Research Square

Preprints are preliminary reports that have not undergone peer review.
They should not be considered conclusive, used to inform clinical practice,
or referenced by the media as validated information.

Proactive health management during healthcare transition among Chinese adolescents and young adults with inflammatory bowel disease: a multi-perspective qualitative study

Xinyi Gao
Shanghai Tenth People's Hospital
Yaxin Xu
Shanghai Skin Disease Hospital
Jun Xu
Ruijin Hospital
Ting Yao
First Affiliated Hospital of Wenzhou Medical University
Yanan Gao
Peking Union Medical College Hospital
Yi Wang
Shanghai Tenth People's Hospital
Yamei Chen
1600238@tongji.edu.cn

Shanghai Tenth People's Hospital

Research Article

Keywords: Healthcare transition, Family caregivers, Inflammatory bowel disease, Proactive health management, Qualitative research

Posted Date: November 19th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-11437755/v1

License: This work is licensed under a Creative Commons Attribution 4.0 International License.
Read Full License

Additional Declarations: No competing interests reported.

Abstract

Background

Healthcare transition involves a gradual shift in disease-management responsibility from family caregivers to adolescents and young adults with inflammatory bowel disease (IBD), while family involvement remains important. However, little is known about how proactive health management is negotiated within patient–caregiver interactions during this transition.

Objective

To explore experiences and contextual conditions shaping proactive health management during healthcare transition among Chinese adolescents and young adults with IBD and their primary family caregivers.

Methods

A qualitative descriptive study involved 13 patients aged 13–20 years and 13 primary family caregivers from two tertiary hospitals in Shanghai, China. Separate semi-structured interviews were analyzed using directed qualitative content analysis informed by Meleis' Transitions Theory.

Results

Six themes and seventeen subthemes emerged: developing transition awareness and recognizing long-term management responsibility; negotiating disease-management responsibility within the family; navigating multilevel barriers to proactive health management; mobilizing supportive resources for proactive health management; contrasting patterns of engagement in proactive health management; and seeking structured and continuous transition support. Proactive health management involved task-specific negotiation of responsibility within families and was shaped by illness-related, psychosocial, informational, family, and healthcare-access conditions.

Conclusions

Proactive health management during healthcare transition was family-embedded, relational, and context-dependent. The findings support gradual, developmentally appropriate redistribution of management responsibility rather than abrupt transfer from caregivers to young people.

1 Introduction

Inflammatory bowel disease (IBD), comprising Crohn's disease and ulcerative colitis, is a chronic inflammatory condition of the gastrointestinal tract(1). Approximately one-quarter of patients with IBD are diagnosed during childhood or adolescence(2). Globally, the number of incident IBD cases among children and adolescents increased by 22.78% from 1990 to 2019(3). During the same period, China showed one of the highest annual increases in pediatric-onset IBD incidence rates, with an annual percentage change of 2.8%(4). As the burden of pediatric-onset IBD increases, more young people will require ongoing disease management across adolescence and into young adulthood, including transition from pediatric to adult-oriented care(5, 6). Planned transition preparation is therefore an important component of long-term IBD care(7).

The onset of IBD during childhood or adolescence poses challenges that extend beyond symptom control. Because the disease occurs during a critical period of physical and psychosocial development, chronic inflammation, malnutrition, and treatment-related factors may affect growth and pubertal development(8). IBD and its treatment can also interfere with school attendance and participation, social life, body image, and psychological well-being(9–11). Transition-aged patients with IBD therefore face the clinical demands of a relapsing chronic illness alongside the developmental demands of adolescence and young adulthood(12, 13).

Family involvement is central to disease management during this period. Parents and other primary family caregivers often remain closely involved in daily disease management and provide practical and emotional support(14, 15). However, as young people approach adulthood, transition preparation increasingly involves greater patient participation and a gradual redistribution of disease-management responsibility between young people and their caregivers(16, 17). Healthcare transition is therefore better understood as a progressive developmental process rather than a single transfer event(6, 7, 17). In China, formal transition pathways and systematic transition support for adolescents with IBD remain limited, and patients, families, and healthcare professionals have reported barriers related to transition awareness, communication, self-efficacy, and healthcare systems(15, 18).

Proactive health management provides a useful lens for examining how individuals actively participate in maintaining health rather than responding only after health problems arise(19). The concept emphasizes individual initiative, prevention-oriented action, ongoing attention to health status, and active engagement with available health resources(19, 20). Applied to healthcare transition in IBD, this perspective draws attention to how young people participate in symptom monitoring, treatment management, preparation for healthcare encounters, help-seeking, and the use of professional and social resources. These activities do not occur in isolation; during transition, they are embedded within family relationships in which patients and caregivers gradually negotiate how disease-management tasks are shared and transferred(16, 17).

Although research on healthcare transition among adolescents and young adults with IBD has increased, existing studies have examined transition readiness and outcomes, patient and parent experiences, and barriers and facilitators to transfer from pediatric to adult care (5, 18, 21). However, proactive health

management during transition, particularly the everyday processes through which young people and family caregivers negotiate disease-management responsibilities, has received less explicit attention. This issue is particularly relevant in the Chinese health care context, where formal transition support remains limited and family caregivers continue to play an important role in disease management(18). Meleis' Transitions Theory conceptualizes transition in terms of the properties of transition experiences, facilitating and inhibiting conditions, and patterns of response(22). The framework is therefore useful for examining how changes in disease-management responsibility occur alongside developmental, family, psychosocial, and healthcare-related conditions during healthcare transition.

Guided by Meleis' Transitions Theory(22), this study aimed to explore factors shaping proactive health management during healthcare transition from the perspectives of Chinese adolescents and young adults with IBD and their primary family caregivers. A multi-perspective approach was used to examine shared, divergent, and complementary perspectives across the two groups. By examining how proactive health management is understood, how disease-management responsibilities are negotiated, and how transition-related challenges are addressed, this study may inform family-centered transition support that promotes patient participation and the gradual adjustment of disease-management responsibilities over time.

2 Methods

2.1 Study design and setting

This study used a qualitative descriptive design(23)with face-to-face, semi-structured interviews. Meleis' Transitions Theory(22)informed the development of the interview guide and data analysis. The study was reported in accordance with the Standards for Reporting Qualitative Research (SRQR) (24), and the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used to guide reporting of the interview-based components(25).The study was conducted in the gastroenterology inpatient wards of two tertiary hospitals in Shanghai, China: a tertiary general hospital and a tertiary children's hospital.

2.2 Participants and recruitment

Participants were recruited from September to November 2023. Purposive sampling, guided by the principle of maximum variation, was used to recruit patients and their primary family caregivers with diverse transition and health-management experiences. Variation was considered in study site, patient age, sex, disease type, disease activity, disease duration, place of origin, medical insurance status, and educational level.

