A Qualitative Study on the Transitional Experience and Rehabilitation Needs of Patients with Rectal Cancer After Sphincter-Preserving Surgery: A Postprint

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Abstract

Background: The discharge transition period is a critical stage for patients undergoing sphincter-preserving surgery for rectal cancer as they transition from hospital treatment to home rehabilitation. However, there is currently a lack of in-depth understanding regarding the lived experiences and rehabilitation needs of patients during this phase. Objective: To explore the lived experiences and rehabilitation needs of patients after sphincter-preserving surgery for rectal cancer during the discharge transition period. Methods: This study employed a descriptive qualitative research design. From April to October 2025, 17 patients who had undergone sphincter-preserving surgery for rectal cancer and were within ≤ 6 months post-discharge were selected using purposive sampling from the gastrointestinal surgery outpatient clinic of Huashan Hospital, Fudan University. Data were collected through semi-structured interviews. NVivo 12 software was used to manage the textual data, and thematic analysis was applied for coding and theme extraction. Results: A total of six themes were identified from the interviews: (1) Symptom shock and multiple physical distresses during the discharge transition period; (2) Complex psychological adaptation processes; (3) Insufficient information support and the dilemma of self-exploration after leaving the hospital; (4) Support experiences from family, fellow patients, and healthcare providers; (5) Restricted social participation and hindered role reintegration; (6) Urgent demand for continuous and individualized rehabilitation support. Conclusion: During the discharge transition period, patients face physiological discomfort and psychological pressure, alongside issues such as inadequate self-management abilities and a lack of authoritative information support. Based on the findings of this study, it is recommended that healthcare professionals provide continuous, timely, and individualized rehabilitation support during the discharge transition period and actively explore transitional care pathways connecting hospitals and communities to promote functional recovery and social role reconstruction for patients.

Full Text

Preamble

Qualitative Study on the Discharge Transition Experience and Rehabilitation Needs of Patients After Sphincter-Preserving Surgery for Rectal Cancer

Abstract

Objective: To explore the real-world experiences and rehabilitation needs of patients with rectal cancer during the transition period from hospital discharge to home after undergoing sphincter-preserving surgery, providing a theoretical basis for developing targeted transitional care interventions.

Methods: Using a phenomenological approach in qualitative research, semi-structured interviews were conducted with 15 patients who had undergone sphincter-preserving surgery for rectal cancer and were in the discharge transition period. The interviews were conducted at the gastrointestinal surgery outpatient clinic of a tertiary grade-A hospital in Guangzhou. The collected data were analyzed, coded, and categorized using Colaizzi' s seven-step method to identify recurring themes.

Results: The discharge transition experience and rehabilitation needs of patients after rectal cancer surgery were summarized into four main themes: (1) Physical and psychological distress (including symptoms of Low Anterior Resection Syndrome (LARS), psychological burden, and sleep disturbances); (2) Challenges in self-management (difficulty in dietary management and lack of professional guidance for pelvic floor muscle training); (3) High demand for information and professional support (desire for diversified health education and continuity of care); (4) Re-evaluation of social roles and life values (changes in social participation and the search for peer support).

Conclusion: Patients undergoing sphincter-preserving surgery for rectal cancer face significant physical and psychological challenges during the discharge transition period. Healthcare professionals should pay close attention to the functional recovery and psychological state of these patients, provide systematic and personalized transitional care, and improve the quality of life during the home rehabilitation phase.

Introduction

Rectal cancer is one of the most common malignant tumors of the digestive tract. With advancements in surgical techniques, particularly the widespread application of Total Mesorectal Excision (TME) and stapling devices, the rate of sphincter-preserving surgery has significantly increased. Although these procedures avoid a permanent colostomy, many patients experience a constellation of bowel dysfunction symptoms postoperatively, known as Low Anterior Resection Syndrome (LARS), which includes increased stool frequency, urgency, and fecal incontinence.

The discharge transition period—the critical window when patients move from the hospital to the home environment—is a high-risk stage for complications and psychological distress. Due to the shortened length of hospital stays, many patients are discharged before they have fully adapted to their physiological changes. This study aims to deeply understand the experiences of these patients.

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Background

The transition period following hospital discharge is a critical phase for patients who have undergone sphincter-preserving surgery for rectal cancer, marking the shift from clinical treatment to home-based recovery. However, there is currently a lack of in-depth understanding regarding the lived experiences and specific rehabilitation needs of patients during this particular stage.

This study aims to explore the lived experiences and rehabilitation needs of patients after sphincter-preserving surgery for rectal cancer during the discharge transition period.

Methods

This study adopted a descriptive qualitative research design. From April to October 2025, 17 patients who had undergone sphincter-preserving surgery for rectal cancer and were within six months post-discharge were selected as research subjects using purposive sampling. These participants were recruited from the gastrointestinal surgery outpatient clinic at Huashan Hospital, Fudan University, for follow-up. Data were collected through semi-structured interviews. NVivo 12 software was utilized to manage the textual data, and thematic analysis was applied for coding and the extraction of core themes.

Results

The interviews yielded six primary themes: (1) symptom shock and multiple physical distresses during the post-discharge transitional period; (2) a complex process of psychological adaptation; (3) insufficient informational support and the predicament of self-exploration after leaving the hospital; (4) experiences of support from family, fellow patients, and healthcare providers; (5) restricted social participation and obstacles to role reintegration; and (6) an urgent demand for continuous, individualized rehabilitation support.

Patients in the post-discharge transitional period face significant physiological discomfort and psychological pressure, compounded by issues such as inadequate self-management skills and a lack of authoritative informational support. Based on the findings of this study, it is recommended that healthcare professionals provide continuous, timely, and individualized rehabilitation support during the transitional period. Furthermore, there is a need to actively explore transitional care pathways that bridge the gap between hospitals and communities to facilitate functional recovery and the reconstruction of social roles for patients.

Keywords: Rectal cancer; Post-discharge transitional period; Rehabilitation needs; Experience; Qualitative study
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Experiences and Rehabilitation Needs of Patients during the Post-discharge Transitional Period after Sphincter-preserving Surgery for Rectal Cancer: a Qualitative Study

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Background

The post-discharge transitional period is a critical stage following sphincter-preserving surgery for rectal cancer, during which patients transition from hospital-based treatment to home-based rehabilitation; however, their experiences and rehabilitation needs during this period remain insufficiently understood.

