use the call bell system to request nutritional education broadcasts, or have fixed time broadcasts ... Play mission and education videos so as to increase the visual impact." (N9)

(2) Construction of a hospital dietary environment: The aim should be to provide patients with standard dietary services and increase the frequency of supply to order and meal delivery services at any time. A nurse said:

"We cannot provide an environment for patients to improve their nutritional status. At present, we cannot provide a proper dining room and an environment for cooking ... However, I think we can provide our own kitchen and some appliances, such as high-speed blender and a microwave oven, to further process the food into refined food and optimize the catering service conditions." (N9)

Another nurse (N7) said:

"Hospitals should provide logistical support, such as the ability to provide patients with cooked nutritious meals, and departments or hospitals can provide facilities for patients to prepare nutritious meals."

Discussion

This study showed that personal cognition, family and social factors, and nutritional management environment and system affected the nutritional management needs from the perspective of participants. In the interview, it was found that the lack of nutritional knowledge, improper nutritional behavior, and influence of related symptoms persisted through the whole process of exploration. Previous studies found that good compliance was an important prerequisite to ensure the effect of nutritional support.²³ The transformation of beliefs in knowledge, attitude, and behavior is the key. Also, a high level of self-efficacy refers to an individual's confidence or belief in his or her ability to achieve behavioral goals or tasks in a specific field in a specific situation, and it can change healthy behaviors. 23,24 Therefore, improving participants' cognition and knowledge of nutrition to improve patients' nutritional status is of great importance. It has been suggested that the assessment of nutritional knowledge and targeted nutritional education should be carried out in the course of nutritional management. During the interview, it was found that patients with esophageal cancer suffered from great diet pain during the peri-radiotherapy period due to dysphasia caused by cancer and radiotherapy-related toxicity, including reduced taste acuity, odynophagia, radioactive oral mucositis, radioactive xerostomia, radioactive tracheitis, tracheoesophageal fistula, and so on. Sandmael et al. found that the side effects caused increasing difficulties with eating and drinking, and loss of appetite was evident while undergoing daily radiotherapy. 12 The patients were seriously deficient in nutritional intake due to the influence of feeding-related symptom clusters. Also, their physical ability was weakened and seriously hindered meeting nutritional management needs, similar to prior research results of Wang et al.²⁵ The severity of feeding-related symptom clusters was high in patients with esophageal cancer, which had adverse effects on the treatment and prognosis of these patients, reducing their quality of life.

Our study indicated that some patients were at increased risk of malnutrition due to inadequate family support, similar to prior research results of Xu et al. ²⁶ The World Health Organization (2006) advocated that the healthcare staff members should focus on the families of patients diagnosed with cancer and treat patients and caregivers as an integral whole. ²⁷ The reduction in the incidence of malnutrition also depends on the care of family members. Patients' ability to care for themselves during the treatment phase is limited, and the primary family caregiver plays a vital role in the recovery process. ¹¹ The interviews of doctors and nurses in this study suggested that it was necessary to improve the cognition and knowledge of nutrition of family caregivers while improving the nutritional cognition knowledge of patients so that the family caregivers and patients could participate together in supporting, encouraging, and supervising to meet the nutritional management needs of patients.

This study showed that patients and their families had a great demand for standardized dietary services and nutritional management in medical institutions. The concept of "hungry-free hospital" was first proposed by Shi, H. in October 2018, and the construction of "hungry-free hospital" was started. ²⁸ The results played an important role in reducing medical costs and incidence of complications; also, patients with malnutrition could benefit from the management of a "hungry-free hospital". ²⁸ It was seen that nutritional management played a crucial role in both social and economic benefits. This will be the goal of our further exploration of the struggle for standardized dietary services and nutritional management in medical institutions.

The theory of motivation, proposed by Maslow, refers to the theory about the generation, mechanism, and relationship between motivation and need, behavior, and goal. ²² Motivation is generated by need, which can be transformed into motivation when the need reaches a certain level and objects are present to meet the need. ²² Self-efficacy was proposed by Bandura in the 1970s. ²⁹ It refers to an individual's confidence or belief in his or her ability to achieve behavioral goals or tasks in a specific field in a specific situation; it has an impact on people's behavioral motivation,

as well as the formation and maintenance of healthy habits. ²⁹ Cheng et al. found that self-efficacy could ease the relationship between health literacy and quality of life for patients with esophageal cancer. The higher the self-efficacy of the individual, the higher the ability to actively deal with disease, and greater the willingness to promote healthy behavior and improve health literacy. ³⁰ Based on the results of this study, it was believed that the patients could be assisted to realize the effect of nutritional management (i.e, personal successful experience), and the role of patients as role models (i.e, indirect experience and persuasive speech) might also enhance a patient's belief in promoting nutrition and good nutritional management behavior.