Inclusion criteria were as follows. Patients with IBD: (1) aged 13–20 years; (2) had a confirmed diagnosis of IBD according to the Chinese Consensus on the Diagnosis and Treatment of Inflammatory Bowel Disease(26); (3) had received transition-related education, participated in discussions about transfer or referral to adult care, or had an established transfer plan; (4) were receiving inpatient treatment for IBD at

one of the study sites during the recruitment period; and (5) were able to communicate in Chinese and participate in the interview. Primary family caregivers: (1) were a first-degree relative of the patient and assumed primary responsibility for the patient's care; (2) were aged 18 years or older; (3) had provided unpaid care for more than 1 month; and (4) were able to communicate in Chinese and participate in the interview.

Exclusion criteria were as follows. Patients with IBD: (1) had a severe psychiatric disorder; (2) had severe major-organ dysfunction; or (3) had another chronic systemic disease requiring long-term management. Primary family caregivers: (1) had a psychiatric disorder or cognitive impairment that could interfere with participation in the interview; (2) had a paid caregiving relationship with the patient; or (3) had language or communication difficulties that prevented participation in the interview.

Data collection and preliminary analysis were conducted concurrently. By the time interviews had been completed with approximately 11 patients and their respective caregivers, no new codes related to proactive health management, family involvement, or the sharing and transfer of management responsibility were emerging. Two additional patients and their caregivers were interviewed to confirm saturation. No new codes or substantively different information emerged, and recruitment was concluded.One eligible patient declined participation because of a scheduled clinical examination; no enrolled participants withdrew. In total, 13 patients and 13 primary family caregivers participated in the study. Patient and caregiver characteristics are presented in Tables 1 and 2. To protect confidentiality, patients were assigned codes P1–P13 and caregivers N1–N13.

Table 1

Demographic and clinical characteristics of patients with IBD during healthcare transition

Code	Age, years	Sex	IBD type	Disease activity	Duration (months)	Education	Residence/insurance
P1	15	Female	CD	Remission	36	Junior high school	Shanghai / Local
P2	17	Female	CD	Remission	50	High school	Anhui / Non-local
P3	19	Male	UC	Moderate	110	University	Shanghai / Local
P4	14	Female	CD	Remission	44	Junior high school	Shanghai / Local
P5	13	Male	UC	Remission	10	Junior high school	Jiangsu / Non-local
P6	20	Male	UC	Severe	26	College	Henan / Non-local
P7	19	Female	CD	Remission	67	University	Shanghai / Local
P8	18	Male	UC	Mild	22	High school	Anhui / Non-local
P9	13	Male	CD	Mild	30	Junior high school	Shanghai / Local
P10	17	Female	CD	Remission	56	High school	Shanghai / Local
P11	15	Female	UC	Remission	27	Junior high school	Jiangsu / Non-local
P12	14	Male	CD	Severe	4	Junior high school	Jiangsu / Non-local
P13	16	Male	UC	Remission	74	High school	Shanghai / Local

Note. IBD, inflammatory bowel disease; CD, Crohn's disease; UC, ulcerative colitis. Disease activity was obtained from patients' clinical records and categorized as remission, mild, moderate, or severe disease activity. Local insurance refers to medical insurance registered in Shanghai; non-local insurance refers to medical insurance registered outside Shanghai.

Table 2
Demographic characteristics of primary family caregivers

Code	Age, years	Sex	Relationship to patient	Marital status	Education	Monthly household income per capita, RMB	Number of children
N1	41	Female	Mother	Married	Bachelor's degree	≥ 8,000	1
N2	50	Male	Father	Married	High school	4,000–7,999	3
N3	43	Female	Mother	Married	High school	< 4,000	1
N4	39	Male	Father	Divorced	Bachelor's degree	4,000–7,999	1
N5	35	Female	Mother	Married	Junior high school	≥ 8,000	2
N6	45	Female	Mother	Divorced	College	4,000–7,999	2
N7	54	Male	Father	Married	Bachelor's degree	4,000–7,999	1
N8	39	Male	Father	Married	High school	< 4,000	1
N9	50	Female	Mother	Married	Junior high school	< 4,000	2
N10	39	Female	Mother	Married	College	≥ 8,000	1
N11	42	Female	Mother	Divorced	High school	4,000–7,999	1
N12	42	Male	Father	Married	Bachelor's degree	≥ 8,000	2
N13	37	Female	Mother	Married	Junior high school	4,000–7,999	1

Note. Caregiver codes correspond to patient codes for participant identification only; for example, N1 was the primary family caregiver of P1. RMB, Chinese yuan.

2.3 Data collection

Data were collected through face-to-face, semi-structured interviews conducted in Chinese. The semi-structured interview guides for patients and primary family caregivers were developed specifically for this study by the research team, informed by Meleis' Transitions Theory(22), the study aim, and relevant literature. The guides addressed participants' understanding of proactive health management, disease uncertainty, changes in health-management roles and responsibilities, family involvement, barriers and

facilitators, and perceived support needs. An English-language version of both interview guides is provided in Additional file 2.

The preliminary interview guide was reviewed by the research team and relevant experts. Pilot interviews were conducted separately with two patients and two primary family caregivers to assess the clarity and feasibility of the questions. Minor wording revisions were made following the pilot interviews, and pilot data were not included in the formal analysis. The final interview guides contained nine questions for patients and nine parallel questions for primary family caregivers (Table 3; Additional file 2). The interviewer used probing questions to clarify and expand participants' responses when necessary.

Table 3
Semi-structured interview guide for transition-aged patients with IBD and their primary family caregivers

No.	Questions for transition-aged patients with IBD	Questions for primary family caregivers
1	What do you understand by proactive health management of your disease?	What do you understand by proactive health management of the patient's disease?
2	To what extent do you think your disease is difficult to predict or control?	To what extent do you think the patient's disease is difficult to predict or control?
3	What do you currently do to manage your health proactively, and how do you do it?	What do you currently do to support the patient's proactive health management, and how do you do it?
4	What effects do you think proactive health management has on your disease control and recovery?	What effects do you think proactive health management has on the patient's disease control and recovery?
5	What difficulties have you encountered during proactive health management, and how have you responded to them?	What difficulties have you encountered while supporting the patient's proactive health management, and how have you responded to them?
6	What roles and responsibilities do you and your family caregiver currently undertake in managing your disease? Have these changed over time?	What roles and responsibilities do you and the patient currently undertake in managing the disease? Have these changed over time?
7	How does your family caregiver's involvement affect your proactive health management?	How does your involvement affect the patient's proactive health management?
8	What support or assistance have you received during proactive health management, and what additional support do you need?	What support or assistance have you received while supporting the patient's proactive health management, and what additional support do you need?
9	What concerns or plans do you have regarding your disease and its future management?	What concerns or plans do you have regarding the patient's disease and its future management?