Objective: To explore the experiences and rehabilitation needs of patients during the post-discharge transitional period after sphincter-preserving surgery for rectal cancer.

Methods

This study employed a descriptive qualitative design. From April to October 2025, 17 patients who had undergone sphincter-preserving surgery for rectal cancer and were within 6 months after discharge were recruited from the gastrointestinal surgery outpatient clinic of Huashan Hospital, Fudan University, using purposive sampling. Data were collected through semi-structured interviews, managed using NVivo 12 software, and analyzed using thematic analysis.

Results

Themes were identified: (1) Symptom burden and multiple physical discomforts during the post-discharge transitional period; (2) A complex process of psychological adaptation; (3) Insufficient information support and self-management through trial and error. Li Z J, Wei S M, Li Y, et al. Experiences and rehabilitation needs of patients during the post-discharge transitional period after sphincter-preserving surgery for rectal cancer: a qualitative study[J]. Chinese General Practice, 2026. [Epub ahead of print] Editorial Office of Chinese General Practice.

Chinese General Practice after discharge; (4) Support experiences involving family, peers, and healthcare professionals; (5) Restricted social participation and hindered role resumption; and (6) An urgent need for continuous and individualized rehabilitation support.

Conclusion

Patients during the post-discharge transitional period after sphincter-preserving surgery for rectal cancer face multiple challenges, including physical distress, psychological stress, difficulties in self-management, and insufficient access to authoritative information and professional support. Based on the study findings, healthcare professionals should provide continuous, timely, and individualized rehabilitation support during this period. Furthermore, continuity-of-care pathways linking hospital and community services should be actively explored to facilitate functional recovery and social role reconstruction.

Introduction

Keywords: Rectal neoplasms; Post-discharge transitional period; Rehabilitation needs; Experiences; Qualitative study

Rectal cancer is one of the most common malignant tumors of the digestive system, and surgery remains the primary treatment modality [?, ?]. With advancements in surgical techniques and increasing patient demands for improved quality of life, an increasing number of patients are opting for sphincter-preserving surgery to avoid permanent stomas. National data indicate that rectal cancer cases account for approximately 76% of all colorectal cancer surgeries, with the proportion of patients undergoing mid-to-low sphincter-preserving surgery reaching as high as 88.8% [?]. However, while sphincter-preserving surgery maintains the anatomical structure of the anus, it is frequently accompanied by a series of functional impairments. Statistics show that 60% to 90% of patients experience bowel dysfunction symptoms, such as fecal incontinence and increased frequency of defecation, collectively referred to in clinical practice as Low Anterior Resection Syndrome (LARS) [?, ?].

LARS can manifest in the early postoperative period, and symptoms are often most severe within the first six months after discharge [?, ?]. This timeframe coincides precisely with the post-discharge transitional period, during which patients transition from the medical facility back to their homes. Generally defined as the six months following discharge, this period is a critical window for rehabilitation as well as a challenging phase for complication management and functional adaptation [?]. During this stage, patients must independently manage various daily rehabilitation issues in an environment lacking immediate professional support.

Previous research has demonstrated that the challenges faced by rectal cancer patients after sphincter-preserving surgery extend beyond bowel symptoms. Patients may also experience pelvic floor dysfunction, sexual dysfunction, chemotherapy-related adverse reactions, and cancer-related fatigue [?, ?, ?]. These overlapping symptoms significantly impair postoperative quality of life [?]. However, under current follow-up models, post-discharge medical attention is largely focused on monitoring oncological outcomes. There is often a lack of systematic guidance and support regarding specific symptom management, psychological adaptation, and behavioral adjustments encountered during home rehabilitation [?].

Existing studies on postoperative functional impairment predominantly utilize quantitative tools, such as the LARS score, for symptom assessment or focus on measuring objective physiological indicators. While these studies effectively monitor the degree of intestinal functional impairment, they fail to capture the authentic lived experiences, psychological trajectories, and self-management barriers faced by patients in a home setting [?, ?]. This limitation hinders the specificity and feasibility of transitional rehabilitation management strategies. Therefore, this study employs qualitative interviews to deeply explore the experiences and needs of rectal cancer patients during the post-discharge transitional period following sphincter-preserving surgery, aiming to provide a foundation for constructing more precise transitional rehabilitation management programs.

1.1 General Data

Using a purposive sampling method, patients who underwent sphincter-preserving surgery for rectal cancer and attended follow-up appointments at the Gastrointestinal Surgery Clinic of Huashan Hospital, Fudan University, were selected between April and October 2025. During the sampling process, a maximum variation strategy was employed to ensure sample diversity by including patients across different genders, ages, postoperative durations, and tumor stages. The researchers conducted preliminary screening and contacted potential participants to invite them for interviews after explaining the study' s objectives, content, and informed consent procedures. Inclusion criteria were:

(1) age ≥ 18 years; (2) postoperative pathological diagnosis of rectal cancer; (3) initial radical sphincter-preserving surgery for rectal cancer, or completion of stoma reversal for those with temporary ostomies, with current restoration of transanal defecation; (4) clear consciousness and ability to communicate in Chinese; (5) ≤ 6 months since hospital discharge following the restoration of transanal defecation; and (6) informed consent and voluntary participation.

Exclusion criteria were: (1) severe dysfunction of vital organs such as the heart, liver, or kidneys, or the presence of other serious complications; (2) a documented history of mental illness or assessed cognitive impairment; and (3) occurrence of severe postoperative complications such as anastomotic leakage requiring reoperation or prolonged hospitalization.

This study did not predetermine a fixed sample size, instead following the principle of data saturation. Data transcription and preliminary analysis were conducted concurrently with data collection. Thematic saturation was considered achieved when new interview data no longer generated new units of meaning, initial codes, or subthemes, and when the existing themes were sufficiently explained by the available data. Following discussion between two researchers, it was determined that no new codes or subthemes emerged after the 15th case. Two additional interviews were subsequently conducted to further verify thematic stability, resulting in a final sample size of 17 cases.

