## A QUALITATIVE STUDY ON THE REAL NEEDS OF PATIENTS AFTER ENDOSCOPIC SUBMUCOSAL DISSECTION WITH EARLY GASTROINTESTINAL CANCER

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#### **ABSTRACT**

**Objective**: To investigate the actual needs of patients after endoscopic submucosal dissection (ESD) with early gastrointestinal cancer, and to provide reference for finding the way of health education for hospitalized and discharged patients, and to satisfy the health needs of the patients.

**Methods**: Thirteen patients with early gastrointestinal cancer who underwent endoscopic submucosal dissection were selected by objective sampling method from a Grade A comprehensive hospital in Suzhou. The data were collected by semi-structured in-depth interview method and analyzed by Colaizzi's phenomenological analysis method.

**Results**: After analysis, 7 themes were extracted: physical discomfort, uncertainty in illness, the need to acquire health knowledge, anxiety, family and economic support needs, fear of cancer recurrence, and the need of continued care after discharge.

**Conclusion**: There are many needs that cannot be met for patients after ESD with early gastrointestinal cancer. It is necessary for the clinical nursing to strengthen the evaluation of patients undergoing ESD with early gastrointestinal cancer, anticipate the individual problems and needs that patients may encounter in advance, and intervene as soon as possible, so as to promote the early recovery of patients.

Keywords: Early gastrointestinal cancer, Endoscopic submucosal dissection (ESD), Experience, Qualitative study.

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### Introduction

The incidence of digestive system tumors in China accounts for more than half of the total incidence of malignant tumors<sup>(1)</sup>. Early gastrointestinal cancer means the infiltration depth of the lesion is confined to the mucosal layer or submucosal layer, regardless of whether there is lymph node metastasis<sup>(2)</sup>. Endoscopic submucosal dissection (ESD) is a new type of surgery gradually developed in China in recent years, which employs endoscopic technology to completely remove the diseased tissue from the submucosal layer<sup>(3)</sup>. Due to the small amount of intraoperative blood loss and fast postoperative patient recovery, it has become the preferred surgical method for early gastrointestinal cancer<sup>(4)</sup>. Despite

its several advantages, patients and their families know little about ESD<sup>(5)</sup>. Patients after ESD urgently need to master relevant knowledge about disease treatment and rehabilitation, while health education by medical staff is the most effective, which can not only help patients improve knowledge and skills in self-care, but also reduce patients' anxiety and fear, reduce postoperative rehabilitation-related risks, improve the quality of life<sup>(6)</sup>. However, studies have shown that there is still a certain difference between the content of patient health education needs and the actual content, so patients' needs are not sufficiently met<sup>(7)</sup>. From the perspective of qualitative research, this study interviewed patients with early gastrointestinal cancer after ESD to understand their disease awareness and health needs, identify current health education weaknesses, and further improve the content and form of health education among such patients to facilitate patients' recovery.

## Objects and methods

## **Objects**

The convenience sampling method was taken to select patients with early gastrointestinal cancer who underwent ESD surgery in the gastrointestinal ward of a third-class A hospital in Suzhou from August 2021 to October 2021.

Inclusion criteria

- Patients definitely diagnosed with early gastrointestinal cancer who underwent ESD surgery for the first time:
- Patients are aware of the disease, agree and are willing to participate in this study, and can fully express their true inner experience.

Exclusion criteria

- Those with mental, hearing, and consciousness impairment;
- patients not undergoing surgery for the first time;
- those refusing to participate in the research. The sample size was determined based on the repeated appearance of the interviewee's data and no presence of new topics during the data analysis. In the final interview, 13 interviewees reached data saturation, including 3 men and 9 women; the age ranged from 36 to 66 years, with an average of (54±9) years old.

#### Methods

#### Data collection

This study adopted phenomenological research methods in qualitative research, and took semi-structured in-depth interviews to collect data. Before the interview, explain the research purpose and methods to the interviewees who meet the inclusion criteria, illustrate the research purpose and seek their consent, and record the interview content. The interview time was in the evening, and the interview location was selected according to the wishes of the interviewees: ward or researcher's office. Self-designed semi-structured interview outline was adopted. The outline content: 1) Do you know what surgery you have received? 2) How do you feel now? 3) What are your thoughts on this disease? 4) Do you need our help at present (after the surgery)?

