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Regaining normality: A grounded theory study of the illness experiences of Chinese patients living with Crohn's disease

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ABSTRACT

Background: Crohn's disease is a chronic condition causing inflammation of the lining of the digestive system. Individuals suffering from this illness encounter various challenges and problems, but studies investigating the illness experiences of patients with Crohn's disease in East Asian countries are scarce.
Objectives: The objective of this study was to explore the illness experiences of patients with Crohn's disease in China and construct an interpretive understanding of these experiences from the perspective of the patients.
Design: A constructivist grounded theory approach was used to develop a theoretical understanding of illness experiences.
Settings: This study included participants from the following four provincial capital cities in China: Hangzhou, Nanjing, Guangzhou, and Wuhan.
Participants: Purposive sampling and theoretical sampling were used to select Chinese patients living with Crohn's disease.
Method: Between February 2015 and January 2018, audio-recorded interviews were conducted. The data analysis included initial coding, focused coding, and theoretical coding using the constant comparative method and memo writing.
Results: Thirty-one participants were included in the study. "Regaining normality" was identified as the core category. The following four categories were conceptualized: comparing, struggling, reflecting, and realizing. Comparing refers to distinguishing the similarities and differences or evaluating the superiority and inferiority of similar things. Comparisons could occur between patients with Crohn's disease and healthy individuals or between patients and people in similar or more unfortunate situations. Struggling reflects the dilemmas experienced by patients with Crohn's disease in acknowledging their patient identity and informing others of this identity. Reflecting refers to the consideration of the values and life attitudes held by patients before and after the diagnosis of Crohn's disease. Realizing involves patients gaining a deeper understanding of the suffering associated with Crohn's disease after experiencing the illness.
Conclusion: This study offers an interpretive understanding of the illness experiences of patients with Crohn's disease. Regaining normality represents the basic social psychological process. Regaining normality is related to reassessing and reconstructing the self after receiving a Crohn's disease diagnosis. This paper provides new insight into patients' lives and describes the strategies patients use to cope with the challenges and problems caused by the illness. These study findings can be used to develop future complex interventions and studies.

What is already known about the topic?

- Patients with Crohn's disease face many challenges and problems after being diagnosed with the illness.
- Some qualitative research studies performed in Western countries and Korea have explored the illness experiences of patients with Crohn's disease using different qualitative methods from different perspectives.
- Understanding patients' needs, perceptions, and concerns can help nurses deliver holistic, patient-centred care.

What this paper adds

- The grounded theory approach helps narrow the gap in the understanding of the illness experiences of Chinese patients with Crohn's disease.

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- This paper explains how patients with Crohn’s disease regain normality through the following four strategies: “comparing”, “struggling”, “reflecting”, and “realizing”.
- Nurses and caregivers can assist Chinese patients with severe Crohn’s disease to cherish life and prevent suicidal thoughts by emphasizing the importance of filial piety.

1. Introduction

Inflammatory bowel disease is a chronic condition that affects over 5 million people worldwide (Groshek et al., 2017). Crohn’s disease, which is a form of inflammatory bowel disease, is a chronic granulomatous disorder that can affect any part of the gastrointestinal tract. This condition typically presents in people aged 20–30 years and is characterized by alternating periods of remission and flare-up. The common symptoms include abdominal pain, diarrhoea, weight loss, and intestinal complications, such as strictures.

Since the turn of the 21st century, Crohn’s disease has become a global disease with accelerating incidence in newly industrialized countries whose societies have become more Westernized (Ng et al., 2017). The incidence rate of Crohn’s disease in China has rapidly increased from 0.28/100,000 between 1950 and 2002 to 1.21/100,000 between 2003 and 2007 (Zheng et al., 2011, 2005).

There is no cure for Crohn’s disease, and patients should be treated over the course of their lifetime. However, conventional therapies could cause intolerable adverse effects (Panés et al., 2007), and modern biological therapies cost nearly 15,000 to 25,000 US dollars per year in most Asian countries (Wei, 2016). Nutritional therapy causes body image dissatisfaction among patients (Li et al., 2014), and surgical therapy is required for 31.7% of patients 5 years after diagnosis, but the overall risk of surgical recurrence is as high as 35.9% (Toh et al., 2018). In addition, patients experience substantial embarrassment and burden from the bowel preparation phase (Denters et al., 2013), and their psychological health and daily lives are extensively affected (Sarid et al., 2018).

Patients with Crohn’s disease are confronted with various challenges and problems. Understanding how these patients address the challenges and problems and gaining insight into their illness experiences are necessary for health professionals to appropriately care for patients. Qualitative research studies conducted in Europe and America have explored this topic from different perspectives, such as the impacts and meaning of the disease (Norton et al., 2012; Sarlo et al., 2008; Wilburn et al., 2017), the experience of youth with the disease (Lynch and Spence, 2008), the life experiences of patients (García-Sanjuán et al., 2018), factors influencing the quality of life (Pihl-Lesnovska et al., 2010), and the lived experience of patients with intestinal failure due to Crohn’s disease (Carlsson and Persson, 2015).

