Patient Preference and Adherence

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ORIGINAL RESEARCH

Experiences and Needs of Patients with Esophageal Cancer Receiving Esophagectomy: A Qualitative Longitudinal Study

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Purpose: With the incidence of esophageal cancer increasing year by year, it is very important to understand the disease experience of patients at different stages of the cancer journey. Supportive care is a long-term task for patients with esophageal cancer. This study was designed to explore the disease experiences and needs of esophageal cancer patients receiving esophagectomy at key time points in their cancer journey.

Patients and Methods: A qualitative longitudinal study based on the Timing It Right framework. A purposive sampling method was used, and a sample of 17 patients completed 79 interviews. One-to-one and semistructured interviews were conducted in a tertiary cancer hospital in China from March to August 2024, and Colaizzi's method was used to analyze data.

Results: Twelve subthemes were identified: the diagnosis phase (deep in fear and excessive worry, desire for comprehensive and professional information), the perioperative phase (multiple pressures and looking forward to humanistic care, not adapted to the ward environment and sleep disorders, urgently require for symptom management program), the discharge preparation phase (home-based rehabilitative information and medication guidance, home self-monitoring and continuous care needs), the adjustment phase (loss of normal "daily life", avoidant social behavior, social support needs), and the adaptation phase (improved health management behavior, integration into society needs and eager for national policy support).

Conclusion: The needs of esophageal cancer patients vary during the diagnosis and treatment process. Continuous and dynamic care should be provided for patients according to their needs in different stages of the disease.

Keywords: disease experience, esophageal cancer, needs, qualitative research, surgery

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Introduction

Esophageal cancer is one of the most common malignant tumors in the upper digestive tract, and the population of this cancer type is growing. According to global cancer statistics, esophageal cancer is the seventh most commonly diagnosed cancer type in the world, and it is also the sixth leading cause of cancer-related death.[1] Surgery is still the first-line treatment and the main curative treatment for patients with esophageal cancer. However, as one of the most complicated surgical operations, esophagectomy causes a long-term burden of symptoms, resulting in significant suffering to patients.[2,3] Moreover, patients undergo a transition period from fasting, liquid food and semiliquid food to a normal diet to avoid anastomotic leakage, which can lead to malnutrition and affect health-related quality of life.[4] Although the prognosis has improved with the development of medical technology, patients with esophageal cancer who are undergoing surgical treatment face significant physical and psychological burdens.[5]

Patients with esophageal cancer usually seek medical attention owing to dysphagia and involuntary weight loss. They reported a serious psychological burden while waiting for surgery in the hospital. With the popularization of minimally invasive technology and the development of enhanced recovery after surgery (ERAS), the average hospitalization time of patients

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undergoing esophageal cancer surgery has decreased.[6] However, the postoperative recovery process of patients with esophageal cancer is lengthy. The existing evidence shows that patients usually have a variety of severe and persistent symptoms after esophagectomy, including some general symptoms (eg, pain and fatigue) and some esophageal-specific symptoms (eg, reflux, bloating and lack of appetite), which can impair patients' function and affect their survival and prognosis.[7] Most symptoms are gradually relieved within one year after surgery, and some gastrointestinal symptoms can persist for years after surgery.[5,8] A shorter hospital stay and more severe symptom burden mean that patients face a variety of unmet needs during hospitalization and after discharge. Some studies have reported that patients with esophageal cancer have a wide range of unmet supportive care needs during the diagnostic, treatment, and follow-up phases, including but not limited to information needs, psychological and physical needs, daily living needs, patient care needs and support needs.[9–11] These research results suggest that medical staff should pay more attention to offering supportive care in time according to patients' needs in their cancer trajectory, thereby improving the quality of cancer care. The theory of chronic disease trajectory model holds that chronic disease itself is a long process, which will inevitably change with the change of time.[12] Esophageal cancer may form different trajectories at different states or periods throughout the entire disease progression. The treatment, care and rehabilitation of esophageal cancer is a complex process, and the patient's needs, behaviors and experiences change dynamically with the stages. Care should be adjusted according to different stages of chronic diseases to help patients control symptoms, reduce the occurrence of complications, maintain a stable psychological state, and ultimately improve the quality of life.

Supportive care framework was put forward by Fitch, which refers to providing necessary comprehensive care around the needs of patients in the stages of disease diagnosis, treatment and rehabilitation.[13] Supportive care is defined as the services necessary to meet patients' physical, psychological, and social needs through the entire cancer experience to prevent, control or mitigate various complications and side effects.[14] The fundamental basis of providing dynamic supportive care for patients is to scientifically and accurately assess the disease experience as well as the dynamic needs of patients in various phases and formulate targeted intervention programs. Timing It Right (TIR) theoretical framework was proposed by Cameron et al in 2008; this framework divides the disease process into five phases: diagnosis, stabilization, preparation, implementation, and adaptation.[15] TIR theory emphasizes that patients' support and needs develop with the progression of the disease phase. Currently, some scholars have used different research methods to explore the dynamic needs of patients and their caregivers in various phases of the disease under the framework of TIR and provide active care for patients.[16–18]

According to our literature review, qualitative research worldwide concerning the full course of the disease experiences and needs of esophageal cancer patients is limited. The concept of "time" has been incorporated into the qualitative longitudinal research, which makes "change" the focus. Through interviews across time points, we can gain a deep understanding of the changes in patients' needs over time.[19] Therefore, to fill this gap, this study aimed to utilize a phenomenological research approach to develop a longitudinal qualitative study using the TIR framework to understand the experiences and needs of esophageal cancer patients receiving esophagectomy at different stages of illness and to provide a reference for the formulation of supportive care programs for this patient population.

