

# A Qualitative Study on the Self-Management Experiences and Outpatient Nursing Needs of Intestinal Stoma Patients During the Post-Discharge Transition Period

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**Abstract:** *Objective:* To explore the self-management experiences and outpatient nursing needs of intestinal stoma patients during the post-discharge transition period, in order to provide a basis for scientific decision-making in patient self-care and improvements in specialized stoma outpatient services. *Methods:* Using purposive sampling, 13 colorectal cancer patients in the post-discharge transition period who had undergone intestinal stoma surgery were selected from a tertiary hospital in Shandong Province between November 2024 and March 2025. Semi-structured interviews were conducted, and data were analyzed using Colaizzi's seven-step method to extract themes. *Results:* Three core themes were identified: challenges in self-management during the transition period, outpatient nursing needs during the transition period, and gaps in doctor-patient information continuity. *Conclusion:* Future efforts should focus on high-risk groups of stoma patients during the transition period by building intelligent and systematic outpatient guidance and support systems to improve their quality of life.

**Keywords:** Transition period; Enterostomy; Self-management experience; Outpatient care needs; Qualitative research

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## 1. Introduction

An intestinal stoma is a surgically created “artificial anus” that connects the intestine to the abdominal wall, allowing feces to be expelled and collected in a stoma bag. Globally, approximately 1 million patients live with an intestinal stoma. The surgery significantly improves the survival rate of colorectal cancer patients.

According to GLOBOCAN 2022, colorectal cancer ranks third in incidence and second in mortality globally. While stoma surgery can extend life, it also alters bowel function, bringing physiological, psychological, and social stress that severely affects patients' quality of life <sup>[1]</sup>. National policies advocate for coordinated and continuous

medical care; however, with the promotion of enhanced recovery after surgery (ERAS), hospital stays have become shorter, and patients often lack adequate preoperative nursing knowledge. As a result, the readmission rate within six months post-discharge is as high as 40% <sup>[2]</sup>.

The first six months after discharge are critical for patients to adapt to bodily changes and learn self-management skills, significantly influencing their recovery and quality of life. Continuity of care is particularly needed during this period, with outpatient services playing a crucial role. Current research mainly focuses on inpatient and home care, often neglecting the outpatient care needs during the transition phase. This study adopts a qualitative approach to deeply interview intestinal stoma patients, aiming to provide theoretical and practical references for optimizing outpatient continuity of care <sup>[3]</sup>.

## **2. Data and methods**

### **2.1. Study participants**

From November 2024 to March 2025, this study adopted purposive sampling to select colorectal cancer patients with intestinal stomas in the post-discharge transition period who were receiving follow-up care at the stoma outpatient clinic of a tertiary hospital in Shandong Province.

#### **2.1.1. Inclusion criteria**

Aged 18–70, clear clinical diagnosis, mentally alert, and voluntarily participating.

#### **2.1.2. Exclusion criteria**

Patients with serious comorbidities, those primarily cared for by others, or those who withdrew midway. The sample size was determined by the principle of data saturation.

## **2.2. Research methods**

### **2.2.1. Development of the interview outline**

Based on a literature review and the research objectives, the research team initially developed an interview outline. Two patients were interviewed in a pilot phase, and based on their feedback, a supplementary question was added: “What do you think are the reasons for the difficulties encountered in self-management during the post-discharge transition period?” The final interview outline included six main questions, covering topics such as knowledge of stoma care, healthcare provider guidance, consistency between self-management and professional expectations, difficulties in self-management and coping strategies, causes of those difficulties, and outpatient nursing service needs <sup>[4]</sup>.

### **2.2.2. Data collection method**

Ethical approval was obtained prior to data collection. A nursing graduate student trained in qualitative research conducted the interviews. Before each interview, the study’s purpose, recording procedures, and privacy protection were explained. After signing the informed consent form, face-to-face interviews were conducted in a private and quiet setting. Each session lasted 15–30 minutes. Interviewers followed the principles of “no interruption, no leading, no judgment” to ensure data authenticity and objectivity.

### 2.2.3. Data analysis method

Interview recordings were transcribed within 24 hours by two graduate students independently (back-to-back). Ambiguous expressions were verified and corrected, with efforts made to retain original phrasing. Transcripts were uploaded to a computer, labeled, and archived. After repeated comparison of audio and transcripts, NVivo 15.0 software was used to perform thematic analysis based on Colaizzi's seven-step method [5].

### 2.2.4. Quality control

The interviewer had received training in qualitative research and was assisted by the director of the stoma outpatient clinic. Trust was established with participants prior to the interviews, and neutrality was maintained throughout to avoid bias. In case of disagreements during data analysis, the research team held discussions or consulted qualitative research experts to ensure the credibility and consistency of the findings.

