

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

Title (Provisional)

An uncertain future: Perspectives of emerging adults with inflammatory bowel disease. A qualitative semi-structured interview study in eastern China

Authors

zhou, yu; Qiao, Ranran; Ding, Tengteng; Li, Hui; Zhang, Ping

VERSION 1 - REVIEW

Reviewer	1
Name	Liu, Zhenrui
Affiliation	Central South University Xiangya School of Medicine
Date	12-Jul-2024
COI	The reviewer declare no competing interest

The overall quality of manuscript is good, and the topic is meaningful and interesting! However, there are still few problems to be mentioned:

1. The language should be improved if you can.
2. The sample size of this research is quite few, maybe you can consider enrolling more patients next time.
3. The results may be affected by the bias caused by heterogeneity due to the patients were only from one hospital, but I consider it to be acceptable.
4. The analysis was conducted manually, the results could be affected by objective opinion.
5. The supplementary files could addressed as "Supplementary Table/File A/B" in your manuscript, not as "Supplementary A/B"
6. In line 168-169, the table caption should demonstrated as simple sentence.
7. In line 256, I think it should be "traditional Chinese medicine" instead of "Chinese medicine".
8. In line 299, it should written as "10 times a day" not "10 times daily".
9. In line 306, "traditional Chinese medicine" should be abbreviation.

Despite the glitches, this research is very inspiring for clinicians and encouraging for patients and their family! Good job!

Reviewer	2
Name	Jones, Katherine
Affiliation	University of Warwick
Date	24-Jul-2024
COI	None

The following manuscript presents the views of emerging adults (ages 18-29) examining the uncertainties and impact IBD can have on aspects of life. This is a really interesting, well written and presented manuscript with some really insightful findings on areas that need to be addressed to support young adults with managing their condition.

This fits within the scope and aims of the journal and I believe it will add value to the body of literature surrounding the impact of IBD in young adults. I do have some minor comments below with some suggestions for improvement:

- “However, no qualitative study on how emerging adults with inflammatory bowel disease cope with these uncertainties exists”. There are papers out there looking at the impact IBD has on young adults, to name a few that might be worth looking at:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10672720/>

https://journals.lww.com/ajg/fulltext/2014/10002/ibd_in_young_adult_patients__impact_on_early.2210.aspx

<https://www.sciencedirect.com/science/article/pii/S0020748918301822>

- Eligibility criteria- Why 6 months diagnosis? Assuming this is due to different views from those that would be more recently diagnosed?
- Page 6, line 148 “...prioritised the development of strong relationships with the participants.” How did they do this?
- Page 7, Table 1- Disease activity, how was this measured? Perhaps worth adding into the table and asterisk. Then a footnote with the scales/inflammatory markers used to assess this, also providing the ranges for activity.
- Page 7, Table 1- Could the authors explain what semi-enteral nutrition is? From my understanding enteral nutrition is tube feeding (orogastric, nasogastric or gastrostomy) but unsure what semi-enteral nutrition is. Also there was a high proportion of participants being administered semi-enteral nutrition, is this normal? Or is this enteral nutritional formula (aka ensure, boost, orgain)
- Page 11, line 232, in the table this participant is down as female but this line says ‘his’

- Page 11, line 237-239 use of the word extent twice in the same sentence could change first extent to some degree
- Page 16, line 387- not a survey. But the inclusion of half of the participants who were in receipt of tube feeding may be a limitation as these participants will have very different views on the impact the disease has on their future- also appointments, requirement for medical treatments as opposed to someone with IBD who was not taking any medication

Reviewer	3
Name	Weidner, Jens
Affiliation	Technische Universität Dresden, Medizinische Fakultät "Carl Gustav Carus" Health Sciences/ Public Health
Date	26-Aug-2024
COI	no conflicts of interest exist

An uncertain future: Perspectives of emerging adults with inflammatory bowel disease. A qualitative semistructured interview study

Summary:

The present qualitative study investigates the experiences and uncertainties of young adults (EAI) with inflammatory bowel disease (IBD) in China. The focus is on the impacts of the illness on education, career, and interpersonal relationships, as well as the psychological challenges associated with the disease. The role of traditional Chinese medicine (TCM) in disease management is also discussed. The methodology includes semi-structured interviews, and the analysis is based on the Colaizzi approach.

Strengths:

1. Relevance of the Topic: The study highlights an important, often neglected issue in healthcare, namely the specific challenges faced by young adults with chronic illnesses.
2. Methodology: The use of a qualitative approach allows for deeper insights into the personal experiences of participants and fosters a better understanding of the uncertainties associated with IBD.
3. Practical Implications: The study provides valuable insights for healthcare providers to improve support for young patients and to integrate TCM into treatment.

Suggestions for Improvement:

1. Clarity of Results: The results could be structured more clearly to highlight the main themes and subthemes more effectively. A visual representation of the themes could enhance understanding.

2. Depth of Discussion: The discussion could be expanded by including current literature on coping with chronic illnesses and the psychological impacts on young adults. Specifically, the psychological burdens and their management should be addressed in greater depth.

3. Patient Perspective: It would be beneficial to emphasize the patient perspective more strongly. How have participants specifically benefited from the proposed TCM methods? A more detailed presentation of their experiences could further underline the practical benefits of TCM.

Conclusion:

Overall, the study makes an important contribution to understanding the uncertainties faced by young adults with IBD. With some minor revisions, particularly regarding the structure of the results and the depth of the discussion, the study can be further improved. I recommend addressing the mentioned points in a revised version to enhance the quality and impact of the work.

VERSION 1 - AUTHOR RESPONSE

Reviewer 1:

Comment 1:

- The overall quality of manuscript is good, and the topic is meaningful and interesting! However, there are still few problems to be mentioned:

The language should be improved if you can.

Response: Thank you very much for your positive feedback on our manuscript as well as your valuable suggestions. We have thoroughly reviewed the language and grammar throughout the article to enhance its fluency.