Materials and Methods

Design

Phenomenology, as a methodological framework, focuses on seeking reality in individuals' narratives and capturing the essence of the lived experiences of a phenomenon.[20] In this study, a qualitative phenomenological design was used to understand the experiences of esophageal cancer patients undergoing surgical treatment in the process of diagnosis, treatment and recovery and to explore the supportive care needs of these patients at each stage of their cancer journey. This study was carried out in accordance with the consolidated criteria for reporting qualitative research (COREQ).[21]

Participants

Using purposive sampling and maximum difference sampling, patients who were hospitalized in the thoracic surgery department of a university-affiliated tertiary grade A cancer center in China from March 2024 to August 2024 were selected. The eligible participants were (1) aged ≥18 years; (2) diagnosis of esophageal cancer for the first time; (3) were scheduled for esophagectomy; (4) had normal cognition and communication ability; and (5) were able to provide informed written consent. The exclusion criteria were as follows: (1) other comorbid types of cancer; (2) severe cardiac, cerebral or renal dysfunction; and (3) scheduled for neoadjuvant chemoradiotherapy before surgery. The participants were purposefully selected according to sex, age, cancer stage and the placement of a gastric tube and/or nasal feeding tube to ensure a heterogeneous sample with broad representation.

Data Collection

On the basis of the TIR theory and the suggestions of clinical and nursing experts, five phases were slightly adjusted: the diagnosis phase (within 48 hours after admission; T1), the perioperative phase (T2), the discharge preparation phase (1–2 days before discharge; T3), the adjustment phase (discharge to 1 months after surgery; T4), and the adaptation phase (1–3 months after surgery; T5). To conduct longitudinal qualitative research, it is necessary to select a specific time point for data collection.[22] Participants with esophageal cancer were interviewed at the five specified time points. The interviews at the first three time points were conducted face-to-face, and the last two interviews were conducted by telephone or during outpatient follow-up examinations.

The one-to-one semistructured interviews were conducted in a separate and quiet room in the department of thoracic surgery, and no other persons were present during the interviews. An interview guide was developed on the basis of a literature review. Before the formal interview, two patients were preinterviewed, and some of the interview outline was amended. The questions of the final interview outline are shown in Table 1. The questions were broad to encourage discussion. The interview time was approximately 15–30 minutes for each interviewee. In the interview process, the interviewer's attitude remained neutral all the time, and there were no hints or guidance. The interviewees were encouraged to fully express their experiences and thoughts, and their facial expressions and body movements were recorded.

Researchers' Positionality

The research team in charge of this research included two nursing graduate students, two hospital nursing administrators and two professors of thoracic surgery. Three members had more than ten years of experience in clinical nursing and nursing management. The interviewers were the first author and the corresponding author with extensive experience in qualitative interviews. Mandarin Chinese was used for the interviews. The female interviewers were not the patients' charge nurses, and they had established a trusting relationship with the participants before the interview.

Table 1 Interview Guide

	Question
The diagnosis phase	1. How did you feel when you learned of your diagnosis? 2. How much do you know about this disease? 3. What are your current problems?
The perioperative phase	1. What are your experiences and feelings during perioperative period? 2. Did you have any physical and psychological discomfort? 3. What has been the biggest challenge and need for you?
The discharge preparation phase	1. How do you feel now that you are about to be discharged from the hospital? 2. What do you think about your recovery at home? What are your plans? 3. What concerns do you have? What difficulties do you think you will have after discharge?
The adjustment phase	1. Could you tell us about the experience after discharge from the hospital? How do you feel your recovery at home? 2. What were the changes in your psychology and daily life ? 3. Is there anything particularly troubling you at present?
The adaptation phase	1. What is your current status? 2. What problems have you encountered in your rehabilitation process? 3. What other assistance do you want? Do you have any other unmet supportive care needs?

Ethical Consideration

The study was conducted in accordance with the Declaration of Helsinki,[23] and ethical approval was obtained from the Ethics Committees of the Henan Cancer Hospital (2022-KY-0163). By replacing names with numbers (eg, P1 and P2) and deleting identifying information from the written records, anonymity and confidentiality were maintained. All participants provided written informed consent for the publication of anonymized responses and direct quotes. The participants were informed that their participation was voluntary and they could refuse or withdraw from the study at any time.

Data Analysis

NVivo 11 software was used to manage the qualitative data. Immediately after the interviews (within 24 hours), the audio-taped interviews were transcribed verbatim via Colaizzi's 7-step analysis method in phenomenology.[24] First, two researchers read all the transcripts several times to understand the meanings conveyed. Second, the researchers found important statements and phrases from each transcript and restated them in general terms. Third, the data hidden in the significant statements of each transcript were described and analyzed. Fourth, the researchers integrated all the results into a narrative and detailed description, and at the same time, they created and validated formulated meanings through the discussion of the research team to reach consensus. Fifth, the formulated meanings were sorted into clusters of themes and categories. Sixth, the fundamental structure of the experience was jointly identified by the members of the research team, who developed a full description of the themes in clear statements. Finally, the participants were asked whether these findings captured the essence of their experiences, thus validating the study. If there was disagreement on the theme, a discussion was conducted by the research team to determine the final theme.

Quality Control

The trustworthiness of qualitative research is determined by the following criteria: credibility, dependability, confirmability and transferability.[25] To achieve credibility, timely verbatim transcription and field notes were used to obtain the exact expressions. For dependability, two researchers independently analyzed and coded the data. To enhance confirmability, this was achieved by rigorously following Colaizzi's method of phenomenological analysis process with a nonjudgmental approach. Finally, for transferability, a detailed and clear description of the research design (open-ended questions), participants, data collection and analysis was provided.

Results

A total of 20 potential participants were identified, but three patients refused to participate because they were not interested in the study. In the end, 17 patients took part in the study and were interviewed at T1, T2, and T3. 14 participants were interviewed at T4 and T5, and three patients withdrew due to ill health. The final dataset consisted of 79 interviews at five different time points, and the demographic characteristics of the 17 patients are presented in Table 2. The average age was 66 years (range 54–75), 65% of the patients had stage I–II disease, and 10 were male.

Five themes and 12 subthemes were constructed from the qualitative data. The qualitative study identified themes of esophageal cancer patients' experiences and needs in each of the five phases (Table 3).

Theme 1.The diagnosis phase: Pessimistic feelings and lack of disease treatment information.