The basic demographic and clinical characteristics of the patients are presented in . This study was reviewed and approved by the Ethics Committee of Huashan Hospital, Fudan University (MR-31-25-039394). All participants provided informed consent and signed written informed consent forms.

1.2.1 Research Design

This study employs a descriptive qualitative research design. The core of this approach lies in presenting the authentic experiences and needs of research subjects within specific contexts. It emphasizes providing a direct description of the phenomenon that remains close to the data itself, with minimal theoretical presuppositions, rather than focusing primarily on theoretical construction or deep interpretation. This methodology is particularly suitable for phenomena that are not yet deeply understood and require a systematic description of their overall landscape. This study focuses on the lived experiences and rehabilitation needs of patients who have undergone sphincter-preserving surgery for rectal cancer during the transition period after discharge. Given that relevant qualitative research in China is currently limited, this method allows for the closest possible alignment with the patients' subjective experiences, revealing the actual difficulties and needs they encounter during the home rehabilitation process.

The design of this study is well-aligned with its objectives, as published in *Chinese General Practice*. This research adopts naturalism as its fundamental epistemological orientation, positing that patients' experiences and needs are formed within their real-life contexts and can be effectively elicited and presented through in-depth interviews.

1.2.2 Determining the Interview Outline

Based on a comprehensive literature review and expert panel discussions, this study developed a self-designed semi-structured interview outline. Prior to the formal interviews, two pilot interviews were conducted to refine and optimize the outline. The detailed interview framework is presented in .

1.2.3 Data Collection

A single trained researcher conducted one-on-one, in-depth interviews with participants using a semi-structured interview outline. Prior to the interviews, the researcher scheduled appointments with the patients and explained the study' s objectives, the content of the interviews, confidentiality principles, and audio recording arrangements. Participants were informed that their involvement was entirely voluntary and that they could withdraw at any time without any impact on their subsequent treatment or care. To establish a rapport and build trust, the researcher began each session with brief, casual conversation on everyday topics to help participants reach a relaxed state before transitioning into the formal interview. For the convenience of the participants, interviews were conducted via telephone, with each session lasting between 20 and 60 minutes. With the participants' informed consent, all interviews were audio-recorded in their entirety. During the process, the researcher maintained synchronized field notes, focusing on paralanguage information such as tone of voice, speaking rate, pauses, and emotional fluctuations.

The aforementioned field notes were organized into interview memoranda within 24 hours of each session and were incorporated into the final analysis alongside the transcribed text.

1.2.4 Organization and Analysis

Interview recordings were transcribed verbatim within 24 hours, and the content was cross-checked repeatedly against the audio to ensure data accuracy. The resulting transcripts were imported into NVivo 12 software for data management. This study utilized the thematic analysis method proposed by Braun and Clarke. The following interview guide was employed for patients during the post-discharge transitional period after sphincter-preserving surgery: "Please describe the entire process from your discharge to the start of your home rehabilitation. What has been your overall experience and feeling during this time?"

Regarding the overall transition experience and perceptions: "What do you feel is the greatest difference between transitioning from the role of an inpatient to a home-based rehabilitator? Compared to your pre-operative expectations, which aspects of this process aligned with your expectations, and which were unexpected?”

“During the process of adapting to home rehabilitation, what facilitating factors (such as personal preparation, family support, medical guidance, or peer experiences) helped you complete the transition more smoothly?”

Regarding facilitators of the transition: “What specific information or guidance provided by the hospital or medical staff at the time of discharge did you find particularly valuable for your home recovery? Which of your own personal traits or behaviors played a positive role in your smooth recovery? Conversely, what major difficulties and obstacles did you encounter during the home rehabilitation process?”

Regarding challenges during the transition: “In what specific areas did these difficulties manifest? When facing these challenges, what kind of help did you most desire? In response to the changes in physical function and daily life following surgery, what primary coping strategies or behaviors did you adopt to manage your health?”

Regarding coping strategies: “What were the sources of these coping strategies? Among the strategies you attempted, which did you find effective and which were less effective? Overall, how would you evaluate your current state of adaptation? Have you established a new sense of stability in life and a sense of self-control?”

Regarding current status assessment: “If you were to rate your current level of adaptation on a scale of 0 to 10, what score would you give yourself, and why? Based on your entire experience, what kind of rehabilitation support do patients need most during the post-discharge transition to better promote health recovery?”

Regarding rehabilitation service needs: “In what form and at what time do you think these services should be provided? Do you have any other thoughts or supplementary comments regarding post-discharge rehabilitation management?” The specific steps of the analysis were as follows: (1) Familiarization with the data: two researchers repeatedly read the full transcripts and recorded preliminary impressions and analytical ideas; (2) Initial coding: two researchers independently performed line-by-line open coding to extract meaningful information units; (3) Inductive sub-theme generation: codes with similar meanings or related content were categorized and integrated to form preliminary sub-themes; (4) Theme development: the internal relationships between sub-themes were examined, and after repeated verification against the raw data, related sub-themes were merged into higher-level themes; (5) Reviewing and naming themes: the scope and connotation of each theme were defined, and final naming was completed; (6) Report writing: the research results were presented using the themes as a framework. The aforementioned analytical process was entirely data-driven; themes emerged from the induction and refinement of the interview data rather than directly corresponding to the dimensions of the interview guide. To enhance the transparency of the thematic analysis reporting, an example of the thematic analysis process is provided in .

1.2.5 Quality Control

The six-phase thematic analysis method was employed to inductively analyze the data. To enhance the credibility and rigor of the research findings, the following measures were implemented throughout the study:

The following measures were taken throughout the research process: (1) The interview outline was developed based on a systematic literature review and expert group discussions, and was further revised and refined following two pilot interviews to ensure the appropriateness of the content. (2) All formal interviews were conducted by the same researcher to ensure consistency in data collection; interviews were audio-recorded in their entirety and transcribed within 24 hours, preserving the respondents' original expressions as much as possible. (3) Two researchers independently coded all texts and performed thematic induction; any disagreements were resolved through discussion with a third researcher. (4) During the data analysis process, researchers simultaneously wrote interview and analytical memos, which were used alongside team discussions to identify and address potential subjective bias. (5) The research team held two formal discussions to deliberate and revise the thematic boundaries, naming, and interpretations.