Comment 2:

- The sample size of this research is quite few, maybe you can consider enrolling more patients next time.

Response: Thank you for your thorough review of our study and insightful suggestions. We appreciate your concerns regarding the sample size in qualitative research.

We acknowledge that qualitative studies typically involve fewer participants compared to quantitative research, which is inherent to their focus on gaining an in-depth understanding of individual experiences and perspectives rather than achieving statistical generalizability.

Our study aimed to examine the uncertainties faced by EAI who have been diagnosed for at least 6 months in eastern China, the potential impact of these uncertainties on their future, and the strategies that these individuals use to cope with those uncertainties. To achieve this, we utilized a purposeful sampling technique to provide a rich and nuanced understanding of the topic. We adhered to the concept of thematic saturation, indicating that additional interviews did not yield new or significantly different themes. Ultimately, we included 14 participants. A systematic review suggests that studies using empirical data often reach saturation within a narrow range of interviews (9–17), particularly those

with relatively homogenous study populations and narrowly defined objectives (<https://www.sciencedirect.com/science/article/pii/S0277953621008558?via%3Dihub>). Therefore, we believe our sample size was adequate to support the objectives and findings of our study. Despite the sufficient sample size, we have acknowledged additional limitations regarding the sample in the manuscript. Thank you again for your valuable comments.

Manuscript pages N: 18

The revised parts are highlighted in blue:

Limitations

This study had certain limitations. First, selection bias may have occurred, as individuals with remission or mild-to-moderate active disease and those interested in the research were more willing to complete the interviews, which may have affected the validity of the results. Second, the conservative nature of Chinese culture may have affected the young participants, potentially leading them not to discuss the impact of the disease on their intimate relationships and sexual abilities. Finally, although a sufficient number of subjects were recruited to achieve data adequacy, this was an exploratory study conducted at a tertiary hospital in eastern China, making the generalisability of the results to other settings limited. These limitations must be accounted for when considering the broad relevance of these findings.

Comment 3:

- The results may be affected by the bias caused by heterogeneity due to the patients were only from one hospital, but I consider it to be acceptable.

Response: Thank you very much for your valuable feedback. We acknowledge that the results may be influenced by bias due to the heterogeneity of the sample, as the patients were drawn from only one hospital. We have addressed this limitation in the limitations section of our manuscript, where we discuss its potential impact on the generalizability of our findings. We appreciate your understanding of this aspect.

Manuscript pages N: 18

The related parts are highlighted in blue:

Limitations

This study had certain limitations. First, selection bias may have occurred, as individuals with remission or mild-to-moderate active disease and those interested in the research were more willing to complete the interviews, which may have affected the validity of the results. Second, the conservative nature of Chinese culture may have affected the young participants, potentially leading them not to discuss the impact of the disease on their intimate relationships and sexual abilities. Finally, although a sufficient number of subjects were recruited to achieve data adequacy, this was an exploratory study conducted at a tertiary hospital in eastern China, making the generalisability of the results to other settings limited. These limitations must be accounted for when considering the broad relevance of these findings.

Comment 4:

- The analysis was conducted manually, the results could be affected by objective opinion.

Response: Thank you for your professional guidance. We acknowledge that manual coding can carry the risk of bias. To mitigate this risk, our team employed a systematic approach during the analysis process. Specifically, the coding was conducted collaboratively, with continuous discussions among team members to refine codes and ensure consistency. Additionally, the main author developed an operational coding tree based on a preliminary review of the transcripts, which served as a guiding framework throughout the coding process. This collaborative and iterative approach aimed to enhance the reliability and validity of our findings. We appreciate your understanding of our efforts in this analysis.

Manuscript pages N: 5

The related parts are highlighted in blue:

Data analysis

The interview recordings were transcribed using WPS Office within 24 hours of the interview, with the interviewees named P1 to P14. The transcripts were manually checked for accuracy and revised accordingly, and supplemented with non-verbal information from the interview notes. The interviews were summarised in WPS Office to facilitate data storage and coding. The research team used the Colaizzi seven-step analysis to analyse the data,²¹ which involved the following processes: 1) comprehensively reading the interview materials to familiarise themselves with all the content provided by the participants; 2) identifying and extracting key statements related to the research content; 3) coding the ideas repeatedly mentioned by the respondents; 4) grouping relevant codes to form topic groups; 5) describing the original respondents' statements; 6) identifying similar views, summarising them, and elevating them into new topics; and 7) verifying the results to ensure accuracy. In this study, data collection and analysis were conducted simultaneously to explore emerging themes from the remaining interviews. No code was predetermined or preset. The team used manual coding to encode the transcription data, marking key units, sentences, and paragraphs. They continuously discussed and improved the prethreshold code. The main author developed an operational coding tree based on a preliminary review of the transcripts and applied it to the remaining transcripts. Two researchers independently completed the coding of the data and held regular coding review meetings. Any discrepancies were discussed within the research group, and a consensus was reached. The researchers examined the code in all interviews, adjusting and organising it to capture emerging patterns of meaning through an iterative process. During this process, the research team organised and refined recurring themes related to potential connections between the research questions and subjects, forming sub-themes and themes. The research team consistently reviewed the interview transcripts and codes to ensure that the themes accurately reflected the participants' descriptions of their experiences. All co-authors examined and provided feedback on the analysis and interpretation of the results. The study results were also shared with the participants for verification.

Comment 5:

- *The supplementary files could addressed as "Supplementary Table/File A/B" in your manuscript, not as "Supplementary A/B"*

Response: Thank you for your kind reminder. We appreciate your attention to detail. We have revised the manuscript to refer to the supplementary files as "Supplementary File A/B" instead of "Supplementary A/B". Your feedback will help improve the clarity and professionalism of our manuscript.