Deep in Fear and Excessive Worry

Esophageal cancer diagnosis signals the start of a difficult phase. People are scared of talking about "cancer" under the influence of traditional thinking. Almost all patients expressed that they had strong pessimism. In addition, due to the uncertainty of surgery, patients' emotions were complex and changeable, and they were eager for psychological support.

> "I just feel a little hard to swallow food recently. However, I was suddenly told that I had cancer. I feel like I am going to die, and my head keeps sweating. I feel like the sky is falling"*(P3).*

> "It is bad anyway. I am nervous, worried, and scared. I have never thought I would have this disease. Cancer is equivalent to a terminal disease" *(P2).*

Table 2 Characteristic of Participants

Participant Number	Gender	Age	Marital Status	Employment Status	With Feeding Tube or Not	Cancer Stage	Hospital Stays (days)
P1	Male	55	Married	Employed	No	IB	23
P2	Male	72	Married	Unemployed	No	IIA	17
P3	Female	69	Married	Unemployed	Yes	IIIB	23
P4	Female	65	Married	Employed	No	IIA	16
P5	Male	67	Married	Retired	No	IIA	11
P6	Male	66	Married	Unemployed	No	IB	18
P7	Male	75	Married	Unemployed	Yes	IIIB	29
P8	Female	67	Married	Unemployed	Yes	IA	15
P9	Male	72	Married	Retired	No	IIIA	18
P10	Male	66	Married	Retired	Yes	IIB	23
P11	Male	61	Married	Retired	Yes	IIA	19
P12	Female	62	Married	Employed	No	IA	14
P13	Female	67	Married	Employed	No	IIIB	15
P14	Female	59	Married	Employed	No	IIA	15
P15	Female	73	Married	Unemployed	Yes	IIIB	19
P16	Male	54	Married	Employed	Yes	IIIA	15
P17	Male	65	Married	Retired	Yes	IIB	30

Table 3 Themes, Subthemes, and Concepts From the Interviews

Themes	Subthemes	Concepts
The diagnosis phase (within 48 hours after admission)	Deep in fear and excessive worry	Will I die? I feel that everything has lost its meaning. I cry every day. Very despairing, devastated kind of thing.
	Desire for comprehensive and professional information	What criteria are used to determine the statistical data of the success rate of surgery? Are there any risks in the surgery? How long will it take to recover after surgery?
The perioperative phase	Multiple pressures and looking forward to humanistic care	My wife actually started all right, but I myself have a heavy psychological burden. Doctors and nurses only care about my illness, and no one asks me how I feel.
	Not adapted to the ward environment and sleep disorders	The ward is too noisy and crowded. I cannot get enough rest. I experienced a sleepless night.
	Urgently require for symptom management program	I feel so painful that I cannot move at all. My mouth is dry, my throat is dry, I have no strength to speak, and my voice is hoarse.
The discharge preparation phase (1–2 days before discharge)	Home-based rehabilitative information and medication guidance	The doctor gave a general statement to keep exercising after discharge. But I still do not quite understand how to do it. How long can the wound be taken out and how long can I take a shower?
	Home self-monitoring and continuous care needs	How do I monitor myself at home? I need to discuss some things with the doctor later, such as my follow-up examination results.

(*Continued*)

Table 3 (Continued).

Themes	Subthemes	Concepts
The adjustment phase (discharge to 1 months after surgery)	Loss of normal "daily life"	My body does not allow me to go out now. I cannot eat anything. I cannot swallow it.
	Avoidant social behavior	I do not want to contact people outside. I no longer take the initiative to associate with friends, and I do not want to meet anyone.
	Social support needs	Family and friends are quite good and they are all very understanding. I feel very warm. I hope the community can provide some care and medical checkups.
The adaptation phase (1–3 months after surgery)	Improved health management behavior	I do not drink any more, and I want to have a healthy body. Nothing is as important as the body. Go to bed early, get up early and exercise more.
	Integration into society needs and eager for national policy support	But I still have to integrate myself into society. I hope the government can provide more financial help.

Desire for Comprehensive and Professional Information

Most of the interviewees said that they lacked knowledge of esophageal cancer disease and surgery. All the interviewees hoped to acquire comprehensive knowledge about surgery, including detailed process, expected curative effect, success rate of surgery, cost and postoperative complications. They acquired relevant knowledge through informal channels such as family members and online publicity. The information obtained by patients was mixed, and patients hoped to obtain accurate information from healthcare professionals in time and understand the details of the treatment plan and prognosis.

> "My son checked some cancer-related information on the Baidu internet via his mobile phone. I do not know how accurate the information is. Do I still need radiotherapy or chemotherapy after surgery"*(P6)?*

> "The doctor said I need an esophagectomy. I want to ask when the operation will be performed? How soon can I discharge from the hospital? Will there be any complications after surgery"*(P10)?*

Theme 2. The perioperative phase: Heavy psychological burden and high symptom burden.

Multiple Pressures and Looking Forward to Humanistic Care

After admission, patients couldn't carry out daily activities as they did before diagnosis, and they often needed the help of others, which led to a serious psychological burden. Moreover, a small number of participants said that they worried about their family's economic situation. Moreover, some participants said that their dignity was damaged due to lack of privacy, communication barriers, loss of control and emotional needs being ignored during hospitalization, and they were eager to get humanistic care from medical staff.

> "The transformation of 'patient identity' makes me feel guilty and self-blaming because my family members have to take turns to take care of me in the hospital. I am concerned about being a burden of them"*(P12).*

> "I feel like I'm dragging my family down. I have spent a lot of money since I was hospitalized. I have to borrow money, and I even develop a sense of guilt (choked up and crying)"*(P10).*

> "Drastic changes in my physical appearance after operation; I gradually became self-denying and grumpy" *(P4).*

> "I always lie alone and look at the ceiling, hoping that some nurses will spend some time chatting with me, but they are too busy" *(P1).*

Not Adapted to the Ward Environment and Sleep Disorders

Owing to the shortage of beds caused by limited medical resources, most wards have multiple beds. Some patients expressed discomfort with the limited ward environment and depressive ward atmosphere after hospitalization. Most interviewees said that the quality of sleep during hospitalization was poor, and the alarm sound of instruments and frequent nursing activities at night interfered with sleep.