However, a review of the literature revealed a paucity of related studies in East Asian countries (Yoo et al., 2013), which share a similar culture (Hofstede and Bond, 1988). Using a grounded theory approach, Yoo et al. (2013) explored the life experience of Korean patients suffering from Crohn’s disease. The core category revealed was “tuning of two conflicting lives”. However, this study was published more than 5 years ago, had a relatively small sample size (12 participants) and the participants were limited to the young and middle-aged patients (17–47 years old). China is an East Asian country with the world’s largest population (1.4 billion), and 92% of the population are Han Chinese (Lio et al., 2018; Wikipedia contributors, 2019). Culturally, China is deeply influenced by Confucianism, Taoism, and Buddhism. Chinese people have a strong “group orientation” due to its collectivist culture (Van de Vliert et al., 2013). Chinese society is strictly organized based on the reciprocation of “guanxi”, “renqing”, and “face” (miàn zi), suggesting that people’s worth is largely defined by what others think of them (Kim and Cohen, 2010; Yang and Kleinman, 2008). In addition, Confucian ideas require children to obey and serve their parents by filial piety (Cheng and Chan, 2006). Due to differences in geographic location, economic conditions, cultural background, and lifestyles, the findings of the qualitative research studies conducted in Europe and America might not be suitable for understanding the illness experiences of Chinese patients. Thus, the aim of this study was to explore the illness experiences of patients living with Crohn’s disease in China and construct an interpretive understanding from the patients’ perspective.

2. Methods

2.1. Design

Symbolic interactionism underpinned this study. A constructivist grounded theory approach was adopted based on the research question, the objective of this study, and the philosophical worldview of the study researchers (i.e., social reality is constructed). Constructivist grounded theory is rooted in relativist ontology and constructivist epistemology, assumes multiple realities and the mutual construction of data through interaction, and aims for an interpretive understanding of historically situated data (Charmaz, 2014).

2.2. Participants and sampling

We recruited 31 participants from six hospitals and a Chinese online inflammatory bowel disease patient support group in four provincial capital cities (Hangzhou, Nanjing, Guangzhou, and Wuhan) in South-eastern and Central China. The inclusion criteria were as follows: (1) diagnosis of Crohn’s disease based on the Chinese criteria released in 2012 (Committee of inflammatatory bowel disease and Chinese Society of Gastroenterology, 2012) and (2) age of 18 years or older. Individuals who had a mental illness or were unable to communicate effectively were excluded.

During the initial stage of this study, purposive sampling was used to recruit participants who might provide rich information. After 20 interviews, categories were tentatively established. Theoretical sampling was used to collect pertinent data to elaborate the categories and their properties (Charmaz, 2014). When theoretical saturation was reached, sampling was stopped.

2.3. Data collection

We conducted 31 face-to-face in-depth interviews between February 2015 and January 2018. An interview guide was developed based on our experience and research interests. Prior to each interview, written informed consent was obtained. The demographic and clinical characteristics, such as disease activity index, were assessed using the Harvey-Bradshaw simple index (Harvey and Bradshaw, 1980), and patients with a disease activity score equal to or greater than 4 were regarded as active, while a disease activity score lower than 4 was defined as remission (Ruan et al., 2017). Initially, the interview questions were open and broad, such as “Tell me about your experiences living with the disease?” and “What impacts has the disease had on your life?”. With the development of the emerging categories, the interview questions became more focused.

The interview locations were selected based on the participants’ preference and are presented in Table 1. All interviews were conducted in Chinese. They were audio-recorded and lasted from 29 to 205 minutes with a median of 80 minutes. After the completion of each interview, field notes were immediately written to record the details of the observations and the process of interactions and encounters. The audio-recorded data were transcribed verbatim by the first author.

Table 1
Interview locations in this study (N = 31).

Interview location	
Hospital wards	10
Coffee shops	8
Parks	3
Restaurants	3
Patients' homes	2
Clinics	2
A tea house	1
A classroom	1
A library	1

2.4. Data analysis

The data analysis and data collection were performed simultaneously and iteratively (Charmaz, 2014). Following the first interview, the data analysis began with manual coding in Chinese. First, initial coding was used to analyse the studied phenomenon while remaining close to the data, preserving actions, and asking questions, such as "What do these data represent?" (Charmaz, 2014; Glaser, 1978). During the following stage, focused coding was applied to sift, sort, and analyse the large amounts of data (Charmaz, 2014). Subsequently, theoretical coding was used to theorize the data and specify possible relationships between the categories (Charmaz, 2014). Additionally, during this stage, the core category was identified by sorting and integrating the memos and writing storylines.

Throughout the data analysis process, a constant comparative method was used to identify the similarities and differences in the codes, yielding dense codes with analytic power and thereby refining the emerging codes and categories (Glaser, 1978). Memos were written freely and immediately as ideas occurred to expedite the analytic work (Charmaz, 2014). An example of a part of a memo is provided (Fig. 1). The memos informed some of the narrative descriptions in the findings, and theoretical sensitivity was enhanced through strategies, such as examining the studied phenomenon from multiple vantage points and closely examining grounded theorists' processual analyses (Charmaz, 2014).

2.5. Ethical considerations

Ethical approval for this study was obtained from Zhejiang Chinese Medical University's Ethics Committee. Prior to the interviews, the participants were informed about the purpose and procedure of the study, the voluntary nature of their participation, and the confidentiality of their data. The interview data were stored securely, and only the research team could access these data.

2.6. Rigour

Methodological congruence and procedural transparency were used to ensure the rigour of the study (Birks and Mills, 2015; Chiovitti and Piran, 2003; Sandelowski, 1986). Methodological congruence is present in this study because the aim of the research, the philosophical position of the researchers, and the methodological approach employed in the study resonate with each other. Procedural transparency is demonstrated as follows: (1) the interviewer was acquainted with thirteen of the participants before the data collection and established trust relationships with all participants; (2) prior to the data collection, we suspended our preconceived notions about the research topic by writing these notions and attempting to remain open and sensitive to the study phenomenon; (3) the data analysis was regularly guided by a grounded theory expert, and the codes and categories were discussed as necessary; (4) a reflective journal was kept throughout the research process to examine how the researchers' experiences, presuppositions, and demographic characteristics (such as age) might influence the interactions between the participants and the researchers and the interpretation of the research results; and (5) a detailed audit trail was maintained, including transcriptions of interviews, numerous interview field notes, memos, and reflective journals.