Note. IBD, inflammatory bowel disease. Parallel guides informed by Meleis' Transitions Theory (Meleis et al., 2000) and the multi-perspective study aim captured the two stakeholder groups separately.

All interviews were conducted by a female master's student in nursing who had received training in qualitative interviewing. The interviewer was not involved in participants' clinical care and had no prior clinical relationship with them. Participants were informed of the interviewer's nursing background and research role before the interviews.

Interviews were conducted in a quiet, private room at the respective study site and lasted approximately 30–45 min. Patients and caregivers were interviewed separately to minimize mutual influence and allow each participant to express their experiences independently. Only the participant and interviewer were

present during each interview. No repeat interviews were conducted. All interviews were audio-recorded with participants' consent.

During and immediately after each interview, field notes were recorded to document nonverbal cues and emotional responses. At the end of each interview, the interviewer summarized the main points and invited the participant to confirm or correct the summary. No substantive corrections were requested. Audio recordings were transcribed verbatim in Chinese within 24 h and checked against the recordings by another researcher.

2.4 Data analysis

Data were analyzed using directed qualitative content analysis(27), informed by Meleis' Transitions Theory(22). The theory informed the initial coding framework, while data that did not fit the theory-informed framework were allowed to generate new codes inductively. The concepts of transition properties, transition conditions, and patterns of response informed the initial analysis, while the study aim additionally directed attention to changes in health-management roles and responsibilities and perceived support needs.

NVivo 12 was used to organize and manage the data. Two researchers independently read the transcripts repeatedly to become familiar with the data and coded meaningful statements line by line. In the initial deductive phase, data were examined in relation to transition awareness, changes in health-management roles and responsibilities, transition-related conditions, patterns of response, and support needs. Data that could not be adequately represented within the preliminary framework were assigned new codes, and the coding framework was revised iteratively as analysis progressed.

Codes with related meanings were compared and grouped into categories and subthemes, which were subsequently integrated into higher-order themes. Patient and caregiver data were initially analyzed separately. The two datasets were then compared to identify shared, divergent, and complementary perspectives and to develop an integrated thematic structure. Disagreements were discussed by the two researchers and, when necessary, with a third senior researcher until consensus was reached.

2.5 Rigor and reflexivity

Strategies addressing credibility, dependability, confirmability, and transferability were used to enhance rigor(28). Credibility was supported through expert review and pilot testing of the interview guide, probing and paraphrasing during interviews, and participant confirmation of the interviewer's end-of-interview summaries. Investigator triangulation was achieved through independent coding by two researchers and discussion of coding and interpretations within the research team.

Dependability and confirmability were supported through independent coding, research team discussion, and documentation of coding decisions, theme development, and researcher reflections throughout the analysis. The interviewer maintained reflexive memos during data collection and analysis to consider how her nursing background and assumptions about adolescent independence and family involvement

might influence interview questioning, interpretation, and theme development. Transferability was supported through maximum variation sampling and detailed descriptions of participant characteristics, study settings, and data collection and analysis procedures.

2.6 Ethical considerations

Ethical approval

for this study was obtained from the institutional ethics committee. The study was conducted in accordance with the Declaration of Helsinki. Before data collection, participants were informed of the study purpose and procedures, the voluntary nature of participation, their right to withdraw at any time, and measures used to protect confidentiality.Written informed consent was obtained from all adult participants. For participants younger than 18 years, written informed consent was obtained from a parent or legal guardian, and assent was obtained from the participants themselves. All transcripts were de-identified to protect participants' confidentiality.

3 Results

Twenty-six participants took part in the study, including 13 adolescents and young adults with inflammatory bowel disease (IBD) and 13 primary family caregivers. Patients were aged 13–20 years, and caregivers were aged 35–54 years. Analysis generated six themes and 17 subthemes describing proactive health management during healthcare transition (Table 4; Fig. 1).

Table 4
Themes and subthemes describing proactive health management during healthcare transition

Theme	Subtheme
1. Developing transition awareness and recognizing long-term management responsibility	1.1 Incomplete understanding of IBD and long-term management
	1.2 Recognizing the need for greater self-management responsibility
2. Negotiating disease-management responsibility within the family	2.1 Caregiver-led management and limited patient participation
	2.2 Tensions in responsibility boundaries
	2.3 Gradual, task-based responsibility transfer
3. Navigating multilevel barriers to proactive health management	3.1 Disease uncertainty and disruption to daily life
	3.2 Stigma and constrained social participation
	3.3 Caregiver anxiety and cumulative family burden
	3.4 Financial and healthcare-access barriers to continuity of care
4. Mobilizing supportive resources for proactive health management	4.1 Supportive family involvement and patient participation
	4.2 Professional and informational support
	4.3 Peer support and shared illness experiences
5. Contrasting patterns of engagement in proactive health management	5.1 Active adaptation and growing management competence
	5.2 Continued dependence and limited perceived control
6. Seeking structured and continuous transition support	6.1 Need for structured and individualized transition guidance
	6.2 Need for guidance on responsibility transfer
	6.3 Need for psychosocial support and continuity of care

3.1 Developing transition awareness and recognizing long-term management responsibility

3.1.1 Incomplete understanding of IBD and long-term management

Patients described an incomplete understanding of the chronic and relapsing nature of IBD, particularly during the early stages of illness. Several initially understood disease management mainly as taking medication and attending hospital appointments, with less awareness of symptom monitoring and other aspects of long-term management. Caregivers described taking responsibility for medication, examinations, and communication with healthcare professionals when patients had limited disease-management knowledge.

“At first, I only knew that I had ulcerative colitis and needed to take medicine. I did not really know what I should pay attention to every day or what I should do if my symptoms changed.” (P5)

“At the beginning, he knew very little about the disease. I remembered the medication, arranged the examinations, and asked the doctor questions. He basically followed whatever we arranged.” (N5)

3.1.2 Recognizing the need for greater self-management responsibility

Patients described gradually recognizing that they would need to assume greater responsibility for disease management as they approached adulthood and adult-oriented care. They expressed intentions to learn tasks such as managing appointments, preparing for consultations, remembering medication, and communicating directly with healthcare professionals. At this stage, recognition of responsibility was often more evident than consistent independent performance.

“I know that when I go to the adult clinic, my parents will not always be able to come with me. I have started learning how to fill out the insurance forms and explain my symptoms to the doctor.” (P3)

“I used to wait for my mother to tell me everything. Now I try to remember the date of my next appointment and prepare the questions I want to ask the doctor.” (P7)

3.2 Negotiating disease-management responsibility within the family

3.2.1 Caregiver-led management and limited patient participation

Both patients and caregivers described disease management as remaining largely caregiver-led in some families. Patients had limited experience with tasks such as arranging appointments, obtaining prescriptions, and making treatment-related decisions, whereas caregivers described continuing to supervise medication and symptoms because of concerns about omissions or inappropriate

management. Participants described this arrangement as maintaining day-to-day disease management while leaving patients with fewer opportunities to practice some management tasks independently.

