



Experience of providing care to a family member with Crohn's disease and a temporary stoma: A qualitative study

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ABSTRACT

Objectives: The aim of this study is to understand the feelings and experiences of the main caregivers of temporary ostomy patients with Crohn's disease (CD). And explore the caregivers' inner feelings, to provide reference and basis for constructing the health education content of the main caregivers of CD patients with a temporary stoma.

Methods: A qualitative descriptive approach was used to conduct an unstructured interview among 11 primary caregivers of CD patients with temporary enterostomy from the gastroenterology department of The Second Hospital of Nanjing. Participants were selected using a purposive sampling technique. Data were collected between July 2021 and September 2021. The interviews were audio recorded and then transcribed for a qualitative thematic analysis.

Results: Five themes and accompanying subthemes were identified: (1) negative psychological experience (2) perceived caregiver burden (3) future uncertainty (4) disease benefit (5) insufficient support system.

Conclusions: Study findings suggest that caregivers of CD temporary enterostomy patients have problems such as negative psychology, heavy caregiver burden, uncertain future, lack of support system, etc., but they also have positive experience of feeling of benefit from the disease, and are eager to obtain more disease information from more channels. Therefore, medical staff should improve their professionalism and health education capabilities, carry out diversified and targeted health education activities to reduce the burden of care, stimulate positive caregiver responses and help caregivers respond to and deal with caregiving problems in a timely and accurate manner.

1. Introduction

Crohn's disease (CD) is a type of inflammatory bowel disease (IBD) that causes gastrointestinal tract inflammation, which has a characteristic "skip lesions" (discontinuous regions of inflamed bowel separated by unaffected mucosa) [1–3]. Despite the increasing number of patients receiving biotherapies, surgery is still an essential tool in the management of patients with CD [4]. The incidence of

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Crohn's disease was found to be much higher in the developed countries of western world than in Asia [5]. However, the incidence and prevalence of CD have been increasing in countries with traditionally low incidence of CD, especially in Asian countries including China [6]. The result of the previous Jiangsu Province in China population-based study has shown that CD incidence is more likely to be concentrated in affluent areas such as Nanjing [7].

Fecal diversion with enterostomy construction can be categorized according to the location and duration. There are three types of enterostomy according to location: jejunostomy, ileostomy, and colostomy [8]. It was adopted to control disease and avoid urgent surgery, while allowing time to optimize health care. Over time, the incidence of CD stoma has increased in epidemiology [9]. In a retrospective study, Blackwell et al. found that 15.0 % CD patients had a temporary stoma and 16.5 % CD patients had a permanent stoma in CD undergoing their first intestinal surgery [10]. Because the location of CD is more common in the terminal ileum, ileostomy is more common (Whitehead and Cataldo, 2017). Compared with colostomy, the discharge of ileostomy is thinner and contains more irritating digestive enzymes, which will bring some erosion and damage to the skin around ileostomy.

Ostomies can bring a series of problems to patients, such as reduced body image satisfaction, sleeping problems, impaired sexual functioning, reduced social interaction and increased sense of stigma [11–13]. In addition, CD patients are more likely to be affected stoma-related complications [14]. Moreover, the lower success rate of closure of temporary enterostomy in CD patient makes the follow-up quality of life of the patients less guaranteed [15,16]. As a result patients with Crohn's disease enterostomies have a higher level of health care utilization and generate greater psychosocial stress. Studies suggest that caring for adults with IBD may lead to significant caregiver burden [17]. At present, limited information is available on the experiences of the main caregivers of temporary enterostomy patients with CD.

In Chinese culture, after the operation, the family will take good care of the patient and provide them with long-time care during the follow-up rehabilitation process [18]. Research shows that people living with ostomies often rely strongly on informal caregivers, usually spouse or close family member, to support them with enterostomy care and related challenges throughout their recovery [18].