2 Results

This study included a total of 17 patients who underwent sphincter-preserving surgery for rectal cancer. Following a qualitative analysis, six primary themes were identified: (1) symptom shock and multiple physical burdens during the discharge transition period; (2) complex psychological adaptation processes; (3) insufficient information support and the dilemma of self-exploration after leaving the hospital; (4) experiences of support from family, fellow patients, and healthcare professionals; (5) restricted social participation and obstacles to role reintegration; and (6) an urgent need for continuous, individualized rehabilitation support.

Theme 1: Symptom Shock and Multiple Physical Burdens During the Discharge Transition Period

During the transition from hospital to home, patients commonly experienced significant intestinal dysfunction, including increased frequency of defecation, fecal urgency, incontinence, and a sense of incomplete evacuation. These symptoms were often accompanied by various discomforts such as perianal pain, fatigue, and treatment-related side effects. Although these symptoms were anticipated during the hospitalization phase, the lack of immediate professional support from healthcare staff in the home environment often resulted in greater coping pressure for patients.

2.1.1 Continuous Disruption of Daily Life at Home by Loss of Bowel Control

The interview results indicate that issues such as increased defecation frequency, urgency, and fecal incontinence severely disrupted the patients' daily routines. Some participants described how the constant trips to the bathroom and the sensation of incomplete evacuation made it difficult to maintain a normal domestic life. Due to the decline in bowel control, some patients experienced leakage even while walking around the house or sharing meals with family members. This loss of symptom control within the home environment caused not only physical exhaustion but also profound embarrassment in front of family members. To cope with this uncertainty, some patients continued to rely on nursing pads used during their hospitalization for nearly a month after discharge to maintain a basic sense of dignity and security.

P1: "At that time, I was passing stool constantly; I couldn' t stand it. I had no control over it at all. Sometimes it would just leak out while I was walking, or I would start passing gas and stool right in the middle of a meal."

P13: "My struggle right now isn' t just the frequency of bowel movements; it' s the feeling of dissatisfaction. I simply can' t empty my bowels completely, and it feels very uncomfortable."

P14: "When I first came home from the house, it was happening more than 20 times a day···I kept using those hospital nursing pads at home for almost a month."

P15: "I felt so exhausted after returning home; it was miserable—honestly, it felt like a fate worse than death. It has been 100 days now, and I haven' t even worn underwear; I just stay in bed on nursing pads. When I try to sit on the toilet, I can' t pass anything, but as soon as I lie back down in bed, it starts coming out···It happens 24 hours a day; there is no way to get any sleep."

2.1.2 Physical and Activity Limitations Caused by Multiple Physical Discomforts

In addition to intestinal symptoms, patients commonly experience issues such as pain, physical weakness, and sleep deprivation. These symptoms interact with and exacerbate bowel dysfunction, creating a compounding effect that makes recovery significantly more difficult. Furthermore, for patients undergoing chemotherapy, adverse reactions—including nausea, loss of appetite, oral ulcers, and numbness in the hands and feet—not only severely hinder physical recovery but can also render patients unable to perform basic activities of daily living or leave their homes.

P3: "When I was discharged, I felt quite miserable because the wound was painful. Even before leaving the hospital, the frequent bowel movements made it hurt; my buttocks were in such extreme pain that I had to apply powder to the area."

P5: "After returning home from the first surgery, I felt terrible. The anal pain was unbearable; I couldn' t sit or stand. The pain hit several times a day, so intense that I would break out in a sweat. I told the doctor, and they said it was just normal intestinal peristalsis, but it was truly agonizing."

P12: "Because I am still undergoing chemotherapy, I feel increasingly nauseous as the treatments progress. I have no appetite, which is a more serious issue, and I also feel some numbness in my fingers, hands, and feet."

P15: "My hands and feet are still a bit numb, likely due to the chemotherapy; I have to wear silk stockings just to be able to sleep."

P16: "If I touch cold water even slightly, my hands feel like they' ve been hit by an electric shock···I also have ulcers in my mouth that bleed at the slightest movement."

2.2 Theme 2: Complex Psychological Adaptation Process

Beyond the direct impact of physical symptoms, patients generally undergo a complex and sustained process of psychological adaptation during the transition period following hospital discharge. Some patients initially experience a sense of relief upon discharge, stemming from the successful completion of surgery and the opportunity to leave the clinical environment. However, upon returning home and confronting persistent physical symptoms, they often gradually develop emotions such as anxiety, frustration, shame, and helplessness. Following this period of negative affect, patients typically move toward a state of resigned acceptance and begin to incrementally adjust their mindset in an effort to readapt to their post-operative life.

2.2.1 Expectation Gap and Emotional Impact After Discharge

Upon discharge, patients generally maintained positive psychological expectations for their recovery at home. However, when symptoms such as abnormal bowel movements, pain, or fatigue failed to alleviate as anticipated, they experienced a significant psychological gap. This discrepancy between expectation and reality profoundly intensified their emotional distress during the initial stages of home-based recovery.

P1: "Before the surgery, they told me that the frequency of bowel movements would increase, but since I hadn' t experienced it yet, I didn' t give it much thought—it was just a term to me. I had no idea I would be defecating from morning until night. Spending 12 hours a day on the toilet is truly unbearable."

P13: "I suffer from anxiety and insomnia, and I am currently on medication for them. If I don' t take my medicine, I simply cannot fall asleep."

2.2.2 Persistent Worry and Anxiety Facing an Unknown Recovery Trajectory

After experiencing the initial impact of post-discharge symptoms, patients' psychological stress does not rapidly subside over time; instead, it evolves into persistent concerns regarding the recovery process and future quality of life. Some patients express apprehension about their perceived lack of home management skills, fearing they will be unable to cope with persistent or fluctuating symptoms. Others experience anxiety regarding when bowel function will return to normal. This concern for the unknown is not a transient state but represents a latent stressor that persists throughout the patient' s entire transitional period.

P4: "My biggest worry in life is that I don' t know how to manage myself or my condition, and I' m afraid of a relapse."