5) What kind of guidance do you want us most to give you at present (after surgery)? The content is mainly open-ended questions. During the interview, the interviewes were encouraged to express freely. Ask for detailed questions appropriately, and observe their facial expressions, movements and other non-verbal behaviors. After the information reached saturation, data collection was stopped. The interview time was controlled within 30~60 minutes.

## Data analysis

Data collection and analysis were simultaneously carried out. The interview content and the expressions and movements of the research subjects were sorted out that very day. The interview recordings were transcribed verbatim and analyzed using Colaizzi's phenomenological analysis. Read all interview records comprehensively, extract important narratives, code recurring views, summarize them after coding, extract and name topics step by step, and finally integrate them into six major topics.

#### Results

Interview data of the 13 patients were repeatedly compared and summarized, and the following seven topics were extracted: physical discomfort, illness uncertainty, health information acquisition, anxiety, worry, family, financial support, fear of cancer recurrence, and health consultation after discharge.

#### Physical discomfort

The ESD surgery time is about 1 hour. It is minimally invasive with less pain compared with traditional open surgery. However, the preoperative preparation process is the same as that of traditional surgery, and routine postoperative monitoring is required. Most interviewees generally have physical discomfort after surgery, such as pain, fatigue, hunger, sleep disorder, etc. N1: "I didn't sleep well all night after the surgery. I was tied to this machine (monitor), and was woken up after sleeping for a while. I didn't sleep well, and the whole person was uncomfortable." N8: "Surgery process is okay. After the surgery, the wound is a little painful after all, but it is tolerable. What I can't stand is that one can't eat anything before the surgery. I have diabetes and felt hungry and dizzy in the morning (before the surgery) since eating is not allowed. I felt better after chewing a candy." N10: "(After the surgery), what I couldn't bear most is the pain. It is better if (medical

staff) informs me of it in advance, so that I have psychological preparation. At first, I thought it was a minor surgery, but it was really painful that day." N11: "I didn't feel any discomfort during the surgery. Since the night of the previous day, I couldn't eat until the next day after the surgery. I felt so hungry and flustered that I felt uncomfortable." N12: "I had stomach discomfort in the first 3-4 hours, and my throat was a bit painful. I know it will definitely be a little uncomfortable after the surgery, but I still hope that the doctors and nurses can explain to me (the reason)."

#### Illness uncertainty

The pathological results and complications of early gastrointestinal cancer after endoscopic resection are difficult to predict. Patients do not know about the follow-up, prevention, and recurrence after the resection. Plus various uncertain factors such as complicated treatment and care, patients are prone to disease uncertainty(8,9). N1: "I didn't have any symptoms at hospitalization, just a healthy (person), I can't figure out how I am a patient?" During the interview, patients with early cancer were quite anxious to know their pathological diagnosis results, eager to know more about their diseases(10). N2: "I just want to know how I got this disease? How is the surgery performed? When will I know the result (pathology)? Is the disease confirmed (as early cancer)?" N4: "I just want to know whether I'll be fine after the surgery is over? What will be bad consequences?" N10: "I'm not clear what is wrong with me. The doctor said that something grows and I will be fine after it is cut off by minimally invasive surgery. What is it (pathological type)? What if I don't know clearly about it?" N12: "I know there will definitely be a little discomfort after the surgery, but I'm still a little worried, afraid of bad problems. I don't know how will it develop?"

## Health information acquisition

At present, the Internet has become the first choice for health information acquisition (11), but the Internet is full of false information. Due to lack of professional knowledge, patients cannot distinguish the authenticity of the information. N1: "I really want to know how ESD surgery is performed? Will perforations develop into big holes?... I get even more scared after Baidu search!... I really need a professional person to tell me and popularize science for me..." N2: "What is the nature of my disease? I know nothing about the disease, just

searching it online. There is too much information on the Internet, and I don't know how to confirm the authenticity." N4: "I'm afraidof complications. I searched postoperative precautions online..." N7: "I hope that doctors can let me know more about the disease and tell me how to pay attention to physical changes. Baidu search result is very scary, but our channel is only limited to Baidu..." In addition to Internet search, traditional ways of health information acquisition including learning from relatives and friends, media reports, doctor consultation or participation in health lectures still play a role(12). N3: "The WeChat group created by Director Wu is very good. I hope to receive professional guidance from doctors." N6: "What the doctor told me during the ward rounds is very useful. I want the doctors and nurses to tell them a few more times when Ihave questions that I can't figure out. Once the doctor explains, I will understand and get relaxed." N7: "I hope that doctor can set up a public account or a Tik Tok account to popularize the disease knowledge among us, such as how to discover it? How is the surgery performed? What to do after the surgery?" N8: "Hopefully (doctors, nurses) can (popularize the disease knowledge) with different methods for different ages. Take the opposite grandmother for example. The nurse told her a lot, and she forgot after a while. Then, when we had chat, we (also patients) repeated it to her again." N12: "I don't like to see a doctor, I haven't thought about consulting an expert, I don't have any information sources, and I don't know how to search online".