The Family Systems Theory was developed by Muray Bowon in the 1960s, which related to human emotional activities and communication behaviors [19]. The theory model provides a framework to view the family as a whole, which means changes in the behavior of one family member will cause changes in the cognition [20], emotion and behavior of other family members. This theory explains the internal mechanism of human mental activity [21]. Chronic illnesses affect the patient's family life more profoundly, and changes in the family environment in turn have an effect on the patient with physical illness [22]. Therefore, experiences with caregiving of family members play an important role in the psychological changes of patients. Especially in the face of CD with ostomies, which requires long-term adherence, the strong belief of the patient and the cooperation and understanding of the primary caregiver are even more needed [23]. As the primary caregiver who has the most frequent contact and the closest relationship with patients, the impact on the psychology and emotion of Crohn's disease patients cannot be ignored. At present, there are related studies on caregivers of cancer colostomy in China, but there is a lack of research on the response of caregivers of CD patients with temporary enterostomy. In addition, only a few published resources address caregivers of patients with Crohn's disease ostomies, but none linked to the local context of China.

The objective of this study was to interview caregivers about their experiences of taking care of their patients and collect their suggestions for improving the health education provided by health care professionals. Therefore, through interviews this study aim to understand the main caregivers of CD patients with a temporary stoma care experience, explore the caregivers' inner feelings, to provide reference and basis for constructing the health education content of the main caregivers of CD patients with a temporary stoma.

2. Methods

2.1. Aim

This study aimed to explore the feelings of the main caregivers of CD patients with a temporary stoma care experience.

2.2. Design

We used semi-structured interview questions to collect descriptive data from the primary caregiver of CD patients with temporary enterostomy. This study followed the Consolidated criteria on reporting qualitative research (COREQ) (File S1).

2.3. Participants

Qualitative semistructured interviews ($n = 11$) were undertaken between July 2021 and September 2021 by face to face interviews. All participants participated in a previous study and were selected using the purposive sampling method, achieving maximal variation purpose. The sample consisted of the primary caregiver of CD patients with temporary enterostomy from the gastroenterology department of The Second Hospital of the Nanjing. The principal investigator contacted participants by telephone to explain the characteristics of the study and to invite them to participate. Eligibility criteria for the CD patients (do not involve in this research) included: (1) who underwent temporary enterostomy for the first time due to the need of CD treatment for less than 1 year; (2) 18 years old \leq age < 65 years old. Eligibility criteria for caregivers included: (1) relatives of patients; (2) age \geq 18 years; (3) not professional or paid caregivers; (4) taking care of more than 3 months; (5) able to speak/read/write Chinese. Exclusion criteria: (1) critical condition; (2) history of cognitive impairment, psychiatric disorders; (3) previous participation or ongoing participation in similar studies; (4)

worsening of the patient's condition or serious adverse effects during the study; (5) voluntary withdrawal from the study due to various personal factors. If the patient has more than one caregiver, choose the caregiver who has the most direct relationship (marital or consanguineous) and the longest duration of care as the main caregiver. This study only interviewed the primary caregivers.

2.4. Data collection

Data was collected through unstructured interviews form mainly at quiet and private places depending on their preferences, lasting approximately 30~60 min. Before the interview, the purpose, method and significance of this study were introduced to the interviewees in detail. The researcher (the first author) was not involved in their care. After obtaining the interviewees' informed consent, the whole interview was audio recorded, and the key emotional expressions and changes, body language were recorded. Data saturation was achieved at the eleventh interview. Based on the review of the literature, an unstructured interview outline was drawn up after discussion with 3 experts from digestive disease treatment center and 2 specialist nurses in wound stoma. Three caregivers of CD temporary enterostomy patients were interviewed in advance, and the problems found in the interview were adjusted and corrected in time, and finally a formal interview outline was formed. The interview began with a broad question, "What was your reaction after enterostomy?" To encourage participants to provide more in-depth responses, this general question is followed by additional questions such as: "What changes have XXX's Crohn's disease and enterostomy brought to your life? Why do you say that?" Other prompting questions were as follows: (1) "How do you think taking care of XXX and taking care of his/her stoma has brought about changes in yourself? You can tell me both the good and the bad." (2) "What other assistance do you hope the medical staff can provide for you?"

2.5. Ethical considerations

This study involves human participants and was obtained from the medical ethic committee of The Second Hospital of Nanjing (2021-LS-ky023). We will strictly abide by the ethical principles. Before the intervention, we will elaborate the significance and process of the intervention to the subjects. After obtaining their consent, we need to sign the informed consent form. Ensure the anonymity of all data collected to protect the privacy of patients, and the data will only be used for this study. Patients had the right to withdraw from the study at any time during the intervention.