P12: "I just can' t manage myself properly; if I eat even slightly the wrong thing, I have constant diarrhea. I have no idea when I' ll get better—it is truly an agonizing experience."

P13: "My entire abdomen hurts when I press on it, and I have pain in the anal region as well. I have already suffered from two intestinal obstructions, and now I am terrified that it will get blocked again."

2.2.3 Resigned Acceptance and Self-Mindset Adjustment

Despite the arduous nature of the process, some patients demonstrated significant psychological resilience. They actively engaged in self-consolation and psychological adjustment, striving to accept their reality while emphasizing the critical importance of maintaining a positive mindset for recovery.

P2: "Whether you live or die, there' s nothing you can do about it; if God wants to take you, you can' t stop it. Once you accept it, you just look forward. Keep a good attitude, stay active when you should, and just be a bit more careful with what you eat."

P3: "My son and daughter encouraged me and told me to enjoy myself and not overwork. Then I thought, since things are already like this, I might as well be happy. I started growing vegetables, cooking, and doing laundry. By not dwelling on it, I slowly started to feel better."

P6: "When I feel anxious, I move around and try to clear my mind so I no longer think of myself as a patient."

P11: "It is what it is now; there' s really no other way. Slowly, I' ve come to accept it. In short, once you get used to it, it' s not so bad."

Theme 3: Insufficient Information Support and Self-Reliance After Discharge

After returning home, patients must assume primary responsibility for their own self-management. However, regarding key aspects such as dietary adjustment and rehabilitation exercises, patients generally face challenges including a lack of knowledge, disorganized information channels, and difficulties in practical implementation.

2.3.1 Dietary Management Confusion and Over-Restriction

Dietary management is the area of greatest concern for patients following discharge, yet it is also the stage where deviations from medical advice are most likely to occur. Most patients reported that the dietary guidance received at the time of discharge consisted primarily of general principles rather than specific instructions tailored to their individual circumstances. Consequently, they often felt overwhelmed when faced with actual food choices at home. Some patients, out of extreme caution, strictly limited their food variety, leading to inadequate nutritional intake and decreased physical strength; others experienced persistent indecision regarding daily dietary choices due to ambiguous information.

P1: “I ate nothing but noodles for two weeks after my surgery, and it made me feel lightheaded⋯I figured that since I had undergone major surgery, I had to be extra careful. I was afraid that eating the wrong things would cause complications.”

P8: “My dietary management is okay for now; I avoid spicy food, pungent flavors, and seafood. However, I still don’ t know how to eat properly sometimes. For example, I haven’ t dared to eat chicken yet—is that allowed?”

P10: “My main issue is diet; I don’ t know what is permissible and what is forbidden. It makes it very difficult for my family to cook. Sometimes the internet says one thing and then says another; I just can’ t figure it out.”

2.3.2 Insufficient Awareness and Execution Deviations in Rehabilitation Exercises

Patients generally recognize the importance of levator ani exercises (Kegels), yet they face significant obstacles during actual implementation. Most participants reported that while they were advised to perform these exercises upon discharge, the lack of detailed demonstrations regarding proper technique and frequency led some to practice incorrectly for extended periods. Furthermore, postoperative fatigue directly hindered the regularity and sustainability of their exercise routines.

P2: “It turns out I’ ve been doing the levator ani exercises wrong; I usually hold my breath while doing them. They didn’ t give me a detailed explanation of the technique; they just mentioned I should do it.”

P11: "I try to practice the exercises a little, but since I' m undergoing chemotherapy, I have no strength at all right now. Even a little bit of exercise leaves me exhausted."

P13: "The levator ani exercises are actually quite strenuous. I honestly don' t even know if doing them at this stage is having any effect."

2.3.3 Information Overload and Difficulty Distinguishing Truth from Falsehood

Regarding information acquisition, patients actively seek knowledge through online social platforms, peer support groups, and other channels. However, the vast amount of available information is often difficult to verify, increasing the challenge of obtaining accurate rehabilitation guidance.

P4: "Of course, I also used my phone to study some things in advance, including bowel care and exercise routines. But I just don' t know if the information is true or false; I don' t know how to judge it. There is simply too much content."

P9: "Sometimes I search for information on my phone for reference, but there is so much of it that it' s hard to distinguish what is real."

P15: "For example, if my wound hurts a little, I don' t know if it' s normal or not, so I search online. The information online is terrifying; I don' t dare to believe it."

Theme 4: Support Experiences from Family, Peers, and Healthcare Professionals

During the difficult transition to home care, a social support system composed of family members, fellow patients, and healthcare professionals provides patients with multifaceted support, including daily care, emotional backing, and informational guidance. However, during the actual home rehabilitation process, this support does not always fully meet the patients' needs, and the perceived benefits and experiences vary among individuals.

2.4.1 Support and Concerns in Family Care

The family serves as the most critical source of support for patients during the post-discharge transition period. Family members not only undertake demanding daily caregiving tasks but also provide immense emotional tolerance, encouragement, and solace, forming the essential foundation for the patient' s psychological stability. However, this support system is accompanied by several challenges. First, family members generally lack professional nursing knowledge; consequently, some well-intentioned caregiving behaviors inadvertently cause new physical harm to the patient. Second, to avoid increasing the psychological burden on their loved ones, patients often choose to suppress their own suffering and refrain from expressing genuine negative emotions in front of their families.

P4: "The person who helps me the most is my wife; she cooks for me every day···and keeps an eye on me. Also, relatives sometimes come over to chat and keep me company."

P11: "My daughter has been the greatest help to me···Every time I come to Shanghai, my son-in-law accompanies me. I' m so lucky to have these two; otherwise, I really wouldn' t have made it through."

P1: "My mother applied medicine to me every day, using some Sanqi powder to keep the wound dry···but after a few days, the area had completely ulcerated, and the surrounding skin turned a frightening shade of red."

P11: "I can' t show my sadness in front of my parents, nor can I show it in front of my daughter. They are already so anxious, which makes me even more afraid to say a word."

2.4.2 Experience and Resonance from Peer Mutual Aid

Communicating with fellow patients who share similar experiences provides a unique and vital form of support. The sharing of experiences among peers is often more persuasive and practical than professional advice alone, while the resulting emotional resonance significantly alleviates patients' feelings of loneliness and anxiety.