3. Findings

Thirty-one participants (17 males and 14 females) aged 19–68 years were included in the study. All participants belong to the Han Chinese ethnic group. Among the participants, 71% were in remission, and the median Harvey-Bradshaw simple index was 2.6. The details of the participants' socio-demographic and clinical characteristics are presented in Table 2.

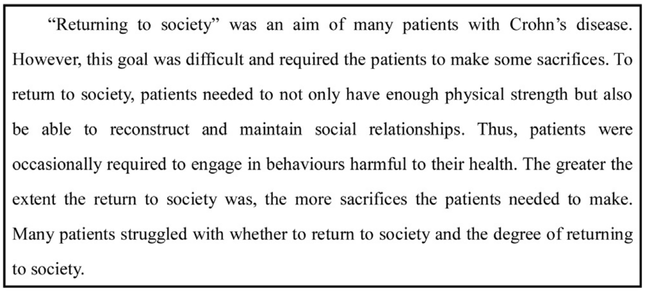
The overall illness experiences of the participants are shown in Table 3. The core category in this study was "regaining normality" (Fig. 2), and one memo was written to describe this category (Fig. 3). Regaining normality is a basic social psychological process. The following four phases of regaining normality were conceptualized: comparing, struggling, reflecting, and realizing. The relationships among the four phrases are not linear but iterative. However, the patients may not have experienced all four phases, and the phases may not have occurred in sequence in each patient. The following discussion provides a depiction of each phase in the form of a category and its subcategories.

3.1. Comparing

3.1.1. Developing feelings of inferiority

This subcategory refers to the negative experiences generated when patients compared themselves to individuals of a similar age with regard to life situations and personal attributes.

3.1.1.1. Comparison with peers produces a psychological gap. When experiencing a relapse of the disease, the participants' life situations were affected, and they had to change their original plans, resulting in feelings of sadness and inferiority. The patients admired their peers, who could implement their plans as scheduled.



"Returning to society" was an aim of many patients with Crohn's disease. However, this goal was difficult and required the patients to make some sacrifices. To return to society, patients needed to not only have enough physical strength but also be able to reconstruct and maintain social relationships. Thus, patients were occasionally required to engage in behaviours harmful to their health. The greater the extent the return to society was, the more sacrifices the patients needed to make. Many patients struggled with whether to return to society and the degree of returning to society.

Fig. 1. An example of a part of a memo regarding returning to society.

Table 2
Study participants' socio-demographic and clinical characteristics.

ID	Gender	Age	Place of residence	Marital status	Education level	Occupation	Religion status	Course of disease (months)	Frequency of operation	Disease activity indices
1	Male	45	Anhui	Married	Secondary	Unemployed	No religion	96	5	0
2	Male	34	Zhejiang	Married	Tertiary or above	Civil servant	No religion	36	4	5
3	Male	35	Zhejiang	Married	Secondary	Freelancer	Buddhist	120	0	4
4	Male	25	Zhejiang	Single	Secondary	Unemployed	No religion	120	1	4
5	Male	27	Zhejiang	Married	Tertiary or above	Unemployed	Christian	24	1	2
6	Female	46	Zhejiang	Married	Secondary	Worker	No religion	96	1	3
7	Female	19	Zhejiang	Single	Secondary	Saleswoman	No religion	11	1	1
8	Male	32	Jiangsu	Married	Tertiary or above	Clerk	No religion	120	1	2
9	Male	30	Hunan	Married	Tertiary or above	Civil servant	No religion	48	0	5
10	Male	68	Jiangsu	Married	Tertiary or above	Retired	No religion	92	0	6
11	Female	20	Zhejiang	Single	Tertiary or above	Student	No religion	41	2	1
12	Male	23	Zhejiang	Single	Tertiary or above	Student	Catholic	17	0	0
13	Female	27	Zhejiang	Single	Tertiary or above	Clerk	Buddhist	48	0	1
14	Male	27	Zhejiang	Single	Tertiary or above	Accountant	No religion	7	0	1
15	Female	60	Zhejiang	Married	Tertiary or above	Teacher	No religion	60	0	0
16	Female	31	Zhejiang	Single	Tertiary or above	Clerk	No religion	55	0	1
17	Male	32	Guangxi	Married	Secondary	Unemployed	No religion	48	1	5
18	Female	47	Guangxi	Married	Tertiary or above	Nurse	Buddhist	180	1	13
19	Female	41	Guangdong	Married	Secondary	Clerk	No religion	31	0	6
20	Male	38	Guangdong	Married	Tertiary or above	Teacher	No religion	60	0	1
21	Female	42	Zhejiang	Divorced	Tertiary or above	Clerk	Buddhist	96	0	3
22	Female	44	Zhejiang	Married	Tertiary or above	Teacher	No religion	101	0	2
23	Male	31	Hubei	Married	Tertiary or above	Clerk	No religion	25	2	0
24	Female	34	Hubei	Married	Tertiary or above	Courier	No religion	36	0	0
25	Male	34	Zhejiang	Married	Tertiary or above	Student	No religion	120	1	0
26	Male	36	Zhejiang	Married	Tertiary or above	Civil servant	No religion	156	1	2
27	Female	29	Zhejiang	Single	Tertiary or above	Self-employed entrepreneur	No religion	180	1	4
28	Female	29	Zhejiang	Single	Tertiary or above	Secretary	No religion	192	1	3
29	Female	22	Zhejiang	Single	Tertiary or above	Dental examiner	Buddhist	13	0	1
30	Male	39	Zhejiang	Married	Tertiary or above	Accountant	No religion	84	1	1
31	Male	32	Zhejiang	Married	Tertiary or above	Social media worker	No religion	4	0	3

> I was going to travel to Qinghai and Tibet. I had booked the ticket. However, the disease relapsed. My friends went, but I could not. I felt so disappointed! (Participant 27)

If relapse was occasional, the feelings of disappointment were not strong, and the participants believed that they could soon return to their former life status prior to their illness.