## 3. Results

### 3.1. General information

A total of 13 patients were interviewed: 7 males and 6 females, aged 25 to 67 years, with an average age of  $46.31 \pm 12.76$  years. The types of stoma included: 3 cases of temporary colostomy, 5 cases of permanent colostomy, 3 cases of temporary ileostomy, and 2 cases of permanent ileostomy. Eight patients experienced complications, including 3 cases of fecal dermatitis, 1 case of parastomal hernia, 1 case of stoma prolapse, 1 case of mucosal granuloma, 1 case of skin-mucosa separation, and 1 case of allergic dermatitis. The study was approved by the ethics committee, and all patients gave informed consent to participate. (See **Table 1** for general participant information)

**Table 1.** General information of interviewees (n = 13)

ID	Gender	Age	Marital Status	Education Level	Insurance Type	Income (CNY/month)	Occupation	Type of Stoma	Complications
P1	Male	28	Unmarried	College or above	Chronic Disease Insurance	3001–5000	Student	Colostomy (Temporary)	Yes (Fecal dermatitis)
P2	Female	56	Married	Primary school or below	Chronic Disease Insurance	≤ 1000	Unemployed	Colostomy (Permanent)	No
P3	Male	66	Married	Secondary school	Chronic Disease Insurance	≤ 1000	Farmer	Colostomy (Permanent)	Yes (Parastomal hernia)
P4	Female	25	Unmarried	College or above	Employee Insurance	3001–5000	Clerk	Ileostomy (Temporary)	Yes (Mucosal granuloma)
P5	Male	46	Married	Secondary school	Chronic Disease Insurance	5001–10000	Self-employed	Ileostomy (Temporary)	Yes (Prolapse)
P6	Female	52	Married	Secondary school	Chronic Disease Insurance	3001–5000	Clerk	Colostomy (Permanent)	No
P7	Male	46	Married	Secondary school	Chronic Disease Insurance	3001–5000	Self-employed	Colostomy (Temporary)	No
P8	Female	45	Married	College or above	Employee Insurance	5001–10000	Clerk	Colostomy (Permanent)	Yes (Fecal dermatitis)
P9	Male	67	Widowed	Secondary school	Employee Insurance	1001–3000	Retired	Ileostomy (Permanent)	Yes (Fecal dermatitis)

**Table 1 (Continued)**

ID	Gender	Age	Marital Status	Education Level	Insurance Type	Income (CNY/month)	Occupation	Type of Stoma	Complications
P10	Female	51	Married	Primary school or below	Chronic Disease Insurance	1001–3000	Farmer	Colostomy (Temporary)	No
P11	Male	38	Married	College or above	Chronic Disease Insurance	3001–5000	Self-employed	Ileostomy (Permanent)	Yes (Skin and mucosa separation)
P12	Female	35	Divorced	College or above	Chronic Disease Insurance	3001–5000	Clerk	Ileostomy (Temporary)	Yes (Allergic dermatitis)
P13	Male	47	Married	Secondary school	Chronic Disease Insurance	1001–3000	Farmer	Colostomy (Permanent)	No

### 3.2. Thematic analysis

This study involved interviews with 13 patients with intestinal stomas during the post-discharge transition period, with each interview averaging 25 minutes. Based on a comprehensive analysis of the interview data, three major themes were identified surrounding the patients' self-management experiences and outpatient nursing needs during the transition period <sup>[6]</sup>.

#### 3.2.1. Theme 1: Challenges in self-management during the transition period

##### (1) Inconsistent knowledge of stoma care

Due to short recovery periods and the heavy workload of medical staff, some patients did not fully grasp stoma-related knowledge and only understood basic bowel function. In contrast, other patients proactively sought information before surgery and achieved better outcomes through self-learning. For instance, patients P2 and P10 had limited understanding, while P13 and P9 were well-prepared preoperatively and demonstrated better post-op care abilities <sup>[7]</sup>.

##### (2) Difficulty in mastering stoma care skills

During hospitalization, stoma care was often handled by family members, so patients only began personal care after discharge. They struggled with tasks like cutting the flange or replacing stoma bags. P4 and P5 reported difficulty cutting the baseplate, P9 worried about improper sizing, and P3 found replacement challenging due to poor visibility of the stoma site.

##### (3) Psychological adaptation difficulties

Changes in bowel function triggered identity crises and psychological resistance among patients. P4 struggled to accept physical changes, P7 felt daily life was affected by the support rod, P8 expressed strong aversion to the stoma, and P3, lacking trust in others to perform care properly, relied heavily on outpatient services <sup>[8]</sup>.

##### (4) Lack of family and social support

Limited caregiving abilities among family members left patients feeling unsupported during the transition period, resulting in a sense of isolation in their self-management journey.

##### (5) Lack of competence in managing complications

Due to insufficient in-hospital education, patients lacked the skills to handle complications during the high-risk transition phase, which often led to improper care and potential readmission. P11: "The skin around the stoma turned red and hurt, I panicked and didn't know what to do". P10: "The stoma bag kept

leaking and wouldn't stick properly, it made me so anxious". P1: "After the support rod was removed, the wound wouldn't heal and kept oozing. I didn't know how to change the dressing".