Table 1
Demographic characteristics of participants.

Characteristics	n
N,total	11
Gender	
Male	4
Female	7
Nation	
China	11
Race	
Han ethnic group	11
Marital status	
Married	9
Widow/Divorced	2
Education	
Primary school graduate or less	2
Junior or senior high school graduate	5
College or university graduate	4
Relationship	
Married/couple	5
Mother	3
Father	2
Sister	1
Conscious health status	
Good	2
General	7
Bad	2
Time to care for patients	
<2	4
2~5	4
>5	3
Months since patient got a stoma	
≤3	8
>3	3

2.6. Data analysis and rigour

We used the qualitative data management program N-vivo Pro11 for data organization and analysis. Transcribed transcripts of the interviews were uploaded to N-vivo. The analysis was conducted independently by the researcher and another research team member. Disagreements were resolved by discussion. This small-scale exploratory study used the method of content analysis described by Hancock B [24]. The data analysis was conducted in a systematic and comprehensive manner and the ideas under each research question were thematized using the following steps. A coding system was developed by the research team for analysis purposes. The concepts were identified from the records and the frequency of similar concepts was calculated. The team then interpreted and categorized the concepts and gave appropriate thematic groupings to the concepts. Finally, the results of the two analysts were compared and discussed with all authors until the final result was unanimously adopted.

3. Results

3.1. Participants

Data were collected from 11 caregivers (7 women and 4 men, mean age 47.8 ± 15.2 years). Patient mean age was 38.5 ± 14.2 years. Of the 11 informal caregivers, 82 % were married, only 18 % self-identify as having a healthy body (Table 1).

3.2. Thematic overview

Five themes with subthemes were identified from the resultant data analysed (Table 2): (1) negative psychological experience, (2) perceived caregiver burden, (3) future uncertainty, (4) disease benefit, (5) insufficient system.

Theme 1. negative psychological experience

Subtheme 1.1. Guilt and remorse

In the process of taking care of patients, the caregivers experience multiple pressure, which is more obvious under the negative stress of ostomy, which makes the caregivers nervous and prone to have negative emotions. N6: "My son's disease recurs because he has to go to work and get tired. If I had spoken a little harder and stopped him from going out to find a job, there might not have been a recurrence and this stoma."

Subtheme 1.2. Anxiety and fear

Although the caregivers had lots of caring experience, they would still fear of colostomy at first glance. N7: "Although my wife has been diagnosed with CD for many years, I have taken care of her all the way. But an old lady like me has never seen an colostomy before, I was afraid and don't know how to deal with it. "

Colostomy cannot cure the disease itself, and the development of ulcers in the exteriorized bowel segment and peristomal fistulas are usually consequence of CD recurrence [25]. N2: "My husband has suffered a lot from Crohn's disease, and now he has a colostomy. Every time I help him change his pocket, I can't help but looking at it for fear that there is something unusual in the stoma. "

Subtheme 1.3. The sense of shame

CD has made the caregivers feel the sense of shame, and colostomy has increased this kind of shame. N4: "After my father diagnosed (CD), the neighborhood talked about that my father's intestines were broken. Now, because the disease he has to create a stoma, I am afraid that they will think more about it."

In order to avoid embarrassment, caregivers will deliberately avoid other patients in the same ward when changing their pockets.

Table 2
Themes and subthemes.

Themes	Subthemes
1. Negative psychological experience	1.1 Guilt and remorse 1.2 Anxiety and fear 1.3 The sense of shame 1.4 Being controlled by CD (Crohn's disease)
2. Perceived caregiver burden	2.1: Emotional burden 2.2: Financial burden 2.3: Physical burden 2.4: Be disturbed in daily life
3. Future uncertainty	worries about temporary enterostomy can't be closed
4. Sense of benefit finding	4.1: Accept actively and deal with effectively 4.2: Explore ways to get along with disease 4.3: Achieve positive personal growth 4.4 changes in personal values 4.5: Enhanced sense of personal achievement
5. Insufficient support system	5.1: Fewer sources of support system 5.2: Eager to obtain multi-channel information

N9: "Although everyone in this ward has CD, we are the only ones who have a stoma. I usually close the bed curtain when I change my husband's pocket, but when I open and change the pocket, I always feel other patients living in the same ward looking at us in a strange way."