> "The patient in the next bed snores at night and is a little bit noisy"*(P17)*.
>
> "There are beds all over the corridor. It is truly crowded. The doctor told me to do more aerobic exercise, but I am afraid I will disturb other people's rest if I want to exercise"*(P5)*.
>
> "I just cannot sleep, and my mind is a mess"(P14).

Urgently Require for Symptom Management Program

Most patients experienced progressive dysphagia and rapid weight loss before esophageal cancer surgery.[26] Moreover, esophageal cancer surgery is related to digestive tract reconstruction and the extensive scope of the operation, which is accompanied by a high incidence of postoperative complications. The participants reported that they usually experienced multiple, persistent and severe symptoms after surgery, including some general symptoms and some esophageal-specific symptoms.

> "My surgical incision and wound were particularly painful a few days after surgery. I did not dare to move even with the anesthetic. In addition, I often feel dizzy and tired. How to deal with it"*(P11)?*
>
> "After esophagectomy, doctors place two tubes in the nose to pump in enteral nutrition solution and some medicine. They (doctors) didn't let me take any food or water by mouth. My throat and lips were particularly dry those days"*(P16)*.
>
> "Reflux and chest tightness occur as long as I lie flat. I can only lift the bedside and lean on it to sleep. The nurse said that I would sleep in a semisupine position for life"*(P8)*.
>
> "I have no appetite at all now. I will feel abdominal distention after eating a little food. By the way, I often cough when I eat, even if I take a sip of water" *(P2)*.

Theme 3. The discharge preparation phase: information about medical care and self-management.

Home-Based Rehabilitative Information and Medication Guidance

With the popularization of minimally invasive surgery technology and ERAS, the average hospitalization time of patients with esophageal cancer has decreased. Most patients had not fully recovered their physical functions and normal diet at discharge, and they were confused about how to continue their rehabilitation after returning home. Most participants expressed a great desire for professional guidance from medical staff and hoped to obtain enough professional home-based rehabilitation information to keep their condition stable.

> "What should I do after discharge? You can give me a rehabilitation plan form, so I know what I have to do every day" *(P1)*.
>
> "I hope that healthcare providers can provide more guidance and patience. However, they are too busy. They have many patients, sometimes I want to ask but dare not, for fear that they will annoy me (laugh)"*(P7)*.
>
> "The doctor asked me to discharge with an enteral nutrition tube. I'm still not sure what I will eat when I go home. Additionally, how to care for this tube? Can you make a plan for me or give me some scientific recipes"*(P6)?*

Home Self-Monitoring and Continuous Care Needs

Many participants expressed their desire for further health-related guidance and supervision from hospital staff after discharge, which they thought was crucial for their physical and psychological recovery because they could know their health status dynamically.

> "Is there an electronic continuous nursing service platform in your hospital to keep in touch and help me manage myself well" *(P8)?*
>
> "Can I have the WeChat of your medical staff? If I have any questions, can I contact you by video consultation? I think it can be more intuitive" *(P12)*.
>
> "I've had fantastic treatment in the hospital. I just feel that when I discharge, I am kind of on my own. I want to receive further care from your doctors and nurses"*(P11)*.

Theme 4. The adjustment phase: changes in living habits and desire for social support.

Loss of Normal "Daily Life"

Almost all patients expressed that they were confronted daily with the limitations of their body symptoms and eating, and they expressed that the activities of daily living were affected by the decline in physiological functioning.

> "Everything changes. I can't eat in the same way I used to… I have to eat semiliquid food slowly, and I have to eat 6--7 meals a day. I cannot eat the same food with my family anymore"*(P8)*.
>
> "You know. I just feel I struggled to adapt to a changed body. The doctor told me to exercise more after meals. However, I cannot control my tired and weak… even though I just sit and I don't do anything"*(P1)*.
>
> "My physical strength has not returned to the same level as before treatment. In addition, I also have reflux and bloating. I'm not sure whether these symptoms will improve over time"*(P9)*.

Avoidant Social Behavior

The interviews indicated that participants avoided interactions with social groups after discharge. Some patients were worried about the social discrimination caused by the diagnosis and their social activities were significantly reduced.

> "I don't want to see people. I just don't want to go out because I am afraid of being looked down upon when I go out. I just want to be alone" *(P16)*.
>
> "I don't go out much. I just feels like there's no interest in doing anything. I also don't want to contact my old colleagues and friends, and I fear that people will ask me about this disease"*(P1)*.
>
> "The biggest concern is that I don't know whether there would be a relapse. It is difficult to plan for the future. I feel that I have no hope for anything, and I just want to stay at home"*(P4)*.

Social Support Needs

With increasing amounts of cancer care being moved to home settings, family caregivers usually take on multiple responsibilities to support patients' recovery and rehabilitation. Family support is fundamentally important to patients' quality of life after being discharged.

> "The family is a motivation. I feel they are there, and they are taking care of me. I feel very warm and have more confidence to go for active rehabilitation" *(P12)*.
>
> "Sometimes I am really tired. I especially hope my daughter can understand more and not always be impatient"(P3).
>
> "Fortunately, there is my lover, which makes me feel very warm and keeps me going" *(P2)*.

Some survivors also mentioned that peer experiences influence their rehabilitation attitudes, and they reported the need to build social connections with other esophageal cancer survivors.

> "There should be more peer support groups. We have the same disease experience, so we have a lot to talk about. Their behaviors more or less also play a certain role" *(P13).*

Many survivors said that in the process of transition from hospital to home, there was limited support currently available from grassroots medical and health services, particularly in rural/remote areas. Seven interviewees expressed the hope that they could receive high-quality reexamination services near their places of residence in the future and improve the accessibility of services.