Manuscript pages N: 5, 6, 20

The revised parts are highlighted in blue:

Procedures

The interviews were conducted in a non-clinical setting within the hospital, with no one present except for the interviewer and the interviewee, in order to prevent disruptions and maintain confidentiality. The interviews were conducted by two nursing graduate students from the research team. Prior to the interviews, the interviewers familiarised themselves with the participants' medical conditions, reiterated the purpose and significance of the study, and, with the participants' consent, recorded the interviews in full. The participants were assured of complete anonymity and that strict confidentiality principles would be adhered to. An interview guide comprising open-ended questions was followed to encourage participants to discuss the impact of the disease on themselves and freely reflect on their experiences of self-management to cope with these effects. The questions covered aspects such as participants' disease knowledge, attitudes, and coping strategies, providing insights into their future uncertainties and coping needs ([Supplementary File A](#)). To ensure the efficacy of the interview guide, it was pilot tested on two individuals who represented the target group (although they were not part of the final sample), resulting in a few minor revisions. Following each interview, interview notes were promptly recorded to capture the details of the interactions, interview environments, and participants' body language. Additionally, telephonic follow-ups were conducted to address unclear audio recordings or uncertainties in the transcribed data. A total of 14 interviews were conducted; the mean duration of the interviews was 58 minutes, ranging from 46–94 minutes.

Rigour

The COREQ checklist was followed throughout the study ([Supplementary File B](#)).²² Three strategies were implemented to ensure the rigor of the study. First, researchers prioritized establishing strong relationships with the participants before conducting the interviews. For example, they added

participants on WeChat, a widely used social media platform in China, and responded to their disease-related questions through the app. This approach to establishing rapport increased the likelihood of obtaining an accurate description of their experiences. Second, prior to the study, the two interviewers systematically studied the relevant theories of qualitative research to ensure mastery of qualitative interview skills. Finally, the analysis findings were shared with the participants to gather feedback on the consistency of their actual experiences.

Supplementary materials

The following supporting information is available upon request: [Supplementary File A](#): An Uncertain Future: Perspectives of Emerging Adults with Inflammatory Bowel Disease – interview script; [Supplementary File B](#): COREQ Checklist.

Comment 6:

- In line 168-169, the table caption should be demonstrated as simple sentence.

Response: Thank you for your valuable feedback. To present the study results more clearly, we have revised this section by replacing the original Table 2 with a Figure, and have included a title.

Manuscript pages N: 7, 27

The revised parts are highlighted in blue:

RESULTS

Fourteen patients with IBD (10 men and 4 women) were interviewed. The disease course varied between six months and seven years. All participants received medical treatments such as biological treatments. The comprehensive demographic and clinical data are shown in Table 1. [The analysis resulted in the identification of four themes and 12 sub-themes, which were distilled in Figure 1.](#)

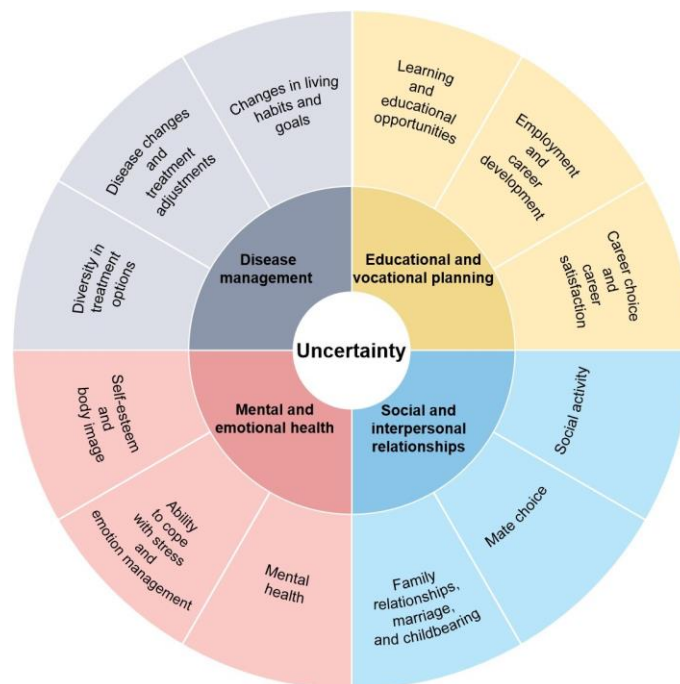


Figure 1 Themes and sub-themes of the study.

Notes: The center circle illustrates the participants' overall experiences. The middle circle displays the four themes, while the outer layer depicts the twelve sub-themes. The themes and their corresponding sub-themes are indicated by the same color family.

Comment 7:

- In line 256, I think it should be "traditional Chinese medicine" instead of "Chinese medicine".

Response: Thank you for your insightful suggestion. We have corrected the manuscript in original line 256 to use "traditional Chinese medicine" instead of "Chinese medicine" for improved accuracy.

Manuscript pages N: 12

The revised parts are highlighted in blue:

During the unique stage of emerging adulthood, individuals become increasingly aware of their body image and its significance. This awareness often leads to a strong desire to appear 'normal' and hide any signs of illness or medical treatment. For instance, one participant expressed concern, stating, '*I do not want others to know that I am sick, so I have applied for a separate dormitory with the school to perform my traditional Chinese medicine (TCM) enema every night*' (P10). Similarly, another participant found creative ways of preserving their appearance while undergoing medical treatment. The participant stated, '*The nasal feeding pump delivers the enteral nutrition solution. I wear a mask to conceal the nasal feeding tube and carry a backpack to hold the nutrition pump discreetly. It is a practical solution for going about my daily activities*' (the participant expressed happiness while describing this approach) (P5).

Comment 8:

- In line 299, it should be written as "10 times a day" not "10 times daily".

Response: Thank you for your helpful suggestion. We have made the modification in original line 299 to change "10 times daily" to "10 times a day" as recommended.