Subtheme 1.4. Being controlled by CD

Caregivers' life is bound by patients' disease and ostomy, so they feel a strong sense of control. They can't help thinking about the physical or work problems that patients will face in their future lives. N3: "If my son wants to find a job, he can only do light work because of Crohn's disease, but this kind of job is hard to find now." N1: "This kind of disease can't be cured! Even if my child gets better after enterostomy, I can't help thinking about its recurrence at home."

Theme 2. Perceived caregiver burden

subtheme 2.1. Emotional burden

Most of the participants said that it was their responsibility and obligation to take care of the patients, but this incurable disease would burden the caregiver with a long-term care burden, which may sometimes exhaust the caregiver. N6: "If you have Crohn's disease, you can't get rid of it. I accompany my son around the disease every day. I not only have to take medicine and treatment, but also accompany him to the hospital for review after a period of time. Sometimes I feel like I'm a patient who always running to the hospital."

Subtheme 2.2. Financial burden

CD cannot be cured, and the long-term demand for medical services has already put a greater financial burden on the whole family. The caregivers in this study are all family members of the patients. because they are unable to work, most patients regard temporary colostomy as the second biggest financial burden. N3: "His father has to go to work at home. He is the only child. My son is ill and can't go to work, and I have to take care of him. Now he has a stoma, I need money to buy pockets and chassis. Where do we have that kind of money?" N8 : "Our parents have always had a heavy burden of this (Crohn's) disease. And now my sister has a colostomy because of Crohn's disease, so we need more money for surgery and colostomy supplies. Now our family's energy is all on my sister." N9: "You see, it's very easy for people to go to the toilet, but it's only since my husband got a stoma because of Crohn's disease that I realized how expensive it is for a stoma maker to go to the toilet."

Subtheme 2.3. Physical burden

All the patients included in this study were ileostomy patients, and most of the respondents said that the sleep quality was poor due to the large discharge of ileostomy and the need to get up regularly at night. N3: "It's too painful for people with Crohn's disease. Of course, as family members, it's hard for us to take care of them all the way. I usually can't sleep well, and I always think about my son's illness, and now he has a colostomy, I have to help him empty his pocket at night, so I can't sleep at all." N1: "Nursing colostomy you have to be careful, you have to have a sense of responsibility, you have to keep in mind all the time, thinking about it, so you can't really sleep."

Due to the double financial burden of Crohn's disease and temporary enterostomy on families, some caregivers say they have to go out to make money even if they are under physical pressure. N11: "I also had an operation three years ago and had a complete hysterectomy, but now my husband's condition costs money for treatment and stoma. I work two shifts and earn two jobs for him."

Subtheme 2.4. Be disturbed in daily life

As CD patients require long-term care, caregivers often have to change their daily arrangements to meet the care needs of the patients for. And nursing care of CD patients with temporary stoma will increase the difficulty of care. N2: "I used to make money from delivering for restaurant, but after I went to the hospital to take care of my husband, I couldn't do this job. He just had a stoma and couldn't live without people at all." N6: "I'll take care of my son in the hospital, and I have to worry about what's going on at home. I'm afraid my granddaughter won't be taken care of at home."

Theme 3. Future uncertainty: worries about temporary ostomy can't be closed

Most respondents said that temporary ostomy would increase their impatience in the process of care, ostomy care increased the burden of care, and caregivers hoped that temporary ostomy could be returned as soon as possible, but they were afraid of the delay in reversing ostomy in patients with CD because of CD recurrence. N1: "It is a big question for us to have this stoma. We all hope that the ostomy can be closed, but it depends on the follow-up of his own disease (Crohn's disease). I'm afraid that my son have to keep this stoma all the time in the future."

Theme 4. Sense of benefit finding

Subtheme 4.1. Accept actively and deal with effectively

Although 7 interviewees have been afflicted with CD in the early stage of care, the caregivers after enterostomy still give themselves positive psychological cues to help and guide patients to adapt to and deal with temporary ostomy effectively." N2: "Actually, I couldn't accept it at first, but just like people have to eat, they have to line upColostomy itself is also a way to maintain life, and that's how I enlighten my husband."