> "The hospital conditions in our county are not good, and many rehabilitation facilities are not available" *(P17).*

> "I hope that the community can provide more medical checkups, some good rehabilitation programs and health talks" *(P9).*

> "Some examinations can only be done in big hospitals, which are far away from us and really inconvenient" *(P11).*

Theme 5. The adaptation phase: adjustment to "new normal"

Improved Health Management Behavior

Patients expressed that this disease experience gave them more time to think about life and death. Some participants said that after experiencing many types of physical and psychological distress, they were more concerned about their own health and reexamined their priorities in life.

> "After everything you've been through, now I feel that health is the first priority. I also started to actively manage myself, exercise regularly, stay optimistic, and pay more attention to my diet as well as regular physical examinations" *(P14).*

> "I began to feel better. Now I am proactively seeking healthy habits to stay healthy. Changing our lifestyle is the most critical thing" *(P15).*

Integration Into Society Needs and Eager for National Policy Support

In the adaptation phase, patients' overall health status steadily improved. Patients with better physical recovery hoped to return to work or return to their original lives, and they needed to maintain autonomy and independence in their everyday lives.

> "Although there are still some symptoms of discomfort, I want to go back to work and earn some money to financially support my family" *(P12).*

> "I don't expect a 100% recovery. I think I can still do some basic housework and do some basic things like grocery shopping. Instead of what others told me, you've been through a lot, so don't do anything. This reminds me that I am a cancer patient"*(P6).*

> "Now I occasionally get together with my friends, and sometimes I call my family to go out to the park. There is still a need to integrate myself into society. It is impossible not to get sick in one's life"*(P10).*

Nearly half of the patients said that they were facing economic pressure and urgently needed policy support, such as the reduction of treatment expenses, the expansion of medical insurance coverage, the increase of reimbursement ratio and the payment of caregivers' subsidies.

> "In fact, many expenses during hospitalization were not covered by medical insurance. I hope the government can pay more attention and introduce policies to help us solve practical difficulties"*(P3).*

> "I hope that the state can give some economic support and social welfare according to the actual situation of cancer patients, so as to reduce the burden of daily life"*(P11).*

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Discussion

Esophagectomy has an extensive scope of operation, including removing esophageal tumors and replacing them with an alternative, usually a portion of the stomach or colon, to reconstruct the digestive tract.[2] The longitudinal qualitative study design provided unique insight into the experiences and specific needs of patients with esophageal cancer at key time points in their cancer journey. On the basis of the TIR framework, we found that patients' experiences and needs changed dynamically with different phases of the disease. In the diagnosis phase, patients usually experienced stressful panic and lack treatment information related to the disease. During the perioperative phase, patients did not adapt to the ward environment, had a variety of psychological pressures and physical burdens, and needed psychological and emotional support from their family members as well as medical staff. During the discharge preparation phase, patients expressed a desire for home-based rehabilitation information and continuous care from medical professionals. In the adjustment phase, patients felt that they had lost their original life and had avoidant social behavior, expecting social support. Finally, in the adaptation phase, patients enhanced their ability to independently manage their health over time, and they wanted to be independent and return to society.

As a major stress event, almost all the participants diagnosed for the first time described the pessimistic feelings (fear, hopelessness, sadness, grief and collapse) that they had to cope with a cancer diagnosis. On the one hand, it stems from insufficient understanding of surgery, unpredictable postoperative survival rate and concern about potential complications; On the other hand, it is related to the long waiting period before operation because of various medical tests. This finding suggested that medical staff should pay more attention to patients' emotional changes and adopt strategies to support patients. Furthermore, most patients knew little about the disease and had limited access to information resources, so Baidu was the main source they relied on. After a simple internet search through mobile phones, they would be more stressful panic and make inappropriate decisions because the quality and credibility of the information on Baidu are different. A previous study also revealed that patients have a deficiency in their comprehension of the disease and that healthcare professionals tend to underestimate cancer patients' need for information.[11,27] Therefore, healthcare professionals should proactively provide tailored evidence-based disease information to patients and their families (including the whole treatment and recovery process) from the beginning of their cancer experience. Studies showed that knowledge education from healthcare professionals help cancer patients correctly cope with disease problems and improve their adverse emotions.[28] Medical staff should communicate with patients in a clear, compassionate, humanistic, and patient-centered way to alleviate patients' fear, thus increasing patients' acceptance of diagnostic information, enhancing treatment compliance and increasing confidence in treatment.

During the perioperative phase, most participants experienced multiple pressures and sleep disorders, and these feelings arose from high cost of esophageal cancer treatment, the long treatment cycle, role change and somatic symptom burden. This coincides with the findings of Ma.[29] They were even worried about becoming a burden to their friends and relatives. Psychotherapists can be engaged as necessary to pay attention to the problem of patients' negative emotions and develop targeted interventions to reduce patients' pressures.[30] In addition, some patients reported that they were not accustomed to the limited space and depressing atmosphere in the ward. Therefore, hospital administrators must never ignore the effects of the ward environment on cancer patients' daily lives and emotions. A bright and spacious hospital environment staffed by empathetic healthcare workers may avoid this situation and promote disease recovery. This study also found that patients often feel lonely, helpless and lack of dignity, and were eager for humanistic care from medical staff during hospitalization. Therefore, nurses should increase bedside nursing time, take the initiative to care about patients' psychological feelings, take various measures to help patients express their needs and increase humanistic care. Symptom management needs are prominent needs after esophagectomy. The participants expressed that they experienced the highest number of symptoms and the most pronounced symptom burden during hospitalization, which is consistent with the findings of previous studies.[7,26] Pain, fatigue, lack of appetite, choking, cough, dysphagia, bloating, and reflux are common and expected adverse consequences of surgery, which would improve over time. In addition, we found that patients with high somatic symptom burden would have more pronounced psychological distress. Therefore, healthcare providers should attach great importance to the dynamic symptom management of patients and provide effective symptom management skills, including medications and nonpharmacological therapies.[31] In addition, patients are confronted with the challenges of daily diet and nutrition problems due to changes in esophageal physiology and transition from fasting to liquid food and semiliquid food.[32] Nurses should pay more attention to patients' dietary and nutritional needs after surgery and provide one-to-one enteral nutrition guidance, intravenous high-nutrition guidance and oral nutritional intake guidance. Notably, eating slowly, consuming small and frequent meals, chewing 50 times, performing chin-down-plus-larynx-tightening maneuvers, and avoiding lying flat immediately after the finish of a meal can prevent digestive tract discomfort in patients with esophageal cancer after eating.[33]