“I have never managed those things, such as appointments or prescriptions. My father mostly handles them for me. He told me I could stop my medication, so I stopped. Then the disease flared up again.” (P8)

“I don’t really feel comfortable leaving it all to him. He is still young, and I’m afraid he may forget his medicine or miss some symptoms. So for now, I still have to keep an eye on these things.” (N5)

3.2.2 Tensions in responsibility boundaries

Patients and caregivers sometimes interpreted continued family supervision differently. Patients could experience repeated reminders and checking as a lack of trust or a restriction on their ability to make decisions, whereas caregivers described the same practices as necessary precautions against missed medication, inappropriate dietary choices, or delayed follow-up. These differing expectations created tension over how much responsibility patients should assume and when caregivers should step back.

“I know there are foods I need to be careful about, but when I want to eat outside, my mother often asks what I am going to eat and reminds me again. I am already grown up, so I hope she can let me make some decisions myself.” (P3)

“I know he has to learn to manage these things gradually, but I am still not sure how much I can let him handle now. Medication and follow-up visits are important; if something is missed, I would feel responsible.” (N13)

3.2.3 Gradual, task-based responsibility transfer

Both groups described responsibility transfer as a gradual, task-based process rather than a single handover. Patients began with manageable tasks, such as arranging appointments, making payments, collecting medication, preparing questions, and speaking during consultations. Caregivers continued to assist with more difficult tasks while gradually reducing their involvement in activities patients were able to perform themselves.

“My father used to handle registration, payment, and collecting medicine at the hospital. Now I can make appointments and payments on my phone and collect the medicine myself. He just waits nearby. At first, I was not used to it, but after doing it a few times, I became more familiar with the process.” (P3)

“At first, I just asked her to tell the doctor how she felt. Now she can remember the appointment date, prepare her questions, and talk to the doctor herself. I still go with her, but I only add something if she misses it.” (N1)

3.3 Navigating multilevel barriers to proactive health management

3.3.1 Disease uncertainty and disruption to daily life

Patients described the unpredictability of disease activity as a persistent challenge. Unexpected flares could disrupt school, social activities, and everyday plans, while uncertainty about recurrence contributed to a sense of limited control over future disease management.

“The worst part is not knowing when it will flare up again. One day I’m fine, but maybe the next I’ll end up in the hospital. It messes up everything.” (P8)

“I do whatever the doctor says, but I still can’t stop worrying that things might get worse. It feels like I have no real control over what happens.” (P6)

3.3.2 Stigma and constrained social participation

Patients described how visible treatment devices, frequent toilet use, and other illness-related differences could make them feel conspicuous among peers. Concerns about being stared at, questioned, or misunderstood sometimes led them to conceal their condition or withdraw from social interactions.

“I have to wear a nasogastric tube to school. I just can’t do it. I’m afraid my classmates will see me and think I’m a freak.” (P1)

“I’m always running to the bathroom. Sometimes I have to leave class two or three times. When my friends ask what’s wrong, I just say I have diarrhea. Later, I stopped explaining. I just stay by myself and leave right after class.” (P11)

3.3.3 Caregiver anxiety and cumulative family burden

Caregivers described persistent concern about disease recurrence and the demands of long-term management. Ongoing monitoring of symptoms, medication, and diet was accompanied by employment and family responsibilities, creating practical and emotional strain over time.

“I am always afraid that her disease will suddenly flare again. Even when she is in remission, I still pay attention to what she eats, whether she has abdominal pain, and whether she has taken her medicine.” (N1)

“I have to work and take care of her at the same time. Sometimes I need to accompany her to the hospital, but I also worry about asking for leave too often. It is difficult to balance everything by myself.” (N11)

3.3.4 Financial and healthcare-access barriers to continuity of care

Caregivers also described financial and practical difficulties associated with maintaining regular care. Treatment costs, repeated follow-up visits, travel, and time away from work placed additional demands

on families. For those receiving care outside the location in which their medical insurance was registered, advance payment and cross-regional reimbursement procedures created further difficulties.

“Our medical insurance is registered in another province, so we often need to pay first and then go through the reimbursement procedures later. Each follow-up visit also involves transportation and time away from work, so sometimes arranging regular visits is difficult.” (N8)

“As a single parent, I have to consider both the treatment expenses and the family’s daily living costs. I try to reduce other expenses as much as possible, but the child’s treatment and follow-up care cannot be delayed.” (N11)

3.4 Mobilizing supportive resources for proactive health management

3.4.1 Supportive family involvement and patient participation

Patients described family involvement as particularly helpful when caregivers provided practical and emotional support while also listening to patients’ views and involving them in disease management. Caregivers similarly described supporting patients while encouraging them to participate in managing their own health rather than making all decisions on their behalf.

“My parents do not simply decide everything for me. They usually ask how I feel and what I think before making decisions about treatment or daily care. This makes me feel that I am also involved in managing my disease.” (P4)

“I know that he needs to learn to manage the disease himself. We still help him, but we also ask him to remember his medication, observe his symptoms, and tell the doctor how he feels.” (N13)

3.4.2 Professional and informational support

Patients valued specific guidance from healthcare professionals about symptoms and daily disease management, while caregivers emphasized the usefulness of accessible educational information that could be reviewed after clinical encounters. Participants described these forms of support as helpful for understanding and carrying out everyday management tasks.

“The nurse told me that I should not only take the medicine, but also pay attention to things like stool frequency and abdominal pain. Before that, I only knew that I had to take the medicine. After she explained it, I knew what changes I should watch for.” (P6)

“Sometimes we cannot remember everything the doctor says during the clinic visit. After going home, I read articles from the hospital’s WeChat account. They are easier to understand, and I can check them again when I am not sure.” (N9)

3.4.3 Peer support and shared illness experiences

Patients described contact with peers who had similar illness experiences as a source of emotional reassurance and practical information. Hearing how others dealt with dietary restrictions, school life, treatment, and social concerns helped some patients feel less isolated and provided examples of how similar challenges could be managed.

“I used to feel that I was the only person around me who had this disease. Later, I talked with other patients and found that they also had to control their diet and worried about needing the toilet at school. Then I felt that I was not the only one like this.” (P11)

“When I was in the hospital, I met a patient who had been treated for longer than me. She told me that she was also very scared at first, especially when classmates asked about her illness, but later she slowly got used to it. After hearing that, I felt a little less afraid.” (P4)

3.5 Contrasting patterns of engagement in proactive health management

3.5.1 Active adaptation and growing management competence

Some patients described increasingly consistent participation in disease management. Their accounts included preparing questions before consultations, explaining symptoms directly to healthcare professionals, remembering medication, and adjusting daily routines. Caregivers also described a reduced need to organize every aspect of disease management as patients became more involved.