P4: "I also added some fellow patients on WeChat, and we chat occasionally. It feels like we are comrades-in-arms, which helps me feel less anxious."

P9: "After my stoma reversal, I joined a 'Panda Group' where people provide guidance···this group helped me avoid many pitfalls."

P14: "My colleague' s brother also had this disease. I asked them if the process was supposed to be like this and what precautions I should take. He told me all about the mistakes and detours he had made so I could avoid them."

2.4.3 Comfort and Security Provided by the Medical Team

Patients maintain a profound sense of trust in and dependence on their primary physicians and nurses. A single word of encouragement or a moment of professional guidance from healthcare staff can provide immense emotional value and the confidence necessary for patients to persevere.

P1: "After the wound sloughed off, pink flesh began to appear···I stopped worrying and feeling agitated. Later, the doctor told me that my recovery was already excellent; I felt that he provided me with significant emotional value."

P14: "Hospitals must provide patients with psychological support. This hospital told me not to worry and that things would definitely improve over time. They built up my confidence, which is incredibly important."

Theme 5: Restricted Social Participation and Barriers to Role Reintegration

The disease and its sequelae affect not only the patient’ s physical health but also exert a severe impact on their social roles and functions. On the path toward reintegrating into society, patients generally face practical difficulties such as restricted social activities, interruptions to their professional careers, and household financial pressures.

2.5.1 Social Avoidance and Travel Restrictions

Unpredictable urges to defecate and the pervasive fear of fecal incontinence frequently lead patients to engage in social avoidance behaviors. Many become hesitant to travel long distances, attend social gatherings, or even leave their homes. Consequently, their social circles are severely restricted, leading to a profound sense of isolation and a feeling of being disconnected from society.

P5: “It is incredibly frustrating; I simply don’ t dare to go out···I’ m also terrified of going to crowded places.”

P15: “It definitely affects my social life. I haven’ t returned to work yet, and whenever I do have to go out, I have to wear adult diapers.”

P17: “First of all, going out is deeply embarrassing. You are a grown adult, and others don’ t necessarily know you’ ve had surgery. The smell of stool is very strong; who could possibly tolerate being around that?”

2.5.2 Occupational Interruption and Financial Pressure

Patients of working age frequently experience career interruptions during long-term treatment and recovery, with some encountering job loss or implicit discrimination. The subsequent reduction in income, coupled with ongoing medical expenses, creates a heavy financial burden for the family.

P7: “Work was definitely affected. My employer told me my position no longer existed; they didn’ t care about labor laws or anything. Now I’ m unemployed ···there is still a kind of social stigma regarding this condition···Economically, it has certainly had an impact. Without a source of income, the quality of life for my family has inevitably declined.”

P8: “My two children just got married, so I still face some financial pressure. After all, I can’ t go out to work anymore, and my income has completely stopped.”

Theme 6: The Urgent Demand for Continuous and Individualized Rehabilitation Support

After experiencing a series of physical and mental health challenges during the transition period following hospital discharge, patients generally expressed a desire for continuous rehabilitation support. This support extends beyond specific guidance on dietary management and rehabilitation exercises to include emotional support, convenient communication channels, and proactive follow-up care. Patients long for sustained professional support during the critical phase of reintegrating into their home and family life.

2.6.1 Demand for Individualized Dietary Guidance

Patients expect healthcare professionals to provide specific, actionable rehabilitation guidance, particularly regarding individualized dietary plans and standardized exercise instruction.

P8: "My dietary management is currently acceptable; I avoid spicy food, pungent flavors, and seafood. However, I am still uncertain at times. For instance, I have not dared to eat chicken until now—is that allowed?"

P16: "It is essential to provide them with detailed guidance. We need to clearly explain how to eat, which foods are permissible, and which should be avoided. Ideally, this information should be provided in writing or sent via WeChat."

2.6.2 Demand for Rehabilitation Exercise Guidance

Although patients are aware of the importance of rehabilitation exercises, they generally lack a comprehensive understanding of the correct methods, frequency, and necessary precautions. There is an urgent need for standardized and intuitive instructional guidance to ensure the effectiveness and safety of these exercises.

P5: "I feel I need more detailed knowledge that can guide my daily life. Since we are older, sending videos would be the best format."

P2: "They didn' t give me a detailed explanation of how to do it; they just told me that I should do it. I hope to have more detailed guidance; that would be best."

2.6.3 Demand for Emotional Support from Professionals

Patients hope that healthcare professionals will be not only healers but also listeners and sources of encouragement. They expect to derive emotional value through effective communication, which helps alleviate anxiety and builds their confidence in the recovery process.

P14: "The hospital must provide patients with emotional support⋯giving me confidence was very important."

P17: "Providing service is like what you are doing now—talking with the patient heart-to-heart and chatting about daily life; it is very good. As the saying goes, when it comes to illness, thirty percent is the treatment and seventy percent is the mindset. Right? You doctors are the psychological counselors for us patients."

2.6.4 Demand for Constructing Doctor-Patient Communication Channels

Patients expect hospitals to establish official and convenient communication channels that allow them to quickly contact professionals and obtain authoritative guidance when encountering problems.

P2: "It would be best if we had your WeChat; that way, we could get your support whenever a problem arises. If that isn' t possible, even just leaving a phone number would work."

P15: "I wonder if a group chat could be created so that we can ask questions directly in the group. Once we are discharged, there is no one to look after us, and at the beginning, we really didn' t know what to do."

2.6.5 Demand for Proactive Regular Follow-up

Patients expect proactive and regular follow-up care from their medical teams. They believe that receiving follow-ups at critical junctures, such as the early postoperative period, not only allows for the timely resolution of medical issues but also serves as a form of care and encouragement. This support provides them with significant psychological comfort and a sense of security.

P4: "I think it would be better to give me a call to check in and offer some encouragement about a week after discharge. The first week back home after leaving the hospital is quite a difficult and trying time."

P13: "I hope the follow-up can happen earlier. If you provide guidance based on my specific condition sooner, I can start following your advice right away. I am afraid that if it happens too late, it might no longer be effective."