Owing to the comprehensive promotion of ERAS, the length of hospital stay of patients has been shortened, and some participants felt that they were not adequately prepared for discharge. This may be because they have low confidence in self-management, including rehabilitation exercise, diet, symptom management and medication taking.[34] Analysis of the reasons, on the one hand, may be that patients need to independently manage their own complex diseases after discharge, and lack of necessary knowledge may lead to their inability to cope with emergencies; On the other hand, it may be that patients do not know enough about postoperative rehabilitation knowledge and face individual differences, which makes patients worry about their recovery after discharge. In addition, most patients with esophageal cancer are older and from remote rural areas, which made follow-up review difficult and weakened medical support.[35] Improving self-management and disease awareness in patients can improve surgical outcomes and promote long-term survival. Consequently, medical professionals must reassess their self-management ability and patient readiness for discharge to provide diverse discharge teaching as well as home-based rehabilitative information to strengthen the memory of the teaching subjects, particularly accounting for patients' cultural context. Some participants showed serious dependency on medical staff and were eager to receive further care from hospital staff after discharge. Some internet-based mobile smart devices should be considered to maintain their continued contact with medical professionals after they return home,[36] and hospitals should carry out hospital-society-family triple-linkage rehabilitation programs to help patients recover.

In our interviews, most participants described their life after going home as "losing normal life" during the adjustment phase period. The patients' original lifestyles were completely disrupted including diet, exercise, recreation, and they were unable to adjust to a rhythm of life within a short period after discharge. The altered dietary habits and uncontrolled symptoms as well as the patient's illness experience may result in withdrawal from social situations and isolation.[37] Therefore, nurses should encourage patients to communicate with others and improve their level of posttraumatic growth.[38] Moreover, some participants were worried about future hardship and cancer recurrence. This shows that it is necessary to inform survivors that recovery is a continuous process and that the length of recovery will vary from person to person. At the same time, nurses can provide timely remote cancer recurrence monitoring education for patients to help them know their health status promptly and dynamically and develop individualized health maintenance plans. During the adjustment phase, the ability of patients to care for themselves is limited. Therefore, adequate social support plays a vital role in promoting patient recovery because esophageal cancer patients need to perceive being loved and cared for by their family members, friends, peers, and other communities in general. Our results are consistent with those of previous studies on other cancer patients, which shows that the social support system of cancer patients is an important factor in their posttraumatic growth.[39] In Confucian ethical concepts, the family is regarded as the basic unit of society, and emotional connections and mutual support among family members are extremely important. The care of family members makes patients feel safe and warm. However, some patients' family caregivers need to go out to work and they cannot stay with patients often, which will lead to weakened family support. Nurses should comprehensively assess the social support system of these patients and provide holistic support and education for patients' family caregivers. Peer support is a unique form of social support and peer experience can enhance the psychosocial well-being of patients during recovery. Therefore, promoting communication among similar patients may be beneficial, and hospitals can establish peer support groups or regularly organize peer meetings and activities to share rehabilitation skills.

Interestingly, we found that patients' self-management was a dynamic process. As time went by, patients would gradually increase their acceptance of symptoms and gradually adapt to a life of recovery living with symptoms. During the adaptation phase, some patients said that this illness experience made them more deeply aware of the importance of health and changed their unhealthy lifestyle to keep their condition stable Some survivors tried to re-establish "normality" in their lives through self-management practices, and they began to downplayed or even ignore some of their symptoms gradually. Furthermore, some participants described that they hoped to maintain autonomy in their everyday lives and that they needed to carry out their daily routine as much as possible. Thus, at this point, their family members should pay more attention to their changing needs over time and take corresponding measures to help such people deal with what they can as soon as possible instead of overprotecting.[40] Research reports that the behaviors of others have profound impacts on patient wellbeing.[41] Inappropriate social support weakens individuals' ability to regain their functional ability, impedes their recovery, affects their self-efficacy and reduces their self-esteem.[42,43] Similarly, cancer survivors will feel guilty owing to their inability to fill their former role, such as a family member, friend, or employee.[44] Therefore, families should recognize the need to lessen their physical support and enhance patients' confidence in their self-care ability. More importantly, state policies are supposed to support the reintegration of cancer survivors into society through various policy benefits.[45] Medical insurance should also increase the reimbursement ratio for cancer patients, and the government should provide certain economic support to cancer patients to alleviate their financial and living pressures. Finally, there are limited hospitals with high-quality medical resources in China, and most of them are concentrated in big cities.The state should pay attention to making up for the shortage of regional medical resources, such as setting up cross-regional medical platforms to provide online medical guidance for patients, avoiding patients' long journey to seek medical treatment and alleviating their pressure.

Relevance for Clinical Practice

The results of this study indicated that at various stages of the cancer journey, esophageal cancer patients had a wide range of needs in terms of health information, symptom management, psychological care, and social support. Healthcare providers should scientifically and systematically assess and provide supportive care to patients. Medical staff should assess the dynamic needs of patients based on their different stages of disease, provide disease education and rehabilitation information, psychological therapy, symptom management skills at appropriate times, and cultivate patients' social support networks, including peer support groups, patient-centered group activity, binary coping of husband and wife, and organization of family meetings. Moreover, it is necessary to use e-health (ie internet or smartphone apps) to provide continuous care services. These interventions play a pivotal role in helping esophageal cancer patients recover and reintegrate into social life.