“Before seeing the doctor, I now think about what has changed recently and what I want to ask. My mother still comes with me, but I try to explain my condition first instead of waiting for her to answer.” (P7)

“She used to ask us about almost everything, including medicine and follow-up visits. Now she remembers many things herself and will tell us if she feels uncomfortable. We still help her, but we do not need to arrange every detail as before.” (N2)

3.5.2 Continued dependence and limited perceived control

Other patients described continued uncertainty about interpreting symptoms and limited confidence in making disease-management decisions independently. They often relied on caregivers to judge whether symptoms required medical attention and to manage communication and follow-up. Caregivers similarly described remaining responsible for many of these tasks.

“When my stomach hurts, I cannot tell whether it is because of something I ate or because the disease is getting worse. I usually tell my mother first and wait for her to decide whether we should go to the

hospital.” (P9)

“He still depends on us for many things. For example, when there is blood in his stool, he is not sure whether it is serious. Follow-up visits, asking for leave, and talking with the doctor are still mostly handled by us.” (N6)

3.6 Seeking structured and continuous transition support

3.6.1 Need for structured and individualized transition guidance

Patients and caregivers described gaps in transition-related guidance. Patients wanted information that was practical, easy to remember, and available for later reference, as well as more opportunities to communicate directly with healthcare professionals. Caregivers wanted stepwise guidance tailored to the patient’s age and current management abilities.

“The doctor told me how to take my medicine and what to watch for. I remembered it clearly at the time, but I forgot after being home for a while. It would be good to have a piece of paper with it written down, or a little notebook to keep track.” (P6)

“When the doctor asks me something, my mom always jumps in to answer. Actually, I know some of the answers too, and I want to say them myself. I hope the doctor could ask me as well, not just my mom.” (P1)

“We don’t know which things she should learn first and which can wait. If the nurses could tell us step by step, according to her situation, that would be really helpful.” (N4)

3.6.2 Need for guidance on responsibility transfer

Caregivers expressed uncertainty about how to determine whether patients were ready to assume particular management tasks, which responsibilities should be transferred first, and when they should reduce their supervision. They also wanted guidance on communicating about responsibility and supervision without increasing parent–child conflict.

“I know she cannot always depend on us, but I still worry when she goes to see the doctor by herself. I am not sure when I should step back and let her handle it.” (N7)

“Sometimes I remind her because I am worried, but she feels that I am controlling her. I hope someone can tell us how to talk about these things better.” (N11)

3.6.3 Need for psychosocial support and continuity of care

Participants described support needs extending beyond disease-related information. Patients wanted access to emotional support outside the family and opportunities to discuss their experiences without

adding to their parents' concerns. Caregivers wanted a reliable way to obtain professional advice when new problems occurred between scheduled follow-up visits.

"Sometimes I feel worried when I think about relapse, but I do not always want to tell my parents. If I tell them, they may become more anxious than me. I think it would be better if there were someone outside the family I could talk to." (P4)

"After we go home, new problems sometimes appear before the next follow-up visit. For example, if he has abdominal pain or eats poorly, I am not always sure whether we should observe first or contact the doctor immediately. I hope there could be a more stable way to ask about these problems between appointments." (N12)

4 Discussion

4.1 Proactive health management as a family-embedded relational process

This study identified proactive health management during healthcare transition as a family-embedded, relational, and context-dependent process. Patients and caregivers described different but interrelated expectations regarding participation, supervision, and responsibility, while disease uncertainty, stigma, family burden, and healthcare-access difficulties were also described in relation to how disease-management responsibilities were managed in everyday life. This highlights the importance of considering the relational and contextual conditions surrounding young people's participation in health management.

Family involvement was described as both protective and potentially restrictive. When patients had limited knowledge or experience, caregivers frequently assumed responsibility for medication, appointments, symptom monitoring, and communication with healthcare professionals. Such involvement was described as important for maintaining day-to-day disease management. However, when caregivers continued to perform tasks that patients were capable of practicing themselves, patients had fewer opportunities to participate in those tasks independently. Previous research has highlighted the importance of family functioning in pediatric IBD(14), while transition-focused studies have described parental difficulty adjusting or reducing involvement as young people move toward adult-oriented care(15, 16).

Patients and caregivers did not always interpret the same family practices in the same way. Patients sometimes perceived repeated reminders or monitoring as limited trust or restricted autonomy, whereas caregivers described these behaviors as precautions against missed medication, delayed follow-up, or disease deterioration. Continued dependence may reflect limited opportunities for practicing management tasks rather than unwillingness to participate in care. Patients may recognize the need for greater responsibility but have limited opportunities to practice particular tasks independently.

Supported participation may provide patients with opportunities to gain experience while preserving access to assistance when needed(16, 17).

Transition assessment should therefore consider how disease-management responsibilities are distributed within the family in addition to patients' knowledge and self-management skills. Clinicians may need to identify which tasks the patient already performs, which remain caregiver-led, and why caregivers may be reluctant to reduce supervision. Such an approach may help distinguish limited experience from limited motivation and support greater patient participation without disregarding caregivers' concerns about safety.

4.2 Responsibility transfer as staged and task-specific

A key finding was that responsibility transfer was not experienced as a single or uniform handover. Instead, patients and caregivers described a gradual process in which responsibility differed according to the type and complexity of the management task. This finding is consistent with previous research on the gradual nature of healthcare transition (6, 29).

Participants described relatively routine tasks, such as preparing questions for consultations, making appointments, completing payments, and communicating symptoms, as opportunities for increasing patient participation. More complex activities, particularly those involving interpretation of symptoms, treatment decisions, or responses to deterioration, were more likely to remain shared with or led by caregivers. Previous research similarly suggests that transition-related skills develop at different rates and that caregiver assessments may not fully correspond with young people's perceived abilities (30, 31). Responsibility transfer may therefore be better considered in relation to specific tasks and circumstances rather than inferred solely from chronological age or an overall readiness score.

Progression in responsibility was also discussed in relation to caregiver confidence as well as patient capability. Patients sometimes wanted greater autonomy before caregivers felt comfortable reducing supervision. Conversely, transferring responsibility before patients felt prepared could be experienced as uncertainty or pressure. Similar tensions have been reported among families navigating IBD transition(16, 29). Alignment between patients' developing abilities, caregivers' confidence, and shared expectations about responsibility may therefore be important during the transition process.

Supported practice may be particularly valuable in this process. Providing patients with opportunities to perform manageable tasks while caregivers remain available may create opportunities for patients to gain experience and for caregivers to observe their developing competence. In contrast, continued caregiver substitution may leave fewer opportunities for patients to practice or demonstrate their abilities. These findings suggest that transition support may be better framed around developmentally appropriate participation and increasing self-management rather than complete independence from family support(6, 16, 17).