3.1.1 Prominent Intestinal Dysfunction During Discharge Transition, Requiring Strengthened Function

Patients undergoing sphincter-preserving surgery (SPS) commonly face intestinal dysfunction during the transition period after discharge, characterized by increased defecation frequency, fecal urgency, incontinence, and evacuation difficulties. These findings are consistent with previous research reporting prevalent residual symptoms such as stool clustering (66.7%) and fecal incontinence (65.2%) in this population. This study found that the challenges faced by patients during the transition period are not only limited to the persistence of intestinal symptoms but also include a lack of specific criteria for judging and responding to changes in bowel function at home. Consequently, patients often rely on personal trial and error for dietary adjustments, bowel management, and rehabilitation exercises. Although some patients receive preoperative counseling, they often lack a sufficient understanding of how postoperative bowel dysfunction will impact their daily lives at home. Park et al. similarly noted that patients frequently focus more on the oncological treatment itself before surgery, leaving them ill-prepared for the impact of postoperative bowel dysfunction on their quality of life.

Therefore, management during the transition period after discharge should focus on the reconstruction of intestinal function, establishing continuous assessment and dynamic intervention starting from the early postoperative stage. Based on established home rehabilitation management consensuses, it is recommended to regularly assess defecation frequency, urgency control, evacuation status, and the impact of these symptoms on daily life after discharge. Follow-up content and frequency should be dynamically adjusted according to the patient’ s recovery progress. For assessment tools, the Low Anterior Resection Syndrome (LARS) score is preferred for rapid screening, making it suitable for outpatient and primary care settings. If a more comprehensive reflection of symptom severity, sensory perception of defecation, and life impact is required, supplementary assessments can be conducted using the Wexner Incontinence Scale and the Memorial Sloan Kettering Cancer Center Bowel Function Instrument (MSKCC-BFI).

In terms of management strategies, a stratified approach based on symptom severity is recommended. For patients with mild to moderate symptoms, management should focus on dietary adjustments, bowel habit training, pelvic floor muscle exercises, and symptomatic pharmacological treatment, with regular follow-up to correct any deviations in execution. For patients with persistent, severe symptoms or significant lifestyle limitations, these basic measures should be combined with biofeedback therapy, transanal irrigation, and systemic pelvic floor rehabilitation interventions to more effectively improve intestinal function and overall quality of life [**?**, **?**].

3.1.2 Implementation of Holistic Interventions to Address Extra-intestinal Symptoms and Side Effects

This study found that, in addition to intestinal symptoms, respondents commonly experienced issues such as perianal or abdominal pain, decreased physical strength, cancer-related fatigue, and chemotherapy-related adverse reactions. Previous research has also demonstrated that colorectal cancer survivors often experience interrelated symptoms—including fatigue, sleep disturbances, emotional distress, and activity limitations—which can persistently hinder the recovery process [**?**, **?**]. Building upon these findings, the results of this study suggest that during the transition period after hospital discharge, these intestinal and extra-intestinal symptoms overlap, further increasing the burden of home-based rehabilitation for patients.

For instance, pain and impaired sleep interfere with essential rest, while decreased physical strength limits activity recovery and functional exercise. Simultaneously, chemotherapy-related issues such as nausea, oral ulcers, and numbness in the hands and feet further disrupt eating, sleeping, and daily routines. Furthermore, while previous studies suggest that patients undergoing sphincter-preserving surgery may face urinary and sexual dysfunction [?, ?], respondents in this study rarely mentioned such experiences voluntarily. This may be attributed to the highly private nature of these issues, as well as the fact that patients are more focused on the immediate distress caused by intestinal symptoms during the post-discharge transition.

Consequently, follow-up care during the transition period should not only assess intestinal function but also screen for issues related to pain, fatigue, urinary and sexual function, and sleep quality. For patients experiencing significant symptom distress, multidisciplinary resources should be integrated to provide individualized nutritional support, symptom management guidance, and rehabilitation interventions, thereby mitigating the cumulative impact of multiple overlapping symptoms.

3.2 Emphasizing Emotion and Illness Uncertainty Management to Promote Psychological Adaptation and Restore Recovery Confidence

In this study, anxiety, fear, a sense of loss of control, and concerns regarding disease progression and recovery prospects were prevalent among patients during the discharge transition period. Notably, the stigma associated with incontinence and the perceived risks of leaving the home were significant drivers of social avoidance and psychological distress. Previous research has similarly indicated that patients with Low Anterior Resection Syndrome (LARS) often reduce their social activities due to the risk of incontinence, the uncertainty of being outdoors, and a general sense of losing control over their lives, which in turn exacerbates their psychological burden [?]. Our results further suggest that these psychological disturbances do not stem solely from the severity of symptoms; they are also closely linked to a lack of confidence in the recovery process following discharge.

While some patients expressed high expectations regarding the successful completion of surgery and sphincter preservation at the time of discharge, they were more prone to anxiety, frustration, and helplessness once they returned home and faced persistent or recurring bowel dysfunction with an unpredictable recovery timeline. Compared to previous studies that focused more on long-term postoperative adaptation, the results of this study highlight that emotional fluctuations and a sense of illness uncertainty are particularly prominent during the early post-discharge phase.

Furthermore, this study found that patients often employ emotional suppression, situational avoidance, and self-consolation to cope with psychological distress. Although these strategies may alleviate stress in the short term, they can lead to delayed expression of needs or a state of prolonged hyper-vigilance regarding symptoms, ultimately hindering social participation and the restoration of role functions. Therefore, it is recommended that psychological assessments be integrated into routine follow-ups during the discharge transition period, with specific attention paid to incontinence-related stigma, social avoidance behaviors, and difficulties in role adaptation. For patients experiencing significant psychological distress, targeted psychological counseling and adaptive support should be provided alongside routine care. Such interventions can help patients gradually regain a sense of control and confidence in their recovery process, facilitating the construction of a patient-centered self-management support system that enhances their ability to manage symptoms and rebuild their lives.