> I just get sick and need to stay in the hospital to receive treatment now. When I recover, I can return to society to work again. Recurrence is temporary. (Participant 20)

However, if relapse was frequent, a substantial psychological gap occurred, and many patients developed a strong sense of inferiority after comparing their lonely lives with the lives of their peers who pursued career advancement.

> I am very unhappy. My peers are all good and making money now. However, I have been sick and lying in bed for more than two months! (Participant 8)

3.1.1.2. I am not like everyone else.

Suffering from the illness caused the participants to feel as if they had two negative personal attributes, resulting in a sense of inferiority. One of the attributes was, "I am carrying an invisible bomb inside my body". This concept reflects that disease relapse is unpredictable and may occur at any time, which increased feelings of uncertainty in the participants' lives.

> I am just like a person who is partially disabled. The disease is in my intestines, not outside. I can't see whether it (the lesion) becomes larger or smaller. So many uncertain factors! (Participant 29)

The other attribute was "I am a burden". This concept indicates that the patients considered themselves a burden to others and felt guilty and useless. This feeling typically occurred among the debilitated patients who received care from others and had difficulty returning their caregivers' kindness.

> I not only make little contribution to my family but I've also become a huge burden to my family now! (Participant 19)

3.1.2. Developing a sense of being fortunate

This subcategory refers to the positive experiences generated when patients compared themselves to individuals in a similar or more unfortunate situation.

Table 3
Overall illness experiences of Chinese patients living with Crohn's disease.

Core category	Categories	Subcategories
Regaining normality	Comparing	Developing feelings of inferiority
		Developing a sense of being fortunate
	Struggling	Pursuing a sense of belonging
		Experiencing a reluctance to disclose one's patient identity
	Reflecting	Reconstructing values
		Changing one's attitude towards life
	Realizing	Suffering from the disease is less simple than thought
		Suffering from the disease is not always a bad thing

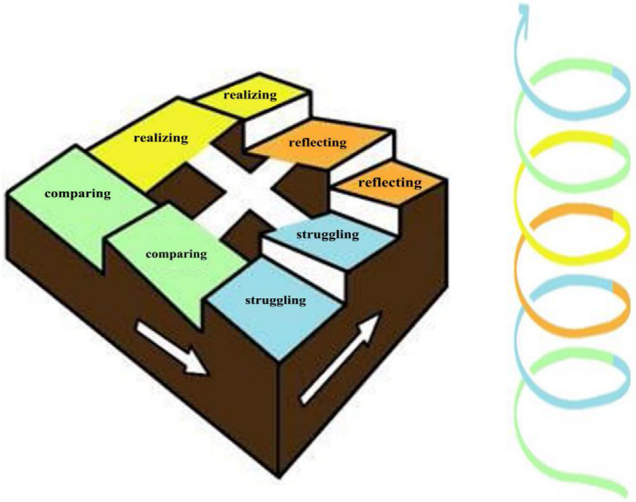


Fig. 2. Core category of regaining normality.

"Normality" is socially constructed and has different meanings in different contexts. After being diagnosed with the disease and suffering from its multiple symptoms, many participants lost the normality they had before the illness. If the disease was controlled very quickly, the participants might believe that they had returned to normality. If the disease relapsed for a long time, many participants might have given up on returning to normality and accepted their present status, which they defined as normal. Regardless of whether the participants reported returning to normality or forming a new meaning of normality, "regaining normality" was the most explanative, analytic, and conceptual category and involved the following four phases: "comparing", "struggling", "reflecting", and "realizing". The term "regaining" reflects a dynamic process and reveals the difficulty in pursuing normality. The term "normality" was frequently mentioned by the participants, demonstrating its importance.

Fig. 3. Memo explaining the core category of regaining normality.

3.1.2.1. Not being alone. During the early stage after receiving the diagnosis, most participants felt very lonely because they thought that few other people suffer from the same disease. When they became acquainted with people with the same diagnosis through the Internet or patient groups, they were surprised and excited.

> At first, I thought I was the only one. Suddenly, I found there were many people with the same diagnosis: "Wow, I have a lot of brothers and sisters! I am not alone." (Participant 24)

China is a country with many chronic disease patients. After realizing this, the participants gradually accepted their diagnosis with this condition.

> There are plenty of chronic diseases, such as diabetes, hypertension, etc. I'm not the only one with a "troubling" disease. (Participant 12)

3.1.2.2. I am not the most miserable person. Some participants found that compared with people in a more unfortunate situation, they were not the most miserable people on earth. This realization was a way to gain psychological comfort. For example, some participants who had health care insurance or were able to afford medicine felt very lucky compared to those who could not afford to pay for their medicines because of low family income or the lack of health care insurance.

> To be honest, many patients could not afford the medicine. Some of them even had to sell their houses (to treat the disease). When I think about this (that I have health insurance), I feel really lucky! (Participant 4)

Crohn's disease is a chronic disease affecting patients' quality of life rather than their life expectancy. Compared with people who die at a young age due to cancer or traffic accidents, some participants felt fortunate.