Viewed through Meleis' Transitions Theory, developing awareness can be understood as a property of the transition experience, whereas disease uncertainty, stigma, family burden, and healthcare access

represent conditions that may facilitate or inhibit transition(22). Family, professional, informational, and peer resources may similarly function as facilitating conditions. The differing patterns of engagement observed in this study can be understood in relation to changing responsibilities and surrounding transition conditions. Negotiation of disease-management responsibility within the family therefore represents an important aspect of healthcare transition in this context.

4.3 Multilevel transition conditions and contextual constraints

The barriers identified extended beyond individual knowledge and self-management skills. Disease uncertainty was evident at the illness level, stigma and social participation at the interpersonal and social level, caregiver anxiety and burden at the family level, and financial and healthcare-access difficulties at the service and health-system level. Proactive health management therefore needs to be understood within the broader conditions in which patients and families manage IBD.

Disease uncertainty was particularly relevant to negotiations of responsibility. Patients described disruption to schooling and everyday activities and uncertainty about whether symptoms indicated disease deterioration. Caregivers, in turn, described continuing vigilance even during periods of relative stability. Similar experiences of uncertainty have been reported among young people with IBD and their caregivers(32, 33). In this context, close supervision may represent an attempt to manage perceived risk rather than simply a reluctance to support autonomy. This finding suggests that discussions about responsibility transfer may need to consider how patients and caregivers interpret disease-related risks. Transition support may therefore benefit from helping families identify warning signs, clarify when professional advice is needed, and discuss circumstances in which greater caregiver involvement may again become appropriate.

Stigma and constrained social participation further showed that disease-management competence must be applicable beyond clinical encounters. Previous research has similarly shown that visible treatments, toilet urgency, body changes, and concerns about disclosure may contribute to feelings of being different among young people with IBD (34, 35). In the present study, concerns about being noticed, questioned, or misunderstood were described alongside reluctance to disclose the condition or seek help in school and social settings. Transition preparation may therefore need to address communication, disclosure, school-related challenges, and psychosocial adjustment alongside medication and clinical follow-up.

Caregiver burden and healthcare-access difficulties were also described in relation to how responsibilities were managed within the family. Caregivers reported treatment expenses, travel, time away from work, cross-regional reimbursement procedures, and competing family responsibilities. Previous research has documented psychological distress among parents of adolescents with IBD(36), while studies in China have also identified substantial economic burden and healthcare-access difficulties among people living with IBD(37). Under such circumstances, caregiver-led management sometimes remained prominent as families sought to maintain continuity of care. Expectations for

greater patient autonomy may therefore be more difficult to meet for families with fewer financial, time, or support resources. These findings highlight that patient participation during transition occurs within broader family and healthcare contexts rather than being determined solely by individual capability.

4.4 Implications for family-centered transition support

The findings support a family-centered, task-based approach to transition preparation. Rather than assessing transition solely through overall readiness, clinicians may consider several interrelated areas: the patient's knowledge and performance of specific management tasks, the caregiver's confidence in transferring those tasks, the current distribution of responsibility within the family, and contextual concerns such as disease instability, emotional distress, stigma, or healthcare-access difficulties.

Transition planning could focus on specific tasks that patients are ready to practice while clarifying how caregivers can provide support without automatically taking over. Progress can be reviewed over time, with responsibility adjusted according to the patient's experience, disease status, task complexity, and need for assistance. Such an approach recognizes that responsibility may advance in some areas while remaining shared in others.

Clinical encounters may also provide deliberate opportunities for patient participation. Healthcare professionals can direct developmentally appropriate questions to the young person, encourage patients to describe symptoms and raise their own concerns, and allow caregivers to supplement information when necessary. Written or digital information that can be revisited after consultations may also help patients and caregivers retain and apply disease-management guidance. These practices are consistent with recommendations for planned, progressive, and coordinated healthcare transition that responds to young people's developmental needs(6, 17, 38).

Transition support should also extend beyond disease-related education and the point of transfer to adult care. Existing recommendations emphasize structured preparation for transfer, standardized transfer information, and coordinated transition planning (38, 39). Multimodal transition interventions have also incorporated individualized assessment, transition navigation, education, and skills-building support(40). The psychosocial, peer, and between-visit support needs identified in this study may therefore be considered alongside these structured transition components. In settings where formal transition pathways remain limited, elements of this support may be incorporated progressively into routine pediatric and adult gastroenterology care. Overall, transition support may aim to expand patient participation while supporting caregivers in gradually adjusting their supervisory roles.

4.5 Limitations

Several limitations should be considered. First, participants were recruited from gastroenterology inpatient settings at two tertiary hospitals in Shanghai. The experiences described in this study may differ from those of patients receiving outpatient care, those managed in primary healthcare settings, or families living in areas with different healthcare resources, which may affect the transferability of the findings.Second, the age range of 13–20 years encompassed different developmental stages. Although

the sample included variation in age and transition experiences, it was not sufficient to allow age-specific interpretation of differences in proactive health management.Third, interviews were conducted at one point in time and therefore could not capture how disease-management responsibilities and patterns of engagement changed throughout the transition process. Longitudinal research may provide further insight into how patient participation and caregiver involvement evolve before, during, and after transfer to adult-oriented care.Fourth, healthcare professionals were not included; consequently, the findings primarily reflect the perspectives of patients and family caregivers and do not capture clinicians' experiences or perspectives regarding transition care delivery. Future research involving diverse healthcare settings and multiple stakeholder perspectives may further enhance understanding of family-centered transition processes.

5 Conclusion

This study suggests that proactive health management during healthcare transition among adolescents and young adults with IBD is a family-embedded, relational, and context-dependent process. Patients emphasized trust and opportunities for participation, whereas caregivers emphasized safety and continuity of care. Responsibility transfer was gradual and task-specific, reflecting differences in patient capability, caregiver confidence, task complexity, perceived disease risk, and broader conditions such as illness uncertainty, stigma, family burden, and access to care.These findings support structured, family-centered, and task-based transition preparation. Health care professionals, particularly nurses, can facilitate this process through task-specific assessment, staged opportunities for patient participation, negotiation of patient and caregiver roles, clear guidance on when to seek help, and continuous informational, psychosocial, peer, and between-visit support. Transition support should aim to promote developmentally appropriate interdependence rather than an abrupt transfer to complete independence.

Declarations

Funding

This work was supported by the National Natural Science Foundation of China (Grant No. 72274135).

Declaration of interest

The authors declare no competing interests.

Ethics approval

This study was approved by the Ethics Committee of Shanghai Tenth People's Hospital (approval number 22K233). The collaborating institution participated under the approved study protocol.