#### Worry and anxiety

ESD has many advantages compared to surgical procedures, such as less trauma, faster recovery, and fewer complications. However, ESD is a new treatment approach, patients and their families do not know much about it. Coupled with worries about the disease itself, patients are prone to negative psychology such as anxiety and depression before surgery. In addition, the main complications of ESD surgery are perforation and bleeding, which undoubtedly increases the psychological burden of patients and their families<sup>(5)</sup>. During the interview, 7 patients all expressed that they have varying degrees of anxiety, hoping to get the attention of medical staff or their family members. N1: "(Before the surgery) I had all kinds of concerns, worry about complications, feel fear, nervousness. I don't know what to do..." N4: "Worries are always there. I'm afraid of complications..." N6: "I was a little worried before the surgery, but after the surgery, I felt better than expected, and then get relaxed. With good mood, illness is gone." N7: "I am very worried (about the disease). I didn't sleep all night after I was informed of the disease on Friday. I searched a lot on Baidu." N8: "I was very, very nervous. I just want to ask any medical worker. I even asked the cleaner aunt. In fact, I knew she didn't know, but I still wanted to ask her."

#### Fear of cancer recurrence

The survival rate of patients with early gastrointestinal cancer is high after ESD, but there is a possibility of recurrence. The recurrence rate of early gastric cancer after ESD is 12.3% within 5 years (13), and the local recurrence rate of early esophageal cancer after ESD can reach 1.35%(14). Therefore, patients will have varying degrees of fear of cancer recurrence after surgery(13,15). N1: "I just concern whether I can return to normal state after the surgery, whether it will affect eating, and whether I will relapse in the future, all kinds of worries." N2: "I'm still a bit afraid, worrying about the procedure before the surgery, also postoperative recovery and the impact on future life after the surgery. One (lesion) is not removed. The doctor asked me to follow up and observe, but I was still a little worried..." N5: "Will my disease never be cured? Is the test (pathological) result available? Will I relapse in the future?" N7: "After knowing that I have developed tumor, I only have one thought, cut it off. After the cut, I want to know if the (pathology) is fine or not? Will tumor further grow?...I'm very worried that I will relapse in the future. My son is still young and I can't collapse." N8: "How about the postoperative recovery process, when will the pathological results come out? What's the disease stage, do I need follow-up treatment?" N13: "There is always tension, fear. It will be anyway fine after the resection, but I'm just afraid of recurrence. I just want the doctor to remove it completely for me, so that there is no problem left."

## Family, financial support

Social support can effectively reduce the pain of individuals in the stress process, and reduce the level of anxiety and depression<sup>(16)</sup>. The traditional Chinese family is a very important social support system. Family support plays an important role in the condition control of patients with chronic diseases and the formation of patients' self-confidence<sup>(17)</sup>. During the interview, most patients said that family

support is quite important, and some patients expressed concern about the economy. N1: "I think family support is very important. I was angry when the family atmosphere was unhappy a while ago. Plus busy work, I don't know whether the disease will be affected? In addition, family members always add seasonings in cooking, and I particularly oppose it, but they don't change the habit." N9: "I originally didn't want to come here, but my son urged me to come. Later, it was found out that there was truly a problem. I originally need look after my grandson, but my son immediately decided to hospitalize me for surgery. In future reexamination, my family will definitely support me." N10: "Fortunately, my husband always accompanies me. My mother planed to come too, but now she can't come (due to the epidemic prevention and control requirements)! Although it was a minimally invasive minor surgery, I was painful before the procedure. It makes me feel better that he is always by my side, so that there is some help anyway." N5 (The patient kept asking questions about medical insurance reimbursement during the interview): "How much can be reimbursed (by medical insurance)? The money is borrowed. Do I need to reexamine it after the surgery? Then the family financial condition will not support it..." N6: "This surgery costs a lot. My family work hard to earn money. The financial status is just so so, but the disease should be treated".