Limitations

This is the first time that the TIR theory has been applied to explore the longitudinal disease experiences and needs of esophageal cancer patients undergoing esophagectomy. There were still several limitations in this study. First, this was a single-center study in one of the large-volume national cancer regional medical centers. Therefore, the generalizability of our results may be limited due to small sample size and single source. Second, patients who received neoadjuvant therapy before surgery were excluded because these patients had to undergo multicycle chemoradiotherapy and long-term repeated hospitalization. Finally, some interviews were conducted by telephone, and some patients were accompanied by their family members. They might not fully express their views.

Conclusion

This research add depth and breadth to the understanding of disease experiences and needs of esophageal cancer patients undergoing esophagectomy in China. Esophageal cancer patients undergoing esophagectomy had interrelated and dynamic experiences and needs in the process of cancer diagnosis, treatment and recovery, and physical and emotional symptoms were interrelated with each other, which have a range of negative effects on their daily lives. Medical professionals should carry out dynamic and individualized interventions as well as provide adequate information resources and social support to reduce symptom burden, improve quality of life and promote long-term survival.

Data Sharing Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Ethics Approval

The program was granted approval by the Henan Cancer Hospital (2022-KY-0163).

Consent

This study obtained written informed consent from participants, reconfirmed by their oral consent prior to the interviews to have the interviews digitally recorded.

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Disclosure

The authors declare no conflicts of interest.

References

1. Bray F, Laversanne M, Sung H, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2024;74(3):229–263. doi:10.3322/caac.21834
2. Griffin SM, Jones R, Kamarajah SK, et al. Evolution of esophagectomy for cancer over 30 years: changes in presentation, management and outcomes. *Ann Surg Oncol*. 2021;28(6):3011–3022. doi:10.1245/s10434-020-09200-3
3. Kuppusamy MK, Low DE. Evaluation of International contemporary operative outcomes and management trends associated with esophagectomy: a 4-year study of >6000 patients using ECCG definitions and the online esodata database. *Ann Surg*. 2022;275(3):515–525. doi:10.1097/sla.0000000000004309
4. Ueda Y, Chujo M. Eating behaviors of postoperative esophageal cancer patients during the first year after surgery. *Yonago Acta Med*. 2020;63(3):173–182. doi:10.33160/yam.2020.08.005
5. Gupta V, Allen-Ayodabo C, Davis L, et al. Patient-reported symptoms for esophageal cancer patients undergoing curative intent treatment. *Ann Thorac Surg*. 2020;109(2):367–374. doi:10.1016/j.athoracsur.2019.08.030
6. Low DE, Allum W, De Manzoni G, et al. Guidelines for perioperative care in esophagectomy: Enhanced Recovery After Surgery (ERAS($^{®}$)) Society Recommendations. *World J Surg*. 2019;43(2):299–330. doi:10.1007/s00268-018-4786-4
7. Chen YQ, Zhong JD, Hong YT, Yuan J, Zhang JE. Patient-family caregiver concordance of symptom assessment for esophageal cancer patients undergoing esophagectomy. *Cancer Nurs*. 47(2):141–150. doi:10.1097/ncc.0000000000001191
8. Markar SR, Zaninotto G, Castoro C, et al. Lasting Symptoms After Esophageal Resection (LASER): European multicenter cross-sectional study. *Ann Surg*. 2022;275(2):e392–e400. doi:10.1097/sla.0000000000003917
9. Choi E, Kim SH, Lee YW, et al. Supportive care needs and health-related quality of life of esophageal cancer survivors. *Asia Pac J Oncol Nurs*. 2021;8(2):164–171. doi:10.4103/apjon.apjon_60_20
10. Ren JY, Zhong JD, Yuan J, Zhang JE, Li CZ, Wei WJ. Unmet supportive care needs and associated factors among Chinese discharged patients with esophageal cancer after esophagectomy: a cross-sectional study. *Eur J Oncol Nurs*. 2020;46:101767. doi:10.1016/j.ejon.2020.101767
11. Bennett AE, O'Neill L, Connolly D, et al. Perspectives of esophageal cancer survivors on diagnosis, treatment, and recovery. *Cancers*. 2020;13(1). doi:10.3390/cancers13010100
12. Corbin JM. The Corbin and Strauss chronic illness trajectory model: an update. *Scholarly Inquiry Nurs Practice*. 1998;12(1):33–41.
13. Fitch MI. Supportive care framework: theoretical underpinnings. 2008.
14. Fitch MI. Supportive care needs of patients with advanced disease undergoing radiotherapy for symptom control. *Can Oncol Nurs J*. 2012;22(2):84–100. doi:10.5737/1181912x2228491
15. Cameron JI, Gignac MA. "timing it right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Educ Couns*. 2008;70(3):305–314. doi:10.1016/j.pec.2007.10.020
16. Yi M, Pan Y. Effects of "Timing It Right" nursing on clinical outcome and psychological resilience for lung cancer patients undergoing radical thoracoscopic surgery. *Am J Transl Res*. 2024;16(1):179–189. doi:10.62347/lumw7355
17. Li T, Zhang YP, Kong JJ, Kong M, Meng G, Shi WX. Effect of "timing it right" on comprehensive unmet needs and psychological pain in patients with head and neck cancer undergoing radiotherapy: a randomized controlled trial. *Support Care Cancer*. 2022;30(8):6573–6582. doi:10.1007/s00520-022-07072-9
18. Pei J, Meng J, Xue Y, Zhang L. Disease experience of patients with differentiated thyroid cancer at different phases based on timing it right framework: a qualitative longitudinal study. *Cancer Nurs*. 2024;47(5):388–396. doi:10.1097/ncc.0000000000001233
19. SmithBattle L, Lorenz R, Reangsing C, Palmer JL, Pitroff G. A methodological review of qualitative longitudinal research in nursing. *Nursing Inquiry*. 2018;25(4):e12248. doi:10.1111/nin.12248
20. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd ed. Philadelphia, PA: Sage; 2013.
21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042
22. Balmer DF, Richards BF. Conducting qualitative research through time: how might theory be useful in longitudinal qualitative research? *Adv Health Sci Educ Theory Pract*. 2022;27(1):277–288. doi:10.1007/s10459-021-10068-5
23. Helsinki WMADO. World medical association declaration of Helsinki: ethical principles for medical research involving human subjects. *Hiv Clinical Trials*. 2000;2(4):92–95.
24. Colaizzi PF. Psychological research as the phenomenologist views it. In: Valle RS, King M, editors. *Existential-Phenomenological Alternatives for Psychology*. Oxford, UK: Oxford University Press.; 1978:48–71.