Manuscript page N: 13

The revised parts are highlighted in blue:

Relapse of the disease leads to changes in the condition and treatment adjustments, and patients may worry about medical costs and financial burdens. One participant stated, '*I had used infliximab for the eighth time, but unexpectedly, I experienced an allergic reaction. The doctor informed me that I had to switch medications, which worried me greatly. On the one hand, other people have been using infliximab without any allergic reactions and have been effectively managing their symptoms, except me. On the other hand, the replacement medication, ustekinumab, is not covered by medical insurance for patients with ulcerative colitis. I have to bear the entire cost myself, which adds to my financial burden*' (P3). Long-term disease progression may cause patients to become anxious about the worsening of their condition and uncertainty about what the future holds. One participant expressed confusion, stating, '*My condition is unpredictable. Suddenly, the number of stools increased to more than 10 times a day, despite following a diet and lifestyle that should not exacerbate my symptoms. The doctor advised me to switch biologics, and it was the third time I had changed medications that year. At that moment, I did not know if I would be able to regain control over my illness, and it felt like my determination was being shattered*' (P14). As the duration of coexistence with the disease gradually increased, participants fervently pursued alternative therapeutic modalities, particularly against the background of the nationwide advocacy of TCM. As one participant conveyed, '*I became aware of Director Shen's profound expertise in the field of TCM, which prompted my decision to seek treatment here... After receiving navel moxibustion treatment, I always feel the warm energy flowing from my belly throughout my body, making me feel energized and alleviating all my fatigue. This has greatly enhanced my confidence and made me more positive in facing my illness*' (P8).

Comment 9:

- In line 306, "traditional Chinese medicine" should be an abbreviation.

Response: Thank you for your suggestion. We have updated the original line 306, using the abbreviation for "traditional Chinese medicine".

Manuscript pages N: 13

The revised parts are highlighted in blue:

Relapse of the disease leads to changes in the condition and treatment adjustments, and patients may worry about medical costs and financial burdens. One participant stated, '*I had used infliximab for the eighth time, but unexpectedly, I experienced an allergic reaction. The doctor informed me that I*

had to switch medications, which worried me greatly. On the one hand, other people have been using infliximab without any allergic reactions and have been effectively managing their symptoms, except me. On the other hand, the replacement medication, ustekinumab, is not covered by medical insurance for patients with ulcerative colitis. I have to bear the entire cost myself, which adds to my financial burden' (P3). Long-term disease progression may cause patients to become anxious about the worsening of their condition and uncertainty about what the future holds. One participant expressed confusion, stating, 'My condition is unpredictable. Suddenly, the number of stools increased to more than 10 times a day, despite following a diet and lifestyle that should not exacerbate my symptoms. The doctor advised me to switch biologics, and it was the third time I had changed medications that year. At that moment, I did not know if I would be able to regain control over my illness, and it felt like my determination was being shattered' (P14). As the duration of coexistence with the disease gradually increased, participants fervently pursued alternative therapeutic modalities, particularly against the background of the nationwide advocacy of TCM. As one participant conveyed, 'I became aware of Director Shen's profound expertise in the field of TCM, which prompted my decision to seek treatment here... After receiving navel moxibustion treatment, I always feel the warm energy flowing from my belly throughout my body, making me feel energized and alleviating all my fatigue. This has greatly enhanced my confidence and made me more positive in facing my illness' (P8).

Reviewer 2:

Comment 1:

- "However, no qualitative study on how emerging adults with inflammatory bowel disease cope with these uncertainties exists". There are papers out there looking at the impact IBD has on young adults, to name a few that might be worth looking at:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10672720/>

https://journals.lww.com/ajg/fulltext/2014/10002/ibd_in_young_adult_patients__impact_on_early.2210.aspx

<https://www.sciencedirect.com/science/article/pii/S0020748918301822>

Response: Thank you very much for your insightful feedback. I have carefully reviewed the articles you recommended and made corresponding modifications to that section for greater accuracy. Additionally, I have cited two of the articles in the manuscript. Thank you again for your suggestions.

Manuscript page N: 1 to 2, 3 to 4, 22

The revised parts are highlighted in blue:

ABSTRACT

Objective: For emerging adults with inflammatory bowel disease, future uncertainty is a critical issue during this pivotal stage of life, study, and career development, as they encounter many unknown challenges and opportunities. However, to our knowledge, only a few qualitative studies on how emerging adults with inflammatory bowel disease cope with these uncertainties exist. This study aimed to investigate uncertainties associated with the future of emerging adults with inflammatory bowel disease and explore coping strategies.

INTRODUCTION

Future uncertainty is a major concern for EA with IBD (EAI) as they encounter various unfamiliar challenges and opportunities. These challenges include a decline in learning abilities, stigma,^{10,11} and limitations in occupational opportunities.^{12,13} Previous research indicated that implementing EA management yields specific outcomes in EAI.^{14,15} However, there are limited qualitative studies that use face-to-face interviews to delve into the experiences and responses of EAI to this uncertainty.^{16,17}

16 Touma N, Zanni L, Blanc P, et al. Digesting Crohn's Disease: The journey of young adults since diagnosis. *J Clin Med*. 2023 Nov 16;12(22):7128. doi: 10.3390/jcm12227128.

17 Fourie S, Jackson D, Aveyard H. Living with inflammatory bowel disease: A review of qualitative research studies. *Int J Nurs Stud*. 2018 Nov;87:149-156. doi: 10.1016/j.ijnurstu.2018.07.017. Epub 2018 Jul 31.

Comment 2:

- Eligibility criteria- Why 6 months diagnosis? Assuming this is due to different views from those that would be more recently diagnosed?

Response: Thank you for your valuable comments and your in-depth analysis of our study. First, IBD lacks a definitive gold standard for diagnosis, requiring a comprehensive analysis that combines clinical symptoms, laboratory tests, endoscopy, imaging studies, and histopathological examinations, along with close follow-up. The choice of a 6-month timeframe ensures that patients have been accurately diagnosed and that their condition is relatively stable following treatment. Second, the essence of qualitative research focuses on gaining an in-depth understanding of individual experiences and perspectives, which requires each participant to provide sufficient information. As the duration of illness increases, particularly after the 6-month mark, many participants gradually come to accept their diagnosis and begin to reflect on their condition and consider how to manage their illness independently. Therefore, we chose to include emerging adults with a disease duration of more than 6 months to better explore the uncertainties associated with IBD. We have made corresponding additions in the main text.