### Health Consultation after Discharge

With the popularization of Internet and mobile information technology, the channels for accessing patient information are diverse and convenient, but generally lacking professional knowledge and medical knowledge, unable to provide professional and scientific judgments on health behaviors and diagnosis and treatment decisions. Although the nurses provide discharge guidance at the time of discharge, the guidance content cannot fully meet patients' needs<sup>(7)</sup>. In this study, most of the patients are quite eager to know about knowledge of home care after discharge and the precautions for followup visits. N5: "I want to know what I can eat after I return? Is there anything I can't eat? When will the test results come out? How can I know?" N7: "What should I pay attention to after the surgery (discharge)? Will it relapse? What symptoms mean thatI need further check?" N8: "How long does it take for me to completely recover? Are there other emergencies? How can I better recover? I hope that there will be guidance in different ways for patients of different ages."N2: "One tumor is still not removed, and I am still a little worried. How will it impact my future life? What should I pay attention to? When should I reexamine it?" N6: "How often should I reexamine it after I am discharged? What should I do for reexamination?"

#### Discussion

Implement specialized nursing measures, provide systematic health information support, reduce patients' disease uncertainty in the early stage after ESD, and increase patient comfort

Although patients have certain understanding of the disease after ESD, they still lack knowledge of postoperative diet, activities, follow-up treatment, prognosis and rehabilitation health care(18). In this interview, it was found that most patients have a sense of disease uncertainty after ESD, and the disease uncertainty may affect patients' psychological adjustment ability and even the disease outcome<sup>(17)</sup>. Therefore, nursing staff should pay attention to and evaluate the patient's disease uncertainty, actively provide patients with systematic and continuous information support, so as to improve their cognitive level and strengthen their rehabilitation behavior. Various channels, such as questionnaires, interviews, etc., can be adopted to know about the information that early gastrointestinal cancer patients undergoing ESD surgery want to know, and then medical staff can jointly formulate active treatment and nursing programs, carry out health education in a form easily acceptable for patients. At the same time, nursing staff should improve their professional nursing knowledge and professional level, communicate with patients in depth, patiently explain the possible causes of postoperative complications and coping methods, improve their awareness of pain, fatigue and other discomforts, and enhance their prevention and coping capabilities. The accelerated rehabilitation surgery (FTS) which emerges in recent years can improve the perioperative metabolic stress response and accelerate patient recovery. Studies have shown that according to FTS theory, instructing patients to take carbohydrates before surgery can alleviate patients' hunger, reduce the occurrence of adverse reactions such as hypoglycemia, and effectively promote postoperative recovery of ESD patients (19). In view of this, in addition to actively implementing conventional nursing measures, such as pain care, sleep care, diet care, etc., nursing staff can try to utilize FTS theory, instruct patients to take carbohydrates before surgery depending on the patient's condition to reduce patient's hunger and relieve the patient's physiological discomfort after surgery.

Comprehensively use multiple methods to meet the needs of patients for access to health knowledge

Studies have shown that hospitalized patients prefer to access relevant health knowledge through written materials and on-site lectures by medical staff<sup>(20,21)</sup>. In this study, almost all patients mentioned that they hope to receive professional explanations from medical workers. In view of this, medical staff can formulate publicity manuals with pictures and texts for patients, and at the same time carefully and patiently explain the publicity contents to the patients, and respond to patients' doubts in a timely manner. However, studies have shown that patients with chronic diseases have certain obstacles in accessing health information due to their lack of understanding of medical terminology, uncertainty of information, and insufficient access to authoritative information. Some interviewees in this research also pointed out that contents found by current search engines are difficult to distinguish between true and false, right and wrong, which is confusing. Medical staff should help patients increase their understanding of medical terminology, teach patients how to identify and use authoritative information resources, and reduce patients' access to inaccurate health information through simple Internet searches. Most patients in this study are willing to join the WeChat group established by the chief surgeon, hoping to receive professional guidance from the doctor at any time after the discharge. In addition, except for the elderly incapable of Internet search, all the interviewed patients expressed their wishes to receive formal education from medical staff through channels such as Tik Tok video, WeChat Moments, and the official WeChat account of the hospital. In view of this, medical staff can record short disease-related education videos and upload them to the Internet public platform according to the needs of patients, and at the same time establish WeChat group to meet the patient needs for access to health information through multiple channels.