In this study, our participants might adopt some ways to overcome difficulties, such as improve personal strength. At present, a considerable gap still exists in the awareness of nutrition in China. Some healthcare staff members still regard nutrition as a supplementary treatment. The "Hospital-Community-Home" nutritional management model was proposed in 2015, while "H2H" (Hospital to Home), which was a patient-centered, continuous, and individualized nutritional management model from hospital to hospital, was proposed in 2016.³¹ All achieved good results in improving the nutritional status of patients with gastrointestinal malignant tumors, reflecting the importance of continuous nutritional management of tumors.³² However, this has not been used in patients with esophageal cancer and thus, requires further investigation in the future to explore the standardization of the continuation of nutritional management to meet patients' needs. At the same time, we should involve nutritionists in the multidisciplinary team (MDT). The purpose of adding a nutrition support team to the MDT is to form the characteristic medical therapy model for patients with cancer; explore more suitable nutritional management for the community of such patients; set up management specifications of clinical nutrition standards, nutritional support, and nutritional risk management;²⁸ and promote the construction of "hungry-free hospital" to ensure enough nutrition to patients. However, how to build the nutritional management scheme to meet the needs of patients with esophageal cancer is worth further discussion.

Conclusions

In this study, a three-level coding method of grounded theory was applied, where patients, main family caregivers, doctors, and nurses were interviewed to obtain the overall status of nutritional management needs of patients with esophageal cancer during the peri-radiotherapy period. The influencing factors for the nutritional management needs of patients and the coping strategies for nutritional management needs to satisfy disorders were identified. Personal cognition, family and social factors, and nutritional management environment and system were the three main areas that influenced nutritional management needs. Coping strategies included standardized nutrition training for staff, patients, and caregivers; multidisciplinary nutritional management; discharge preparation service; social support system; and construction of the organization and management system. Fully understanding the impact of various factors on the nutritional management needs of patients with esophageal cancer can provide a basis for the construction of a new nutritional management scheme to meet the needs of patients in the future. Based on motivation theory and self-efficacy theory, enhancing patients' belief in nutritional rehabilitation, improving a nutritional management scheme, promoting the construction of "hungry-free hospital," ensuring the nutritional rehabilitation of patients, instituting a new nutritional management scheme, and forming medical nutrition alliances may be the effective means to promote the formation of a standardized and individualized nutritional management scheme for patients with esophageal cancer during the peri-radiotherapy period.

Strengths and limitations

Nutritional management is a key point that patients with esophageal cancer, caregivers, radiotherapy doctors, and nurses need to pay

attention to. Based on the perspective of patients, their major family caregivers, doctors, and nurses, the qualitative methodological approach used in this study, resulted in the collection of rich data and a deep understanding of the experiences and perceptions of patients with esophageal cancer regarding nutritional management needs during the periradiotherapy period. In this study, the focus was on those directly involved with daily nutritional management practices; however, nutritionists did not participate. The inclusion of nutritionists might have provided some additional insight into the findings, especially perhaps in addressing the more structural limitations raised. Further, the proposed coping strategies for nutritional management disorders were only preliminary explorations, which need to be verified by clinical practice.

Relevance to clinical practice

The present study provided in-depth insights into the experiences and perceptions of patients with esophageal cancer regarding nutritional management needs. This qualitative study found that the participants in a variety of positions understood the importance of nutritional management for patients with esophageal cancer. Further, the themes identified about the influencing factors and overcoming barriers to changing care practices highlighted that despite some knowledge of related beneficial care practices, healthcare staffs needed organizational support to use and build on this knowledge. These themes also suggested that healthcare staff needed education and training about evidence-based practices to facilitate effective nutritional management for patients with esophageal cancer during the peri-radiotherapy period. In addition, exploring factors related to nutritional management among patients with esophageal cancer would help develop more individual and effective interventions. Hence, patients with esophageal cancer would obtain support to assist in coping with the malnutrition. Further multicenter and large-sample studies are needed in the future to explore an individual cancer nutritional management scheme based on patients' needs.

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Declaration of competing interest

None declared.

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