> After all, Crohn's disease is chronic not (as fatal as) cancer. What I have is not malignant, and I have a chance to be cured! This comparison gives me consolation. (Participant 18)

3.2. Struggling

3.2.1. Pursuing a sense of belonging

To avoid loneliness and alienation or relieve related feelings, the participants sought to obtain a sense of belonging from patient groups and/or society.

3.2.1.1. Blending into patient groups. Currently, several patient groups, such as a Crohn's forum and the China Crohn's and Colitis Foundation, are available. Some participants struggled with whether to join such groups. On the one hand, the participants were eager to engage in group activities; on the other hand, they were afraid of their patient identity being known by others.

> Some patients wanted to join patient group activities, but they didn't want people around them to know they had the disease . . . This made them feel really conflicted about whether or not to participate. (Participant 28)

Some patient groups were not managed well. The members of the groups frequently shared negative information, and when other members received this information, they shared similar information. This negativity created a pessimistic atmosphere, which prevented the patients from gaining a sense of belonging.

> Although I have joined a Crohn's forum, I don't want to browse the information in it. The patients there always compare themselves with each other to see who is the most miserable . . . When I saw this, I felt so scared! (Participant 17)

3.2.1.2. Struggling to return to society. The patients were able to gain a sense of belonging by returning to society; however, there were some moments of struggle. The question of whether they should return to society was troubling for many patients as one young participant mentioned,

> Although I wanted to return to society to start a career, I was afraid that working hard would be bad for my health. I felt so conflicted. (Participant 14)

Some patients decided to return to society. Participating in social activities, such as hosting, attending parties, and enjoying nightlife, were beneficial for acquiring social resources and constructing relationships, but these activities were harmful to the patients' health. Many patients struggled with the extent to which they should return to society, and a few patients chose to sacrifice their own health.

> To work on others' projects, you have to build good relationships with them . . . I accompanied my clients and enjoyed activities and entertainment until 1 a.m. or 2 a.m. in the morning. I just slept for several hours and got up early to work again. It was very laborious! (Participant 8)

3.2.2. Experiencing a reluctance to disclose one's patient identity

This subcategory refers to patients who were hesitant about whether to disclose their patient identity and the extent to which they should disclose this information.

3.2.2.1. Deciding whether to disclose one's patient identity. From the participants' perspective, the advantages of disclosure primarily included gaining support, testing relationships, showing confidence, demonstrating honesty, and preventing suspicion. The disadvantages of disclosure mainly consisted of the potential effects on dating and marriage, the influence on career development, the possibility of losing privacy, and the potential of being stigmatized. These disadvantages were primarily based on the patients' imagination or disclosure experiences of other individuals in a similar context.

When the advantages of disclosure clearly outweighed the disadvantages or vice versa, it was easy for the participants to make a quick decision regarding whether to disclose their diagnosis.

> To inform others that I have this disease only causes disadvantages for me without any advantages. So, I chose to keep it a secret. (Participant 13)

It was sometimes difficult for the patients to weigh the advantages and disadvantages of disclosure. Some patients faced a dilemma regarding whether to disclose their diagnosis.

> (If I don't tell), there will be much work pressure on me without a doubt . . . I have worked so hard to pursue my career goal. Now, I am close to it. If I tell (I won't reach this goal), but my colleagues will. (Participant 26)

3.2.2.2. Strategic disclosure. If the patients decided to disclose their diagnosis, they needed to make a choice between the following two strategies: "complete disclosure" or "selective disclosure".

Complete disclosure involved completely revealing one's patient identity. Some patients exposed themselves on social media to gain more attention and promote a public understanding of the illness. However, as one participant mentioned, this way of disclosing might actually deepen the public's misunderstanding.

> Some eye-catching news about Crohn's disease was reported, such as about a civil servant with bowel perforation who was still working while receiving nutrition therapy through a feeding tube. The public might think this was such a horrible and serious disease! (Participant 13)

Selective disclosure involved the participants revealing their patient identity selectively depending on the time, context, and relationships between the parties involved. For example, some participants chose to disclose their diagnosis to their intimate friends.

> Whether or not to tell others about my diagnosis was related to the relationships between us. In fact, a few intimate friends know that I am a patient with Crohn's disease. (Participant 31)

Because some patients strategically disclosed their diagnosis, some people knew the participants' patient identity, while other people did not. To avoid having their patient identity known by the latter group, the participants had to create a series of lies to hide their diagnosis, which generated substantial psychological pressure.

> When I could not tell (I had Crohn's disease), I felt really stressed. I also wanted them (my friends) to understand why I could not travel with them. However, I could not tell the truth. (Participant 27)

3.3. Reflecting

3.3.1. Reconstructing values

This subcategory refers to changes in attitudes towards different things after suffering from the illness for a long period.

3.3.1.1. Health is the most important consideration. Many participants took their health for granted before their diagnosis. These participants stayed up late working or entertaining, which caused physical exhaustion. After their disease was diagnosed or they had experienced severe complications, they became aware of the importance of health and prioritized their health in their work and life.

> Health is the most important thing! It is the precondition for pursuing further education and career. (Participant 22)

Based on this understanding, some patients established exercise plans and attempted to perform some moderate exercises.

> I made an exercise plan for myself. To do 4 sets of 20 sit-ups every day. (Participant 14)

To control the disease, some patients even accepted treatment methods that could cause physical discomfort and evoke negative emotions, such as nutrition therapy via nasogastric feeding.

> I had no choice. I had to accept the insertion of the nasogastric feeding tube because I wanted to live! (Participant 7)

3.3.1.2. Greater concern for spiritual wealth. Many Chinese people pursue material wealth. After receiving their diagnosis and experiencing severe complications, the participants found that material wealth could not confer permanent happiness but that spiritual wealth could. Therefore, the participants attempted to perform good deeds, such as helping others, to accumulate spiritual wealth.