Thank you again for your attention and suggestions regarding our work.

Manuscript page N: 4

The revised parts are highlighted in blue:

INTRODUCTION

As the duration of the disease increased, especially 6 months post-diagnosis, most patients gradually accepted the reality of their illness and began to reflect on and manage their disease independently.^{18,19} Therefore, this study aims to examine the uncertainties faced by EAI who have been diagnosed for at least 6 months, in eastern China, the potential impact of these uncertainties on their future, and the strategies that these individuals use to cope with those uncertainties.

18 Chen L, Wang D, Zhou Y. The illness experiences of Chinese adolescent patients living with Crohn disease: A descriptive qualitative study. *Gastroenterol Nurs*. 2023 Mar 1;46:95–106. doi: 10.1097/SGA.0000000000000723.

19 Chen L, Zhou Y. The symptom experience of newly diagnosed Chinese patients with Crohn's disease: A longitudinal qualitative study. *J Adv Nurs*. 2023 Oct;79(10):3824-3836. doi: 10.1111/jan.15721. Epub 2023 May 26.

Comment 3:

- Page 6, line 148 "...prioritised the development of strong relationships with the participants." How did they do this?

Response: Thank you for your friendly guidance. We have added specific methods used to prioritize the development of strong relationships with the participants into the manuscript.

Manuscript page N: 6 to 7

The revised parts are highlighted in blue:

Rigour

The COREQ checklist was followed throughout the study (Supplementary File B).²² Three strategies were implemented to ensure the rigor of the study. First, researchers prioritized establishing strong relationships with the participants before conducting the interviews. For example, they added participants on WeChat, a widely used social media platform in China, and responded to their disease-related questions through the app. This approach to establishing rapport increased the likelihood of obtaining an accurate description of their experiences. Second, prior to the study, the two interviewers systematically studied the relevant theories of qualitative research to ensure mastery of qualitative interview skills. Finally, the analysis findings were shared with the participants to gather feedback on the consistency of their actual experiences.

Comment 4:

- Page 7, Table 1- Disease activity, how was this measured? Perhaps worth adding into the table and asterisk. Then a footnote with the scales/inflammatory markers used to assess this, also providing the ranges for activity.

Response: Thank you for your valuable guidance. We have added an asterisk next to the "Disease activity" in Table 1 and have included a footnote that explains the specific scales and score ranges used to assess disease activity. We appreciate your insightful comments, which have greatly contributed to strengthening the presentation of our research.

Manuscript page N: 8

The revised parts are highlighted in blue:

Projects	Disease type	
	CD	UC
Age (years), Mean ± SD	23.83 ± 3.13	22.75 ± 3.54
Gender		
Male	4	6
Female	2	2
Expense category		
Medical insurance	4	8
Self-payment	2	0
Occupation		

Student	2	3
Waiting for employment	1	0
Company staff	2	3
Freelancer	1	0
Resigned due to illness	0	2
Education level		
Senior high school	0	1
Junior college	2	3
Undergraduate course	3	3
Graduate student	1	1
Marital Status		
Married	1	2
Unmarried	5	6
Course of disease (Months), Mean \pm SD	34.00 \pm 29.50	27.13 \pm 17.82
Disease activity*		
Remission	1	6
Mild activity	3	1
Moderate activity	2	1
Current treatment		
Aminosalicylates	3	3
Biologic therapies	5	5
Nutrition therapies	3	4
Traditional Chinese medicine therapies	3	4

Abbreviations: CD, Crohn's disease; UC, ulcerative colitis; SD, standard deviation.

* Measured by the modified Mayo score for UC: a score of ≤ 2 points with no individual item score > 1 indicates remission; scores of 3-5 indicate mild activity, 6-10 indicate moderate activity, and 11-12 indicate severe activity. For CD, the Crohn's Disease Activity Index: a total score < 150 indicates remission, while ≥ 150 indicates active disease, with 150-220 indicating mild activity, 221-450 indicating moderate activity, and > 450 indicating severe activity.

Comment 5:

- Page 7, Table 1- Could the authors explain what semi-enteral nutrition is? From my understanding enteral nutrition is tube feeding (orogastric, nasogastric or gastrostomy) but unsure what semi-enteral nutrition is. Also there was a high proportion of participants being administered semi-enteral nutrition, is this normal? Or is this enteral nutritional formula (aka ensure, boost, orgain)

Response: Thank you for your friendly guidance. Upon reviewing the literature, we would like to clarify that enteral nutrition refers to a specialized diet that can include liquid nutritional formulas delivered orally or through feeding tubes. Partial enteral nutrition (PEN) is a specific category of enteral nutrition, defined as enteral nutrition accounting for 35% to 50% of an individual's daily food intake, which can include oral nutritional supplements. PEN is a form of nutrition therapy for patients with IBD (<https://rs.yiigle.com/cmaid/1375333>). Some studies refer to PEN as "semi-enteral nutrition" (for example: <https://onlinelibrary.wiley.com/doi/10.1111/jan.15721>).

The "Chinese Consensus on Nutrition Therapy for Inflammatory Bowel Disease" indicates that enteral nutrition therapy should be prioritized and implemented whenever there are indications and no contraindications. The role of enteral nutrition in ulcerative colitis primarily revolves around correcting malnutrition and minimizing nutritional risks. In Crohn's disease, enteral nutrition not only addresses malnutrition and reduces nutritional risks but also plays a crucial role in inducing and maintaining remission (<https://zhxhbyyzzz.cma-cmc.com.cn/CN/10.3877/cma.j.issn.2095-2015.2021.01.002>). Therefore, in our study, seven out of fourteen participants received these nutritional therapies, which we consider to be a reasonable proportion.