### **3.2.2. Theme 2: Outpatient nursing needs during the transition period**

#### **(1) Need for professional guidance**

Most patients expressed a strong desire for standardized care instruction at outpatient clinics, including techniques for stoma bag replacement and managing complications <sup>[9]</sup>. T10: "I hope they hold more nursing seminars, with live demonstrations to teach us how to change stoma bags". T6: "Having professionals guide me gives me peace of mind". T1: "The clinic acts as a safety net, it's crucial to have access to help when problems arise".

#### **(2) Need for psychological support**

Psychological support was also seen as essential. Patients hoped for emotional comfort and encouragement through peer exchange and counseling. T11: "I hope regular support group meetings are organized so we can share experiences". T4: "People who haven't gone through this don't understand, it's incredibly tough. Without support and encouragement, it's hard to come to terms with such a body change". T8: "I need help not only with daily life but also emotionally". T13: "Joining mutual aid groups for stoma patients really helps, it allows us to encourage each other".

#### **(3) Need for continuity of care**

The demand for continuity of care is increasingly prominent. Patients expect services like online consultations, routine checkups, and home visits. T6 suggested establishing a hybrid online-offline communication system after discharge. T9 hoped for mutual aid via group chats. T13 pointed out the need for home services when mobility is limited. T3 mentioned that some patients, due to their dependence on the clinic, lacked the confidence for independent care.

#### **(4) Need for resource accessibility**

Access to resources was a shared concern. Patients called for broader availability of stoma care products and improved distribution of healthcare resources. T6: "There should be more diverse care products and better access to nearby medical resources". T12: "I hope the outpatient clinic can stock various brands and models of stoma bags, so we can try them and find the most suitable one".

### **3.2.3. Theme 3: Gaps in doctor-patient information continuity**

The study revealed significant disconnects in information exchange between patients and healthcare providers. Discharge instructions were often brief and lacked hands-on practice, leaving patients confused and unprepared for home care <sup>[10]</sup>. While hospitals prioritize efficiency, families value comfort, leading to mismatched expectations. Moreover, patients had limited access to reliable information, often turning to online sources or peer advice instead of timely, authoritative professional guidance, further complicating the care process.

## **4. Discussion**

### **4.1. Enhancing doctor-patient information continuity and strengthening knowledge and skill training to build confidence**

With the implementation of enhanced recovery after surgery (ERAS), hospital stays have become shorter, leaving

patients inadequately prepared for discharge and creating gaps in information continuity <sup>[11]</sup>. This has resulted in uneven understanding of stoma care, poor complication management, and psychological maladaptation. High-risk patients should be identified early and provided with personalized guidance before discharge to improve their self-management abilities and caregiving skills, thereby enhancing confidence. After discharge, regular outpatient follow-up should be conducted, with particular attention to high-risk individuals. Continued skill instruction and health consultations are essential. Ongoing education and psychological support can help patients recognize and handle complications, improve their mental state, and build confidence in adapting to life with a stoma <sup>[12]</sup>.

#### **4.2. Addressing patient needs by improving outpatient decision-making systems to support transitional and continuous care**

Patients in the transitional period have clear demands for continuity of care, yet current discharge planning practices remain underdeveloped, making it difficult to ensure care continuity and potentially leading to adverse outcomes. A decision support system which combining online and offline services and grounded in nursing theory, should be established to assist patients in making optimal care decisions regarding safety, cost, and other factors. Such systems can reduce patient anxiety, enhance their ability to address care challenges, and improve treatment adherence and care outcomes <sup>[13]</sup>. This approach is vital for improving outpatient care quality and achieving sustained nursing support.

#### **4.3. Leveraging artificial intelligence to optimize outpatient nursing models and expand information access**

National policies advocate for using AI and the Internet of Things (IoT) to streamline nursing workflows. Currently, some outpatient clinics suffer from uneven resource distribution and limited product options, affecting patient satisfaction and choice <sup>[14]</sup>. It is necessary to enhance both hardware and software infrastructure and optimize resource allocation to improve the healthcare experience. Stoma clinics should not only provide basic care but also expand services such as online consultations, Q&A support, and follow-up visits <sup>[15]</sup>. Developing an information-sharing platform between hospitals, communities, and families can ensure comprehensive and personalized continuous nursing care that meets diverse patient needs.

### **5. Conclusion**

This study reveals that patients with intestinal stomas face multiple self-management challenges during the post-discharge transition period, including gaps in knowledge and skills, psychological adjustment issues, lack of social support, and difficulty managing complications. Their outpatient nursing needs are urgent. Moving forward, leveraging technologies such as artificial intelligence to improve outpatient care systems, enhance nursing education, and provide psychological support will be key to comprehensively improving patients' quality of life.

#### **Disclosure statement**

The authors declare no conflict of interest.

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