> I can help many people . . . Now, my life is not only wonderful but also meaningful! (Participant 26)

However, this realization did not result in the patients completely abandoning the pursuit of material wealth. Instead, the participants managed their money wisely and tried to maintain a balance between material wealth and spiritual wealth.

> It is such a good thing to make other patients take fewer detours by sharing my illness experiences. I feel very happy and fulfilled. (Participant 3)

3.3.1.3. Being alive is intrinsically valuable. Chinese people value the sense of wholeness, and death is a taboo subject in China. As long as the patients were alive, the patients' family integrity remained intact, and the face of the family members and the position of the patients' household in their surroundings were not lost.

> As long as I am alive, my family is complete. It won't affect my son looking for a partner. (Participant 1)

Chinese culture emphasizes that children should practice filial piety to their parents, and one way to accomplish this is by cherishing life and exerting all possible efforts to prolong it.

> My parents gave me life and raised me. Although I had a disease, they never abandoned me. I should show filial piety to them and not abandon my life! (Participant 29)

3.3.2. Changing one's attitude towards life

This subcategory refers to changes made by the participants after reflecting on their previous life attitudes.

3.3.2.1. Living in the present. "Living in the present" reflects a life attitude of appreciating what one has and living every day to the fullest. The patients began to cherish things that they previously took for granted, such as sunshine, air, peace, time, and living family members.

> Suffering from disease makes you appreciate the world, your time, and the people around you more. (Participant 13)

Influenced by this positive attitude, the patients did not make meaningless assumptions about their futures and exerted efforts to improve their quality of life, such as by actively cultivating interests.

> I attend a traditional Chinese painting class. I feel so great! (Participant 15)

3.3.2.2. *Let it be.*

"Let it be" refers to the patients' attitude towards the uncertainty of life after reflection. This subcategory includes the following two aspects: "let it be passively" and "let it be actively".

The concept of let it be passively was observed in patients whose disease frequently recurred and was typically not a choice the patients made. The patients who held this attitude often had less hope for life and the future; they lived one day at a time.

> I am protecting my body now. Although I thought many things, I did nothing. I am just living one day at a time. (Participant 25)

Patients living with severe conditions reflected upon whether they could live, their possible survival time, and their way of living. A few participants chose to live a natural and unrestrained life in their limited lifetime, such as eating whatever they wanted and having fun to die with no regrets.

> It will be such a pity if I die without enjoyment and a lot of suffering. So, I chose to enjoy myself now as I live one day at a time. (Participant 9)

The concept of let it be actively was typically a rational choice made by the patients. The participants who held this attitude viewed the uncertainty of life rationally and accepted the potential that the disease could cause their deaths. In these participants' opinion, the suffering associated with birth, ageing, sickness, and death is an inescapable part of life.

> I was fully at ease. Birth, ageing, sickness, and death were really normal things. (Participant 10)

This positive attitude was typically held by the patients who had more disease knowledge as the greater the patients' knowledge, the calmer they felt.

> We gradually knew this disease would progress like this or that . . . The more you know about the disease, the more you are not afraid of it. (Participant 26)

3.4. *Realizing*

3.4.1. *Suffering from disease is less simple than thought*

This subcategory refers to patients' realization that living with the disease and receiving relevant treatment could significantly influence their life.

3.4.1.1. *Diet modifications.*

The participants attempted to avoid or reduce gastrointestinal discomfort by modifying their diets but did not always have the knowledge necessary. The participants consulted doctors and nurses for answers, but only vague answers were provided, which caused more confusion.

> At the beginning of being diagnosed, I asked several physicians what I could eat. However, they could not give me a precise answer and just told me roughly not to eat spicy and irritating food. (Participant 3)

Although some participants knew that their diets should be individualized, adhering to a diet plan was not easy. In some social situations, the patients could not choose suitable food and had to eat food that could cause gastrointestinal symptoms to conform to the situation.

> (At my friend's wedding party), I didn't want to eat, just staying here, but the attendees around me would ask, "Hey, why didn't you eat?" . . . Afraid of being embarrassed, I forced myself to eat some foods that might be harmful to my body and cause abdominal pain. (Participant 6)

3.4.1.2. *Altered body image.*

"Altered body image" reflects how the disease and its treatment impaired the body images of the patients, impacted their psychological health, and altered their self-image.

Some participants received nutrition therapy via a nasogastric feeding tube and thought that their appearance, which involved a nasogastric tube in their nose, made them look like a "monster".

> After all, a plastic tube was inserted through my nostrils. Just like a monster! (Participant 4)

Some patients needed to abstain from eating for the long-term and, therefore, received nutrition therapy via nasogastric feeding tubes. These patients described themselves as "robots completely dependent on nutrient solutions to work". Nutrient solutions were equated to the "engine oil" used to keep robots running.

> I had a nasogastric feeding tube inserted to receive nutrition therapy. I felt like I was being fed fuel continuously. Just like a robot whose life entirely relies on nutrient solutions. (Participant 30)

Some participants who had experienced surgery expressed a sense of deformity and described themselves as "someone who had been deformed".

> (After a partial small intestinal resection), I felt there was a piece of metal in the operating region. I was just like someone who had been deformed! (Participant 5)

3.4.1.3. *Modification of activity spaces.*

The concept of "modification of activity places" involved the patients modifying their activity locations due to disease relapse and treatment.

To avoid soiling their clothes due to frequent bowel movements, the patients heavily depended on access to toilets. Once the patients left their homes, they had to be aware in advance of the locations of toilets.