To ensure clarity, we have summarized this information as "Nutrition therapies" in Table 1.

Thank you again for your attention to detail.

Manuscript page N: 8

The revised parts are highlighted in blue:

Table 1 Participants' demographics and clinical characteristics (N = 14)		
Projects	Disease type	
	CD	UC
Age (years), Mean \pm SD	23.83 \pm 3.13	22.75 \pm 3.54
Gender		

Male	4	6
Female	2	2
Expense category		
Medical insurance	4	8
Self-payment	2	0
Occupation		
Student	2	3
Waiting for employment	1	0
Company staff	2	3
Freelancer	1	0
Resigned due to illness	0	2
Education level		
Senior high school	0	1
Junior college	2	3
Undergraduate course	3	3
Graduate student	1	1
Marital Status		
Married	1	2
Unmarried	5	6
Course of disease (Months), Mean \pm SD	34.00 \pm 29.50	27.13 \pm 17.82
Disease activity*		
Remission	1	6
Mild activity	3	1
Moderate activity	2	1
Current treatment		
Aminosalicylates	3	3
Biologic therapies	5	5
Nutrition therapies	3	4
Traditional Chinese medicine therapies	3	4

Abbreviations: CD, Crohn's disease; UC, ulcerative colitis; SD, standard deviation.

* Measured by the modified Mayo score for UC: a score of ≤ 2 points with no individual item score > 1 indicates remission; scores of 3-5 indicate mild activity, 6-10 indicate moderate activity, and 11-12 indicate severe activity. For CD, the Crohn's Disease Activity Index: a total score < 150 indicates remission, while ≥ 150 indicates active disease, with 150-220 indicating mild activity, 221-450 indicating moderate activity, and > 450 indicating severe activity.

Comment 6:

- Page 11, line 232, in the table this participant is down as female but this line says 'his'

Response: Thank you for your kind reminder, and we appreciate your attention to detail. We have revised the manuscript to ensure consistency.

Manuscript pages N: 10

The revised parts are highlighted in blue:

Support from family members is crucial in increasing the self-confidence of individuals with IBD. One participant emphasised the significance of this support, stating, *'My parents and my partner understood me and provided unwavering support, which greatly encouraged me'* (P4). Regarding participants who were already parents or considering parenthood, concerns arose regarding the potential effect of the disease on pregnancy and fertility and the possibility of transmitting the disease to their children. A participant expressed **her** anxieties, explaining, *'I am concerned about the potential consequences of using biological agents before and during pregnancy. Additionally, I am worried about the possibility of passing the disease on to my children'* (P4).

Comment 7:

- Page 11, line 237-239 use of the word extent twice in the same sentence could change first extent to some degree

Response: Thank you for your considerate reminder, and we sincerely appreciate your keen eye for detail. We have diligently revised the manuscript.

Manuscript pages N: 9

The revised parts are highlighted in blue:

Theme 3: Uncertainty in mental and emotional health

The symptoms of the disease impacted the participants' psychological state and, to some degree, restricted their daily activities. This affected their mental and emotional health to an extent that could not be ignored.

Comment 8:

- Page 16, line 387- not a survey. But the inclusion of half of the participants who were in receipt of tube feeding may be a limitation as these participants will have very different views on the impact the disease has on their future- also appointments, requirement for medical treatments as opposed to someone with IBD who was not taking any medication

Response: Thank you for your valuable guidance. We have corrected the text in the original line 387 to use "the interviews" instead of "the survey" for improved accuracy.

Regarding the inclusion of participants receiving enteral nutrition, we would like to clarify that enteral nutrition refers to a specialized diet that can include liquid nutritional formulas delivered orally or through feeding tubes. Upon reviewing our original data, we found that only two participants used a nasal feeding tube. We appreciate your concern about the perspectives of participants using nasal feeding tubes. And we have included relevant citations regarding their experiences in the Results section, which provide insight into their unique viewpoints.

Thank you again for your valuable guidance.

Manuscript pages N: 18

The revised parts are highlighted in blue:

Limitations

This study had certain limitations. First, selection bias may have occurred, as individuals with remission or mild-to-moderate active disease and those interested in the research were more willing to complete the interviews, which may have affected the validity of the results. Second, the conservative nature of Chinese culture may have affected the young participants, potentially leading them not to discuss the impact of the disease on their intimate relationships and sexual abilities. Finally, although a sufficient number of subjects were recruited to achieve data adequacy, this was an exploratory study conducted at a tertiary hospital in eastern China, making the generalisability of the results to other settings limited. These limitations must be accounted for when considering the broad relevance of these findings.

Manuscript pages N: 12

The related parts are highlighted in blue:

RESULTS

Theme 3: Uncertainty in mental and emotional health

During the unique stage of emerging adulthood, individuals become increasingly aware of their body image and its significance. This awareness often leads to a strong desire to appear 'normal' and hide any signs of illness or medical treatment. For instance, one participant expressed concern, stating, 'I do not want others to know that I am sick, so I have applied for a separate dormitory with the school to perform my traditional Chinese medicine (TCM) enema every night' (P10). Similarly, another participant found creative ways of preserving their appearance while undergoing medical treatment. The participant stated, 'The nasal feeding pump delivers the enteral nutrition solution. I wear a mask to conceal the nasal feeding tube and carry a backpack to hold the nutrition pump discreetly. It is a practical solution for going about my daily activities' (the participant expressed happiness while describing this approach) (P5).

Reviewer 3:

Comments to the Author:

Strengths:

1. *Relevance of the Topic:* The study highlights an important, often neglected issue in healthcare, namely the specific challenges faced by young adults with chronic illnesses.
2. *Methodology:* The use of a qualitative approach allows for deeper insights into the personal experiences of participants and fosters a better understanding of the uncertainties associated with IBD.
3. *Practical Implications:* The study provides valuable insights for healthcare providers to improve support for young patients and to integrate TCM into treatment.