Subtheme 4.2. Explore ways to get along with disease

In this study, some respondents said that they were exploring actively how to live peacefully with the disease. N1: "It's easy to get sick after ten degrees below zero. Over the years, my son and I have gradually found it out. Once my son went to learn to drive, probably because it was too cold, Crohn's disease relapsed again. You have to live in peace with this disease. If you disobey it, it will

quit. If you don't offend it, it will live peacefully with you. "

Subtheme 4.3. Achieve positive personal growth

Caregivers continue to accumulate care experience in the process of care, they will have richer emotional experiences and become stronger in their hearts at the same time. Caregivers said that they were more compassionate right now. N6: "Sometimes I see that the child with this disease is even younger than my son, I felt so sad."

By getting help from others, caregivers learn to be grateful and willing to help others. N3: "We came here to be hospitalized. Some patients helped us carry out our luggage. We appreciate their help very much. So we also help others when they need help. As the saying goes: love is to be passed on. "

Subtheme 4.4. changes in personal values

All the caregivers in the study said that after their family members got ill, they began to understand the meaning of life, re-examine their own value pursuit, think about what is the most important thing in life, and change their life pursuits, cherish everything in front of. N11: "I said to my son, 'what if you have a stoma? What if you get Crohn's disease? No one knows who will get sick one day, and I don't want to get rich or anything. I just want to lead a pretty mundane existence.No matter how much money we have, it's useless without good health! " N6: "I think it doesn't matter if I eat and live badly as long as my son is in good health. I hope he doesn't get sick anymore. "

Subtheme 4.5. Enhanced sense of personal achievement

Most caregivers said that after learning the knowledge of ostomy nursing skills, their sense of personal achievement was enhanced after being encouraged by nurses and family members, thus stimulating their desire to learn. N10: " When I changed my husband's pocket for the first time, he praised me for learning well. Like the mood of getting a good result in the exam, I would be more confident in changing his pocket."

Theme 5. Insufficient support system

Subtheme 5.1. Fewer sources of support system

While caring for patients, caregivers themselves were also experiencing great physical and mental pressure and need support from many aspects. N2: "During the epidemic, the hospital had requirements, and it was not allowed to accompany too many people. I was the only one who take care of him in the hospital." N10: "The nurse has taught me to how to change pockets, but I'm not very skilled yet. Do you have a pocket change manual or video for me? I can learn to do it by watching the video. " N9: "Crohn's disease has cost a lot of money. After discharge, all the things you need for nutrition solution and stoma are at your own expense. If a better reimbursement policy or fund could be provided us with us, it will be better."

Subtheme 5.2. Eager to obtain multi-channel information

Most patients seek medical treatment from other places. In order to deal with the various problems encountered after discharge, caregivers are eager to establish more convenient channels of communication with health care workers. N1: "More than anything, I'd like to get guidance on this disease. My family is not local, so it is not easy to come here. For fear of meeting any problems after discharge, I asked the attending doctor for a phone number in case of any emergency." N8: "I live in countryside, there is no specialist nursing clinic, stoma has questions do not know who to ask. I wish there was a way to get in touch with the nurses here and solve the problems we encountered in time. "

4. Discussion

As a result of CD develops progressively in the way of remission-relapse-remission, CD patients often have frequent demands for medical services such as multiple operations, routine reexamination, medical treatment, which will increase patients' dependence on their main caregivers to accompany them to seek medical treatment and provide daily care [26]. Bedford's study have shown that the level of stoma acceptance of patients is significantly related to the time after colostomy [27,28]. Therefore, during the period of continuous adaptation to enterostomy, the main task of enterostomy nursing is undertaken by their main caregivers, which is consistent with the results of this study. The results of this study showed that the main caregivers of CD temporary enterostomy patients play multiple roles, such as enterostomy caregiver, companion, psychological counselor and the caregiver burden was heavy. Studies have shown that colostomy can increase the risk of depression in CD patients [29], and CD patients with depressive symptoms will promote the release of pro-inflammatory cytokines, increase the risk of CD recurrence and readmission [30,31]. As the main caregiver of patients, they should not only provide care in daily life, but also take care of patients' feelings of loss, which undoubtedly adds a burden to caregivers. In this study, the main caregivers are family members of patients, and the role of caregivers of CD temporary enterostomy patients is particularly important. However, most caregivers of patients with inflammatory bowel disease bear a high level of nursing burden, accompanied by high anxiety and depression, and a decline in quality of life [32]. The results of this study showed that the caregivers of CD temporary enterostomy had heavy physical and mental burden and complex negative emotions. Only 2 caregivers felt that they were in good physical condition at present. Caregivers with care burden are less efficient in caring for patients.