> At that time, I had diarrhoea every day. Thus, I had a map of all the toilets available in Yangzhou and knew exactly where the toilets were located. (Participant 8)

To monitor their condition and medication side effects, have their prescriptions filled, and be checked regularly, the patients had to frequently visit hospitals. If the disease was active, they went to the hospital nearly every day.

> When I had free time, I just went to the hospital to get a physical check-up or fill a prescription. (Participant 16)

3.4.2. *Suffering from the disease is not always a bad thing*

As the disease duration increased, some participants gradually realized that suffering from the disease was not always a bad thing.

3.4.2.1. *Maturing.*

"Maturing" reflects the personal growth of the patients throughout the course of their illness. This concept includes the following two main aspects: "increasing empathy" and "becoming strong".

Some participants mentioned that having the disease changed their perspectives of others and provided them with a better understanding of what other people might have endured.

> Previously, I didn't know the experiences of people with a severe disease . . . Now, I understand that those with a serious condition have very hard experiences. (Participant 11)

During the illness process, the patients confronted many challenges, such as disease recurrence and having a nasogastric feeding tube for a long time. Some patients dealt with these challenges bravely and subsequently became stronger.

> I've become stronger through the hardship. Now, when I meet with difficulties, I think anything could be overcome. (Participant 6)

3.4.2.2. Improving relationships. "Improving relationships" refers to improvements in the relationships between patients and other individuals due to the patients' suffering from the illness. The improved relationships primarily involved family affection and friendships.

The increase in family affection mainly reflects two aspects. First, relatives never gave up on patients or left them alone. Second, the patients cherished their relatives even more after their illness experiences.

> At that time, I was diagnosed with the disease. I was in debt and had no money . . . My wife was eight months (pregnant). Someone who was in a similar situation would choose to abort the foetus and divorce. She chose to stay with me. Now, I cherish her very much and treat her quite well. After all, we went through so much hardship together. (Participant 3)

The patients' friendships also improved because the patients received their friends' care and support.

> Friends, they all care about you . . . It definitely didn't happen previously (before illness). So, my relationships with friends were enhanced. (Participant 24)

4. Discussion

A theoretical understanding of regaining normality was developed in this study. As chronic illness assaults the body and disrupts the self (Charmaz, 1995), most patients reassess normality and fight to maintain it (Hall et al., 2005). For example, patients with inflammatory bowel disease in the UK fight for "health-related normality" (Hall et al., 2005). Patients with Crohn's disease in the Korea, New Zealand, Spain and Sweden try to get their life back on track and struggle to maintain normality (Carlsson and Persson, 2015; García-Sanjuán et al., 2018; Lynch and Spence, 2008; Yoo et al., 2013). Besides, patients with rheumatoid arthritis in England also struggle for normality (Sanderson et al., 2011), and following the diagnosis of a childhood chronic disease, individuals in Italy reconstruct normality (Germeni et al., 2018). According to Kelleher (1988) and Sanderson et al. (2011), normalization is a process that incorporates an illness into a person's life (Hall et al., 2005). Normality is a constructed concept achieved by comparing, struggling, reflecting, and realizing.

Comparing is related to the self (Chadee, 2011). Festinger's theory of social comparison suggests that people with a serious health problem select similar others for self-evaluation to maintain a stable and accurate self-view (Festinger, 1954). However, comparisons might also endanger one's self-esteem (Chadee, 2011). This notion explains the behaviour of the participants in the present study who compared themselves with their peers and developed feelings of inferiority. This finding is supported by literature, which suggested that patients with Crohn's disease considered themselves worse than others, and even had a sense of failure when compared themselves with others of same age (Pihl-Lesnovska et al., 2010; Sarlo et al., 2008). Comparisons could also be made between the past self and the present self. Charmaz (1994) indicated that patients with chronic illnesses attempt to recapture their past positive self. Due to frequent flare-ups, many Crohn's disease patients feel that they are a burden to others and suffer a loss of their previous self-identity; illness becomes the major source of their present self. Due to this considerable gap between their past self and present self, patients feel useless and guilty (Charmaz, 1983). García-Sanjuán et al. (2018); Pihl-Lesnovska et al. (2010) and Wilburn et al. (2017) also reported that patients with Crohn's disease doubted their value, worth and capability and even thought they were not of any use to anyone anymore. To protect or enhance their self-view, individuals compare themselves with inferior standards (downward comparisons) (Chadee, 2011; Wills, 1981). This approach explains why the participants compared themselves with individuals in a more unfortunate situation. Norton et al. (2012) also found that patients with Crohn's disease felt they were doing all right when they compared with other patients with more severe conditions about their own personal health. Nurses could use this finding to help patients gain psychological comfort and build confidence about the future.

Struggling was related to self-identity (Charmaz, 1987), and belonging was an embodiment of identity. Pursuing a sense of belonging is particularly important for Chinese individuals. In contrast to individualistic countries, such as the United States and Western European countries, whose societies focus on centralizing the individual (Oyserman et al., 2002), in Chinese cultural contexts, social relationships, norms and group solidarity are more central to social behaviour than an individual's demands (Taylor et al., 2004). This interdependent view of the self requires an individual to conform to social norms by seeking consensus and compromising rather than bringing personal beliefs, problems, or needs to the attention of others. This concept explains why the participants in this study preferred to sacrifice their health rather than prioritize their personal needs, which caused a sense of struggle during the process of returning to society. This finding has not been reported elsewhere before.