25. Polit DF, Beck CT. *Nursing Research: Generating and Assess- Ing Evidence for Nursing Practice*. 10th ed. Philadelphia, PA: Lippincott Williams & Wilkins.; 2016.
26. Wang Y, Xie Z, Liu Y, Wang J, Liu Z, Li S. Symptom clusters and impact on quality of life in esophageal cancer patients. *Health Qual Life Outcomes*. 2022;20(1):168. doi:10.1186/s12955-022-02084-9
27. Su X, Ma S, Yang X, Zhang C, Chen W. Health literacy needs of acute pancreatitis patients during the diagnosis and treatment process under the lens of the timing it right theory: a qualitative study. *Patient Prefer Adherence*. 2024;18:507–517. doi:10.2147/ppa.S444955
28. Song C, Yao L. The experience of social alienation in elderly lung cancer patients: a qualitative study. *Asian Nursing Research*. 2024;18 (3):281–287. doi:10.1016/j.anr.2024.07.007
29. Ma S, Yang X, He H, et al. Psychological experience of inpatients with acute pancreatitis: a qualitative study. *BMJ Open*. 12(6):e060107. doi:10.1136/bmjopen-2021-060107**.**
30. Bussmann S, Vaganian L, Gerlach AL, Kusch M, Labouvie H, Cwik JC. Screening and assessment for cancer patients' psychosocial support needs: development and validation of the psychosocial risk questionnaire. *Eur J Oncol Nurs*. 2023;63:102240. doi:10.1016/j.ejon.2022.102240
31. Yorke J, Johnson MJ, Punnett G, et al. Respiratory distress symptom intervention for non-pharmacological management of the lung cancer breathlessness-cough-fatigue symptom cluster: randomised controlled trial. *BMJ Support Palliat Care*. 2023;13(e3):e1181–e1190. doi:10.1136/spcare-2022-003924
32. Wang P, Zheng X, Luo Z, Wang Y, Guo Z, Zhou Y. Perceptions and experiences of nutritional management needs for patients with esophageal cancer during the peri-radiotherapy period: a qualitative study. *Asia Pac J Oncol Nurs*. 2022;9(4):202–209. doi:10.1016/j.apjon.2022.01.002
33. Yang F, Zou L, Li L, et al. Effect of Chin-down-plus-larynx-tightening maneuver on swallowing function after minimally invasive esophagectomy: a randomized controlled trail. *Cancer Med*. 2020;9(16):5889–5898. doi:10.1002/cam4.3280
34. Li ZY, Ren JY, Zhong JD, Zhang JE. Understanding the supportive care needs among discharged patients with esophageal cancer after esophagectomy: a qualitative study. *Eur J Oncol Nurs*. 2023;64:102337. doi:10.1016/j.ejon.2023.102337
35. Morgan E, Soerjomataram I, Rumgay H, et al. The global landscape of esophageal squamous cell carcinoma and esophageal adenocarcinoma incidence and mortality in 2020 and projections to 2040: new estimates from GLOBOCAN 2020. *Gastroenterology*. 2022;163(3):649–658.e2. doi:10.1053/j.gastro.2022.05.054
36. Verma R, Saldanha C, Ellis U, Sattar S, Haase KR. eHealth literacy among older adults living with cancer and their caregivers: a scoping review. *J Geriatr Oncol*. 2022;13(5):555–562. doi:10.1016/j.jgo.2021.11.008
37. Toh Y, Morita M, Yamamoto M, et al. Health-related quality of life after esophagectomy in patients with esophageal cancer. *Esophagus*. 2022;19 (1):47–56. doi:10.1007/s10388-021-00874-6
38. Menger F, Mohammed Halim NA, Rimmer B, Sharp L. Post-traumatic growth after cancer: a scoping review of qualitative research. *Support Care Cancer*. 2021;29(11):7013–7027. doi:10.1007/s00520-021-06253-2
39. Sayılan A A, Demir Doğan M. Illness perception, perceived social support and quality of life in patients with diagnosis of cancer. *Eur J Cancer Care*. 2020;29(4):e13252. doi:10.1111/ecc.13252
40. Lee G, Kim SY, Ahn A, et al. Adjustment to "new normal" after cancer among non-small cell lung cancer survivors: a qualitative study. *Palliat Support Care*. 2024;22(3):487–492. doi:10.1017/s1478951523001815
41. Andreasen TK, Boje IR, Tolstrup LK, Missel M, Larsen MK. Treatment and rehabilitation for esophageal cancer-striving to meet obstacles and long-term impacts: a qualitative descriptive study. *Cancer Nurs*. 2024. doi:10.1097/ncc.0000000000001359
42. Wang X, Liu X, Gu Z, Li X, Shu Y. Experiences and requirements in nutritional management of patients with esophageal cancer: a systematic review and qualitative meta-synthesis. *Support Care Cancer*. 2023;31(12):633. doi:10.1007/s00520-023-08100-y
43. Adriaans DJM, Rosendaal M, Nieuwenhuijzen GAP, et al. Expectations and needs of patients with esophageal cancer during curative treatment regarding self-management, self-management support and eHealth: a qualitative study. *Eur J Oncol Nurs*. 2024;71:102638. doi:10.1016/j.ejon.2024.102638
44. Henshall C, Greenfield S, Gale N. the role of self-management practices as mechanisms for re-establishing normality in cancer survivors. *Qual Health Res*. 2017;27(4):520–533. doi:10.1177/1049732316651252
45. Franco-Rocha OY, Carillo-Gonzalez GM, Garcia A, Henneghan A. Cancer survivorship care in Colombia: review and implications for health policy. *Hisp Health Care Int*. 2022;20(1):66–74. doi:10.1177/15404153211001578