Response: Thank you very much for recognizing the significance of our study. We are committed to further improving our work and hope to make a meaningful contribution to the understanding and support of emerging adults with IBD.

Comment 1:

- *Clarity of Results:* The results could be structured more clearly to highlight the main themes and sub-themes more effectively. A visual representation of the themes could enhance understanding.

Response: Thank you for your insightful comments. We have carefully revised the relevant section of our manuscript. Specifically, we have replaced the original Table 2 with a Figure that visually represents the main themes and sub-themes of our results. We believe that this visual representation will enhance readers' understanding and appreciation of the key insights from our study. We sincerely appreciate your guidance, which has contributed to improving the overall clarity of our results.

Manuscript pages N: 7, 27

The revised parts are highlighted in blue:

RESULTS

Fourteen patients with IBD (10 men and 4 women) were interviewed. The disease course varied between six months and seven years. All participants received medical treatments such as biological treatments. The comprehensive demographic and clinical data are shown in Table 1. The analysis resulted in the identification of four themes and 12 sub-themes, which were distilled in Figure 1.

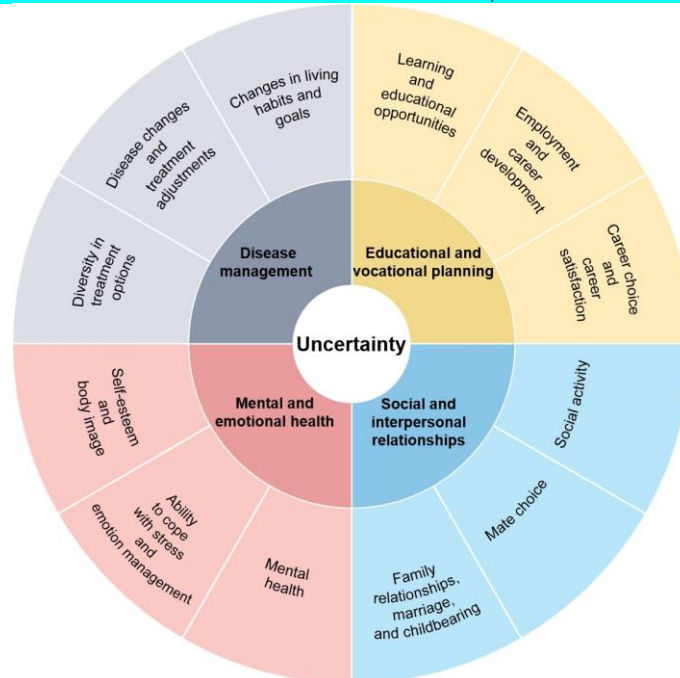


Figure 1 Themes and sub-themes of the study.

Notes: The center circle illustrates the participants' overall experiences. The middle circle displays the four themes, while the outer layer depicts the twelve sub-themes. The themes and their corresponding sub-themes are indicated by the same color family.

Comment 2:

- *Depth of Discussion: The discussion could be expanded by including current literature on coping with chronic illnesses and the psychological impacts on young adults. Specifically, the psychological burdens and their management should be addressed in greater depth.*

Response: Thank you for your valuable feedback regarding the depth of our discussion. We have expanded our discussion to include recent literature on coping with chronic illnesses and the psychological impacts on young adults. Specifically, we have incorporated studies that address the psychological burdens faced by young adults with chronic diseases and explored strategies for their management. We believe that these additions will provide a more comprehensive understanding of the challenges and coping mechanisms relevant to our study population. Thank you again for your insightful guidance.

Manuscript pages N: 15 to 18

The revised parts are highlighted in blue:

In our study, some participants reported experiencing mental and emotional health problems, as well as difficulties in coping. This indicates that EAI face psychological and emotional challenges, including anxiety, depression and social isolation, similar to those experienced by young individuals with chronic diseases such as diabetes, vitiligo, and kidney disease.²⁹⁻³¹ Addressing mental health issues is a critical element that influences the transition of young adults living with chronic conditions.^{29,32} During our interviews, some participants expressed a desire to gain coping experiences from peer support groups or online platforms. Thus, suggesting that effective psychosocial support can not only meet the emotional needs of patients but may also positively influence the physiological processes of the disease. Studies have shown that psychological interventions³³⁻³⁴ are significantly effective for patients with chronic diseases. Our research further emphasizes the need to integrate these methods into clinical practice. Additionally, the potential of TCM to improve emotional issues in chronic disease patients should not be overlooked. For instance, a randomized, single-blind study demonstrated that herb-partitioned moxibustion could alleviate symptoms, anxiety, and depression and improve the quality of life of patients with UC³⁵. Additionally, another randomized controlled clinical trial revealed that qigong exercise may be beneficial in reducing depression and negative thoughts while enhancing the quality of life in patients with gastrointestinal cancer³⁶. These findings suggest that TCM techniques could be a beneficial complement to the treatment of EAI. Therefore, we propose the following recommendations. First, clinical doctors should collaborate with mental health counsellors to master and apply psychological intervention techniques such as cognitive-behavioural therapy, mindfulness therapy, and music therapy to help patients manage their emotions. Second, the number of group health education meetings organized by the digestive department must be increased to promote communication among patients, strengthen peer support, and teach them skills to cope with adverse emotions. An online study demonstrated that online peer support can improve health outcomes in individuals with chronic diseases.³⁷ Third, collaboration should be done with non-profit organizations and caring individuals to raise public awareness of IBD through media and professional platforms, thereby reducing the social dilemmas faced by EAI. Finally, the application of TCM techniques in IBD patients, such as Ba Duan Jin, Tai Chi, or aromatherapy, should be explored to improve patients' emotional well-being, as these methods have been proven effective in other chronic diseases.³⁸⁻⁴⁰