A reluctance to disclose one's disease identity was another source of struggle. This reluctance was mainly related to the stigma associated with Crohn's disease due to the embarrassing symptoms (such as frequent, urgent, or bloody diarrhoea) and the unpredictable nature of the disease (Frohlich, 2014). This reluctance was more apparent among the participants who were teenagers or early adults, which are life stages during which people are generally more concerned about their body image and intimate relationships. In Asia, bowel problems, especially those involving faeces, are regarded as taboo (Bischoff, 2011). The loss of face violates key reciprocity norms in Chinese society and increases an individual's stigma experience (Yang and Kleinman, 2008). This concept explains why our participants were more concerned about their self-identities and struggled with whether to disclose their patient identity.

Hiding and concealing one's illness is a common phenomenon in patients with Crohn's disease (Barned et al., 2016; Carlsson and Persson, 2015; Defenbaugh, 2013; Norton et al., 2012; Wilburn et al., 2017). In the present study, the disadvantages of disclosure were mainly based on the participants' imagination rather than their personal experiences. As reported, perceived stigma was not always equivalent to enacted stigma (the actual experience of being discriminated by others) (Frohlich, 2014). Patients with inflammatory bowel disease mostly report very positive experiences after sharing information about the disease with others, such as significant others and family members (Defenbaugh, 2013; Frohlich, 2014; Norton et al., 2012). Disclosing one's patient identity strategically, such as considered the time, context and the severity of the illness and the quality of the relationships in the disclosure decision (Barned et al., 2016; Defenbaugh, 2013), might be a suitable way for patients to reduce the psychological stress of keeping a secret. Nurses should create a supportive environment for these patients and encourage them to disclose their disease to trusted individuals (such as close family members and friends). Further studies are needed to explore stigma among patients with inflammatory bowel disease in the Chinese context.

Reflecting is a process of examining the self and a way of developing one's self (Donovan, 2007; Huitt, 2004). Illness experience is accompanied by many changes in one's life. The participants changed their attitudes towards life and reconstructed their values; they reunified their self accordingly to live a life with an altered sense of self through reflection. “Being alive is intrinsically valuable”, which is one of the adjustment strategies under “reconstructing values”, is embodied through Chinese cultural characteristics and presents a perspective of the value of living. This finding was rarely reported in the other studies and it can be explained by the following two aspects.

Reciprocity is regarded as a core principle that governs everyday social behaviour in China (Yang and Kleinman, 2008). When an inauspicious event (such as dying at a young age) occurs, the vital connections linking families to social networks can be severely influenced. Because some Chinese people are afraid that bad luck will spread to them and their families by interacting with individuals associated with an inauspicious event (Yang and Kleinman, 2008), they stay away from those individuals. To avoid this phenomenon, patients, especially those with severe illness, attempt to live and maintain their family’s integrity.

Filial piety, which is the first virtue of Chinese traditional culture, regulates the relationship between children and parents and requires children to serve their parents and repay their indebtedness (Hsu et al., 2001; Kao and Sinha, 1997). Cherishing life and preserving one’s body from injury is one way to practice filial piety in China (Kao and Sinha, 1997). According to Confucian philosophy, one’s body, skin, and hair are received from one’s parents (Friedman, 2015). This finding provides a way for health care professionals to help patients change their minds about perceiving themselves as worthless and prevent the occurrence of extreme events (such as suicide attempts).

Realizing helps patients develop a better understanding of the suffering resulting from illness. The concepts of “suffering from disease is not always a bad thing” in the present study and “a gift wrapped in barbed wire” described in a Canadian study (Purc-Stephenson et al., 2015) demonstrate that patients find positive meaning from self and illness, which is related to the concept of post-traumatic growth (Tedeschi and Calhoun, 2004). Similar finding is also reported in the literature (Carlsson and Persson, 2015; Lynch and Spence, 2008; Pihl-Lesnovska et al., 2010; Sarlo et al., 2008). Notably, not all participants experienced growth because some traumas are inadequate to facilitate meaning-making and deliberative rumination about the event, which are two important processes for growth, or a loss was associated with an adjustment-related factor and did not result in thriving and resilience (Jayawickreme and Blackie, 2014; Sirois and Hirsch, 2017; Tedeschi and Calhoun, 2004). A recent cross-section study suggested that the negative effects of post-traumatic stress disorder on post-traumatic growth after an earthquake were weakened by the moderating role of resilience (Meng et al., 2017). Currently, studies involving patients with Crohn’s disease have mainly focused on loss responses (such as perceived stress) rather than how those individuals achieve positive growth. The underlying mechanisms of post-traumatic growth among these patients need further exploration.

5. Conclusion

To the best of our knowledge, this study is the first to explore the illness experiences of Chinese patients living with Crohn’s disease. Regaining normality is a basic social psychological process of the participants. Regaining normality is related to reassessing and reconstructing the self after receiving a diagnosis of Crohn’s disease. Different comparisons lead to different assessments of the self in these patients. Belonging and disclosing issues deteriorate their self-identity dilemma in Chinese social contexts. The participants changed their perspective towards life and illness and regained their previous normal after reflection. These findings can be used to help health professionals deliver holistic, patient-centred care based on patients’ perceptions, needs, and concerns. This study also offers a potential understanding of patients with Crohn’s disease from other East Asian countries. Future research involving adolescent patients or caregivers might extend the explanations regarding regaining normality. In addition, the concepts of patients defining themselves as a burden, patients’ impaired body image, and post-traumatic growth might be important areas for future studies.

6. Limitations

This study has some limitations. First, the participants involved in this study were all Han Chinese and had a relatively high education level; thus, these participants do not represent the general Crohn’s disease population. In addition, theoretical saturation is a relative concept, and although reached in this study, with further interviews, the densities and dimensions of the categories of this interpretive understanding might be enriched.

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Ethical approval

This study received approval from Zhejiang Chinese Medical University.

Conflicts of interest

None declared.

Contributions

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