Provide individualized whole-process psychological care intervention, strive for active family and social support, reduce patient anxiety and worries, and ease the fear of cancer recurrence

Studies have found that early cancer patients undergoing ESD have varying degrees of anxiety before and after surgery<sup>(5,22)</sup>. In accordance with

it, 8 people in the interview expressed varying degrees of anxiety. As a newly emerging diagnosis and treatment technology in recent years, ESD is relatively safe and effective, but it has not been developed for a long time in China, and patients have very little information on this aspect, which will cause anxiety and fear, such as worries about complications, decline in quality of life, prognosis, heavy financial burden to the family, etc. Anxiety can reduce the pain threshold of EGC patients and hinder the wound healing of EGC patients after the tumor dissection. In severe cases, neuropsychiatric symptoms can occur, which can increase pain and affect the treatment effect<sup>(23)</sup>. In addition, studies have shown that 61.2% patients after ESD have a fear of cancer recurrence(15), and long-term fear of cancer recurrence will affect the physical and mental health of patients<sup>(24)</sup>. About half of the interviewees in this study also expressed a certain degree of fear for recurrence. Factors affecting the fear of cancer recurrence include age, gender, economic status, multi-site lesions, pathological results suggesting early cancer, H. pylori positive, postoperative complications, social support and positive coping styles. Where, favorable social support, better economic conditions and active coping styles can alleviate the fear of cancer recurrence(25). Family support is the most basic form of social support. Active family support can enable patients to get more understanding and support from family members. It can not only provide patients with material and financial tangible support, but also satisfy patients' psychological needs for love and being loved, thereby helping to alleviate patients' psychological pressure, so that they positively cope with disease occurrence and development<sup>(9,26)</sup>. Therefore, nursing staff should pay attention to patients' psychological problems and implement necessary nursing interventions. Various forms can be adopted, such as the combination of written materials and multimedia, face-to-face communication between patients and medical staff. It is possible to encourage patients in the recovery period after surgery and discharged from the hospital to exchange experiences with patients undergoing treatment, thus providing patients with rehabilitation health care and behavioral guidance, and reducing their psychological pressure. At the same time, encourage patients to actively seek family support, encourage their families and other family caregivers to provide relevant support to patients, create a favorable social support environment, improve patients' self-efficacy and active coping ability,

and reduce their anxiety, fear of cancer recurrence and other psychological problems, thus facilitating patients' recovery.

# Improve discharge assessment and guidance, strengthen continuous nursing

Studies have shown that high-quality discharge guidance is conducive to further rehabilitation and recovery of patients at home after discharge from the hospital, thus reducing the rate of readmission<sup>(27,28)</sup>. Abundant discharge guidance includes medical and nursing information onself-care, emotional adjustment, medical treatment, rehabilitation training, and how to seek help after the patient is discharged from the hospital. Continuous nursing extends the care services for patients from the hospital to the family or community, which can alleviate the physical and mental symptoms of patients after discharge, improve patients' quality of life, reduce the rate of readmission, save medical resources, and reduce the economic burden of patients and their families, demonstrating good social and economic benefits<sup>(29)</sup>. In this study, most interviewees hope to access information on how to conduct self-management, when to reexamine, and how to reexamine after discharge from the hospital. Nursing staff should understand the difference between the patient's acquired knowledge and the expected discharge guidance content, and improve the knowledge transfer methods and skills by education video broadcasting, graphic explanations, etc., to personalize health education and ensure the quality of discharge guidance. At the same time, it is necessary to strengthen the continuous nursing care after discharge, and employ multiple channels, such as telephone return visits, home visits, WeChat groups, public accounts, various "Internet +" APPs, etc., to listen to and answer patient questions, let patients and family members participate in public education, so that patients better adapt to life after discharge.

#### Conclusion

ESD is a new technology gradually developed in China in recent years for the treatment of early gastrointestinal cancer. Despite its several advantages, patients and their families know very little about it. This study summarizes and finds that early gastrointestinal cancer patients undergoing ESD surgery generally have a sense of disease uncertainty, and there are many unsatisfied needs or

insufficient information, such as disease knowledge, information acquisition, psychological and family support, discharge guidance, etc. It suggests that in clinical care, we should strengthen assessment of early gastrointestinal cancer patients undergoing ESD surgery, foresee individualized problems and needs that patients may encounter in advance, intervene early, provide multi-channel and multi-form targeted health education and information resources, focus on improving the quality of discharge guidance, and facilitate patients' early recovery.

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