For the transitional preparedness of IBD patients, previous studies have focused on adolescents.⁴¹⁻⁴² However, our study emphasizes the specific needs of patients aged 18–29, who are also transitioning into adulthood and need to take responsibility for understanding and managing their disease rather than relying on their parents. These patients need to gain essential skills for early independent disease management. In the Netherlands, transitional outpatient clinics have been effective in managing such patients, demonstrating lower rates of disease activity and relapse in the year following the transition, as well as positive experiences and satisfaction with the transfer process.⁴³ These findings provide valuable insights for healthcare providers in managing the transition of these patients. Furthermore, our research discovered that EAI face considerable challenges in disease management, primarily due to the relapsing nature of the illness and individual variability. This uncertainty affects not only patients' treatment decisions but also significantly diminishes their quality of life. Notably, post-discharge patients generally lack self-management skills and continuous medical guidance. In response to these issues, we propose the following specific and feasible measures. First, during the provision of medical services, healthcare providers should enhance patient engagement by considering personalization.^{26,44} Providers should conduct comprehensive assessments and communicate with patients to implement individualized care. When formulating treatment plans, it is essential to explain the advantages and disadvantages of each option in detail, thereby increasing

patients' sense of involvement and trust. During follow-up visits, patients should be encouraged to ask questions and provide feedback, ensuring they feel valued throughout the treatment process. Second, the services of chronic disease management platforms should be improved. This includes consistently offering one-on-one follow-up services, such as telephone consultations and online health education, to ensure that patients receive professional guidance while at home. Additionally, enhancing patients' self-management capabilities through digital health platforms,⁴⁵⁻⁴⁷ such as mobile applications, has shown positive results. Third, we have established specialized TCM clinics for disease management. TCM specialist nurses will provide comprehensive management plans tailored to patients based on TCM syndrome differentiation, including personalized dietary recommendations aimed at alleviating symptoms such as abdominal pain and diarrhoea.⁴⁸ Furthermore, we will utilize five-element music therapy for emotional support and teach patients about TCM qigong (such as Ba Duan Jin, five-animal boxing, and Tai Chi), as well as moxibustion, cupping, and aromatherapy, to improve their physical fitness and emotional well-being.^{38-40,49} Additionally, by holding TCM health lectures, we aim to improve patients' health literacy. In summary, by implementing personalized medical care, enhancing chronic disease management platform services, and integrating TCM nursing interventions, we can help EAI effectively address the uncertainties in disease management, thereby improving their self-management capabilities and quality of life.

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Comment 3:

- *Patient Perspective: It would be beneficial to emphasize the patient perspective more strongly. How have participants specifically benefited from the proposed TCM methods? A more detailed presentation of their experiences could further underline the practical benefits of TCM.*

Response: Thank you for your insightful comment regarding the importance of emphasizing the patient perspective. We have added a more detailed presentation of the participants' experiences with the proposed TCM methods. Specifically, we include direct quotes from participants to illustrate how they have benefited from these methods in managing their condition. We believe that highlighting these experiences will further underscore the practical benefits of TCM and enhance the overall understanding of its impact on patient well-being. Thank you again for your valuable feedback.

Manuscript pages N: 13 to 14

The revised parts are highlighted in blue:

Theme 4: Uncertainty in disease management

One patient expressed it as follows; *'I was diagnosed with ulcerative colitis six months ago, and while I followed the doctor's treatment and dietary recommendations during my hospital stay, I felt completely uninformed once I returned home. TCM is known for its emphasis on health preservation, and I particularly desire to receive ongoing professional guidance even after being discharged. Through understanding the principles of TCM, I realized that recovery from illness involves not only treating the disease but also addressing factors such as diet, exercise, and emotions. Currently, I have joined the continuity of care group for discharged patients in the gastroenterology department, which makes me feel more at ease because I know there are professionals who can help me manage my condition in daily life, and I can share my experiences with other patients. I no longer feel isolated and helpless'* (P9).

As one participant conveyed, *'I became aware of Director Shen's profound expertise in the field of TCM, which prompted my decision to seek treatment here... After receiving navel moxibustion treatment, I always feel the warm energy flowing from my belly throughout my body, making me feel energized and alleviating all my fatigue. This has greatly enhanced my confidence and made me more positive in facing my illness'* (P8).

Another participant said, *'I used to like playing basketball, but now I am afraid to play because I worry it might worsen my symptoms. I cannot continue to do what I like, which made me sad for a long time. Later, I realised that changes had to be made, and during my hospitalisation, the tai chi exercise organised by the gastroenterology department strongly piqued my interest. By participating in Tai Chi, I not only found a new way to exercise but also experienced relaxation in my body and peace in my mind. The practice of Tai Chi has not only helped me alleviate anxiety but also allowed me to rediscover my love for exercise and life'* (P2).

VERSION 2 - REVIEW

Reviewer	1
Name	Liu, Zhenrui
Affiliation	Central South University Xiangya School of Medicine
Date	12-Oct-2024
COI	

The revised manuscript is satisfying, good job!

Reviewer **3**
Name **Weidner, Jens**
Affiliation **Technische Universität Dresden, Medizinische Fakultät**
"Carl Gustav Carus" Health Sciences/ Public Health
Date **25-Oct-2024**
COI

Dear Authors,

Thank you for submitting your revised manuscript, which I have reviewed with great interest. I appreciate how thoroughly you have addressed the previous comments.

Overall Assessment

Your qualitative study addressing the perspectives of young adults with inflammatory bowel disease (IBD) tackles an important and understudied topic. The use of semi-structured interviews is methodologically appropriate for your research question and provides valuable insights into the subjective experiences of those affected.

Strengths

The methodological approach is clearly structured and well-documented

The study population selection and inclusion criteria are thoroughly justified

The results are presented with nuanced analysis and supported by meaningful quotes

Revisions

The implemented changes have significantly enhanced the manuscript's quality. In particular:

The methodology section has been refined

The discussion has been expanded with relevant aspects

The limitations are appropriately addressed and reflected upon

Recommendation

In its current form, the manuscript meets scientific standards and makes a valuable contribution to understanding the specific challenges faced by young adults with IBD. I recommend the paper for publication in its present form.

Best regards