Author contributions

XG: Conceptualization, Methodology, Writing – original draft, Writing – review & editing. YX: Investigation, Data curation, Formal analysis, Writing – review & editing. JX: Formal analysis, Writing – review & editing. TY: Writing – review & editing. YG: Supervision, Writing – review & editing. YW: Methodology, Project administration, Supervision, Writing – review & editing. YC: Funding acquisition, Resources, Supervision, Writing – review & editing.

All authors contributed to the article and approved the submitted version.

Acknowledgments

None.

References

1. Chang JT. Pathophysiology of Inflammatory Bowel Diseases. N Engl J Med. 2020;383(27):2652–64.
2. Rosen MJ, Dhawan A, Saeed SA. Inflammatory Bowel Disease in Children and Adolescents. JAMA Pediatr. 2015;169(11):1053–60.
3. Zhang ZM, Lin ZL, He BX, Yan WT, Zhang XY, Zhang ZH, et al. Epidemiological analysis reveals a surge in inflammatory bowel disease among children and adolescents: A global, regional, and national perspective from 1990 to 2019 - insights from the China study. J Glob Health. 2023;13:04174.
4. Wang Y, Pan CW, Huang Y, Zheng X, Li S, He M, et al. Global Epidemiology and Geographic Variations of Pediatric-Onset Inflammatory Bowel Disease: A Comprehensive Analysis of the Global Burden of Disease Study 1990 to 2019. Inflamm Bowel Dis. 2025;31(2):376–85.
5. Bihari A, Olayinka L, Kroeker KI. Outcomes in Patients with Inflammatory Bowel Disease Transitioning from Pediatric to Adult Care: A Scoping Review. J Pediatr Gastroenterol Nutr. 2022;75(4):423–30.
6. Vernon-Roberts A, Chan P, Christensen B, Havrlant R, Giles E, Williams AJ. Pediatric to Adult Transition in Inflammatory Bowel Disease: Consensus Guidelines for Australia and New Zealand. Inflamm Bowel Dis. 2025;31(2):563–78.
7. Shapiro JM, El-Serag HB, Gandle C, Peacock C, Denson LA, Fishman LN, et al. Recommendations for Successful Transition of Adolescents With Inflammatory Bowel Diseases to Adult Care. Clin Gastroenterol Hepatol. 2020;18(2):276–. – 89.e2.
8. Amaro F, Chiarelli F. Growth and Puberty in Children with Inflammatory Bowel Diseases. Biomedicines. 2020;8(11).
9. Claytor JD, Kochar B, Kappelman MD, Long MD. Body Image Dissatisfaction among Pediatric Patients with Inflammatory Bowel Disease. J Pediatr. 2020;223:68–e721.
10. Cooney R, Tang D, Barrett K, Russell RK. Children and Young Adults With Inflammatory Bowel Disease Have an Increased Incidence and Risk of Developing Mental Health Conditions: A UK Population-Based Cohort Study. Inflamm Bowel Dis. 2024;30(8):1264–73.

11. Rice J, Wilkinson C. School and School-Related Experiences of Children and Adolescents With Inflammatory Bowel Disease: A Scoping Review. Child Care Health Dev. 2026;52(3):e70249.
12. Alwassief A, Abbas QL, Al Busafi S, Al Lawati TT, Al Shmusi K. Transitioning Pediatric Patients with Inflammatory Bowel Disease: Key Considerations for Adult Gastroenterologists. Pediatr Gastroenterol Hepatol Nutr. 2025;28(3):141–7.
13. Vuijk SA, Camman AE, de Ridder L. Considerations in Paediatric and Adolescent Inflammatory Bowel Disease. J Crohns Colitis. 2024;18(Supplement2):ii31–45.
14. Cushman G, Shih S, Reed B. Parent and Family Functioning in Pediatric Inflammatory Bowel Disease. Child (Basel). 2020;7(10).
15. Tan B, Ong D. Pediatric to adult inflammatory bowel disease transition: the Asian experience. Intest Res. 2020;18(1):11–7.
16. Bihari A, Goodman KJ, Wine E, Seow CH, Kroeker KI. Letting go of control: A qualitative descriptive study exploring parents' perspectives on their child's transition from pediatric to adult care for inflammatory bowel disease. J Health Psychol. 2025;30(2):310–23.
17. Fu N, Bollegala N, Jacobson K, Kroeker KI, Frost K, Afif W, et al. Canadian Consensus Statements on the Transition of Adolescents and Young Adults with Inflammatory Bowel Disease from Pediatric to Adult Care: A Collaborative Initiative Between the Canadian IBD Transition Network and Crohn's and Colitis Canada. J Can Assoc Gastroenterol. 2022;5(3):105–15.
18. Zhou M, Xu Y, Zhou Y. Factors influencing the healthcare transition in Chinese adolescents with inflammatory bowel disease: a multi-perspective qualitative study. BMC Gastroenterol. 2023;23(1):445.
19. He J, Wang T. The community proactive health management model based on the grounded theory: The case of Beijing, China. Heliyon. 2023;9(4):e14992.
20. Liu J, Li W, Yao H, Liu J. Proactive Health: An Imperative to Achieve the Goal of Healthy China. China CDC Wkly. 2022;4(36):799–801.
21. Feingold JH, Kaye-Kauderer H, Mendiolaza M, Dubinsky MC, Keefer L, Gorbenko K. Empowered transitions: Understanding the experience of transitioning from pediatric to adult care among adolescents with inflammatory bowel disease and their parents using photovoice. J Psychosom Res. 2021;143:110400.
22. Meleis AI, Sawyer LM, Im EO, Hilfinger Messias DK, Schumacher K. Experiencing transitions: an emerging middle-range theory. ANS Adv Nurs Sci. 2000;23(1):12–28.
23. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40.
24. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245–51.
25. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.