3.3.1 Providing Precise Health Guidance to Promote Execution of Rehabilitation Skills

This study found that the majority of patients reported receiving health education upon discharge that consisted primarily of general principles rather than specific guidance tailored to their individual conditions. Consequently, patients were forced to rely on personal experience and trial-and-error during home recovery, leading to issues such as excessive dietary restrictions and improper execution of functional training. Previous research has similarly noted that postoperative rectal cancer patients often manage bowel dysfunction through trial-and-error and expressed a universal desire for continuous and specific professional information support [**?**]. Building on these findings, the present study further suggests that the discharge transition period is a critical window for correcting cognitive errors and behavioral deviations. If improper exercise techniques or unreasonable dietary patterns are not addressed during this stage, they may become habitual over time, thereby seriously hindering the patient’ s rehabilitation process.

Existing research indicates that pelvic floor muscle training conducted under specialist guidance and continuous follow-up support can not only alleviate symptom burden and promote functional recovery but also exert a positive influence on psychological adaptation [**?**]. A study by Li et al. [**?**] also confirmed that structured self-management interventions can improve bowel symptoms and quality of life within the first six months post-surgery. Furthermore, remote interaction and digital follow-up models have provided new pathways for enhancing patients’ self-management capabilities. Therefore, health guidance during the discharge transition should place greater emphasis on the specificity and individualization of content. Before discharge, clinicians can verify patient understanding of dietary management, defecation scheduling, and training methods through questioning and feedback. After discharge, proactive follow-up should be conducted—incorporating symptom changes, bowel movement logs, and practical difficulties—to provide timely, targeted guidance and corrective measures. This approach aims to improve the accuracy of rehabilitation skill execution and bolster patient confidence in self-management.

3.3.2 Improving Authoritative Information Support Channels to Reduce Information Asymmetry

This study found that after discharge, patients frequently obtain rehabilitation information through online platforms, social media, and patient support groups. However, due to the complexity of information sources and inconsistent content, patients often struggle to judge the accuracy and applicability of the information, which instead makes them more susceptible to confusion and anxiety. This result is consistent with previous research indicating that patients with Low Anterior Resection Syndrome (LARS) have significant needs for information and support. During the transition period after discharge, the informational challenges faced by patients lie not only in a lack of acquisition channels but also in the absence of stable, authoritative professional support capable of responding to individual questions in a timely manner. For patients who need to adjust dietary behaviors and perform rehabilitation exercises in a home environment, the lack of clear information sources and consistent guidance can easily hinder their judgment and behavioral execution. Therefore, transitional care management must go beyond providing routine health education to establish fixed, authoritative channels for information support. It is recommended that patients be informed of their primary follow-up coordinator and contact methods upon discharge, and be provided with corresponding written or digital instructional materials. In subsequent follow-ups, efforts should be made to ensure consistency in guidance and to update support content based on common patient questions, thereby reducing the adverse effects of information interference on decision-making and behavioral execution.

3.4.1 Leveraging Family and Peer Support to Buffer the Impact of Stigma on Social Participation

The results of this study demonstrate that the family plays a vital role in areas such as daily caregiving, emotional acceptance, and accompaniment during medical visits, serving as the primary source of support for patients. However, family support is not always entirely effective. Some patients reduce the disclosure of their needs and refrain from seeking help due to concerns about increasing the burden on their family members. Furthermore, some family members lack specific knowledge regarding rehabilitation care, which can lead to inappropriate practices during caregiving and subsequently increase the coping difficulties faced by patients during home recovery. Additionally, this study found that intestinal symptoms and the resulting sense of shame keep patients in a state of high vigilance in public settings, further restricting their social participation and the reconstruction of their social roles. Previous research on early postoperative LARS experiences has similarly documented phenomena such as persistent hypervigilance, social withdrawal, and limited social participation [**?**]. In this context, family understanding and acceptance, along with support formed between patients and peers based on shared experiences, are of great significance for buffering patients' sense of shame, reducing feelings of self-blame, and enhancing social adaptation. Previous studies have also indicated that peer support can play a positive role in improving the quality of life, anxiety, depression, and self-efficacy of cancer patients [**?**]. Community follow-up services could incorporate joint education for family members into routine practice. Establishing structured peer communication platforms led by healthcare professionals may help alleviate patients' feelings of shame and self-blame while promoting the restoration of their social participation.

3.4.2 Addressing Follow-up Gaps to Reduce Uncertainty and Improve Hospital-Community Continuity

This study found that patients generally desire more timely and continuous professional support following hospital discharge. However, there is currently a widespread lack of stable follow-up mechanisms and effective channels for seeking help, which places patients at a significant risk of care fragmentation during home rehabilitation. This dependence on professional guidance is particularly pronounced during the early post-discharge phase, as patients must manage symptom fluctuations and lifestyle adjustments while independently navigating dietary management, functional training, and the identification of abnormal clinical signs. Expert consensus in China similarly emphasizes the need for professional-led mechanisms to establish continuous follow-up and referral systems, while simultaneously strengthening family involvement and self-management. Therefore, transitional care should prioritize the seamless continuity between hospital and home settings. Before discharge, follow-up priorities should be clarified based on the patient' s primary concerns; after discharge, proactive and stratified support should be provided according to symptom changes and practical difficulties. Continuous care should encompass symptom management guidance, information support, emotional counseling, and social adaptation assessments. Given that many issues in home rehabilitation are persistent and routine, relying solely on specialist follow-up at tertiary hospitals often presents limitations. This suggests that community health service teams and general practitioners can play a vital role in extending specialist care during the discharge transition. Future research should explore corresponding continuous care pathways to improve the continuity and accessibility of rehabilitative support.

Limitations and Prospects

This study has several limitations. First, the sample was drawn from a single-center outpatient follow-up population. Consequently, the results primarily reflect the experiences of those able to attend follow-up appointments and willing to participate in interviews, potentially excluding the perspectives of patients lost to follow-up, those facing severe home management difficulties, or those in poor physical condition. Second, the interviews relied on retrospective accounts of the transitional period, which may introduce recall bias regarding symptom fluctuations and emotional changes. Furthermore, this study did not include the perspectives of primary caregivers or community healthcare providers. Future research should employ multi-center, longitudinal qualitative designs that incorporate the viewpoints of caregivers and primary care teams. Additionally, intervention studies could be conducted to verify the feasibility and effectiveness of different follow-up and support models.

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Note: Figure translations are in progress. See original paper for figures.