26. Chinese consensus on diagnosis and treatment in inflammatory bowel disease. (2018, Beijing). J Dig Dis. 2021;22(6):298–317.
27. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–88.
28. Korstjens I, Moser A, Series. Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. Eur J Gen Pract. 2018;24(1):120–4.
29. de Gooyer M, Mackay MI, Mikocka-Walus A, Biurra YC, Emerson C, Klas A, et al. She just wants to be a normal kid: Adolescents with inflammatory bowel disease and their caregivers' transition from paediatric to adult care. Br J Health Psychol. 2026;31(2):e70079.
30. Stollon N, Zhong Y, Ferris M, Bhansali S, Pitts B, Rak E, et al. Chronological age when healthcare transition skills are mastered in adolescents/young adults with inflammatory bowel disease. World J Gastroenterol. 2017;23(18):3349–55.
31. Vernon-Roberts A, Musto F, Aloi M, Bowcock N, Lemberg DA, Day AS. Can Parents Provide Accurate Proxy Reports of Self-Management Skills for Their Child with Inflammatory Bowel Disease? Gastrointest Disorders. 2026;8(1):4.
32. Xu H, Wu C, Chen C, Yan B, Zha N, Zhang K, et al. Caregiving Experiences of Caregivers of Adolescents With Inflammatory Bowel Disease: A Qualitative Meta-Synthesis. Nurs Open. 2025;12(7):e70267.
33. Zhou Y, Qiao R, Ding T, Li H, Zhang P. An uncertain future: perspectives of emerging adults with inflammatory bowel disease-a qualitative semistructured interview study in eastern China. BMJ Open. 2024;14(11):e089213.
34. Barned C, Fabricius A, Stintzi A, Mack DR, O'Doherty KC. The Rest of my Childhood was Lost: Canadian Children and Adolescents' Experiences Navigating Inflammatory Bowel Disease. Qual Health Res. 2022;32(1):95–107.
35. Muse K, Johnson E, David AL. A Feeling of Otherness: A Qualitative Research Synthesis Exploring the Lived Experiences of Stigma in Individuals with Inflammatory Bowel Disease. Int J Environ Res Public Health. 2021;18(15).
36. Nomura S, Hirano Y, Takeuchi I, Shimizu H, Arai K, Anxiety. Depression, and Quality of Life in Parents of Adolescents with Inflammatory Bowel Disease: A Longitudinal Study. Pediatr Gastroenterol Hepatol Nutr. 2023;26(5):239–48.
37. Yu Q, Zhu C, Feng S, Xu L, Hu S, Chen H, et al. Economic Burden and Health Care Access for Patients With Inflammatory Bowel Diseases in China: Web-Based Survey Study. J Med Internet Res. 2021;23(1):e20629.
38. Zeky N, Hellmann J, Whaley G. Pediatric to Adult Transition of Care in Inflammatory Bowel Disease: Keeping Patients on Track. Curr Treat Options Pediatr. 2025;11(1):36.
39. Benchimol EI, Afif W, Plamondon S, Newhook D, Nicholls SG, Lévesque D. Medical Summary Template for the Transfer of Patients with Inflammatory Bowel Disease from Pediatric to Adult Care. J Can Assoc Gastroenterol. 2022;5(1):3–11.

40. Bollegala N, Barwick M, Fu N, Griffiths AM, Keefer L, Kohut SA, et al. Multimodal intervention to improve the transition of patients with inflammatory bowel disease from pediatric to adult care: protocol for a randomized controlled trial. BMC Gastroenterol. 2022;22(1):251.

Figures

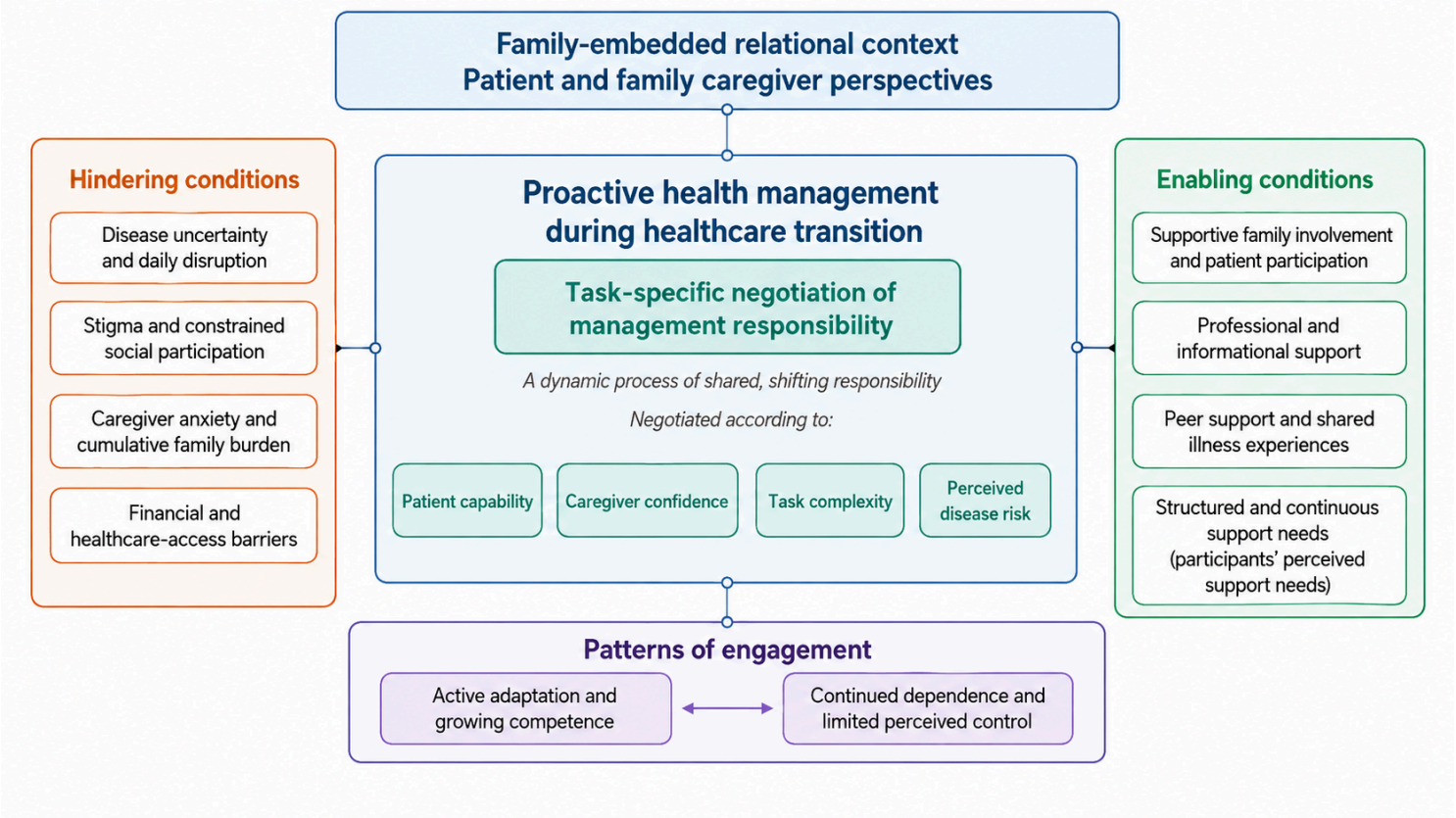


Figure 1

Conceptual model of proactive health management during healthcare transition among Chinese adolescents and young adults with inflammatory bowel disease. The model illustrates the family-embedded relational context, hindering and enabling conditions, task-specific negotiation of management responsibility, and contrasting patterns of engagement, integrating perspectives from patients and primary family caregivers.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table.docx
- AdditionalFile2InterviewGuides.docx