Skin care in ileostomy care is more important [33,34]. The incidence of complications related to CD colostomy was significantly higher than that of ulcerative colitis [35]. Studies have shown that the occurrence of stoma-related complications in patients with CD is mostly related to the recurrence of CD, suggesting that there is a risk of intestinal inflammatory activity in patients with CD [36]. Patients with ostomies are often rely heavily on caregivers to support their stoma care and related challenges throughout the recovery

process [37]. In Nihal's research, caregivers reported having inadequate psychological preparation for stoma surgery and very limited hands-on training on the practicalities of stoma care and stoma appliances, so encouraging them to receive health education is very important [38]. The Canadian Society for Rapid Rehabilitation (ERAS) issued a guide on best practices in care of enterostomy patients (ERAS) [39] in 2016 to encourage families and caregivers to receive health education, and to further strengthen the preoperative health education for patients and their families after colostomy, such as colostomy products, colostomy care skills, introduction and management of common colostomy complications.

Studies have shown that because of the nature of CD relapse and remission, CD caregivers must adapt to the evolution of the disease and master care skills, and they are more eager to get effective support from health care workers [40]. Only when the caregivers have a full knowledge of the disease, will they take correct care behavior and give patients a better care experience [41]. Timely evaluate the level of disease-related knowledge and skills of caregivers, understand the needs of caregivers, and provide personalized daily care guidance for caregivers by combining dietitians, enterostomy nurses and digestive multidisciplinary forces. At the same time, doctors and nurses should improve their professional literacy and health education ability, and carry out diversified and targeted health education activities, such as the distribution of colostomy nursing manuals, off-line communication meetings and online fraternities. To help caregivers respond to and deal with care problems timely and accurately, we can establish convenient Internet doctor-patient communication platforms, such as Wechat and QQ (QQ is a kind of similar MSN chat tools that enable people to communicate).

After qualitative interviews with 11 caregivers of CD temporary enterostomy patients, it is concluded that the caregivers of CD temporary enterostomy patients have some problems, such as negative psychology, heavy burden on caregivers, future uncertainty, insufficient support system and so on, but they will also gain the positive experience of disease benefit and are eager to obtain more disease information. While the study by Canova [42] showed no statistical difference in quality of life scores between cancer and non-cancer stomas. Krouse [43] found that cancer patients who underwent colostomy had higher quality of life scores than those who underwent colostomy for reasons other than cancer. In response to this result, Krouse interpreted the difference in quality of life in this study as likely due to the better overall health of cancer ostomy patients, as most cancer ostomy patients may be cured of cancer at the time of quality of life assessment, whereas non-cancer ostomy patients may still have disease-specific symptoms. The results of the study by Femke [44] showed that, compared to non-cancer ostomy patients, there was no significant difference in quality of life, except in mental health, cancer ostomy patients had statistically significant higher quality of life scores for their ostomates. Although foreign studies have shown that patients with stomas experience relief from adverse bowel symptoms after stoma surgery due to the preoperative treatment phase of refractory CD, they may view the stoma as a positive change. However, enterostomy can have a negative impact on patients' lives. And because of the difference in cultural values between China and the West, the collectivist "face culture" exhibited by the Chinese can exacerbate this negative experience. There are even fewer studies of caregivers of patients with Crohn's disease enterostomies. Therefore, in addition to paying attention to CD colostomy patients, health care professional should also give some care and support to their family caregivers to help caregivers reduce negative psychology, improve care ability and reduce care burden.

The results of this study showed that caregivers take care of patients at the same time, their own care experience is also experiencing dynamic changes, such as actively adapting to the role of caregivers, but also perceiving the growth experience brought about by caregivers, namely the sense of benefit, also known as benefit finding [45]. Studies have shown that a higher sense of benefit can help improve the pain of caregivers, relieve their care stress, promote physical and mental health, and improve the quality of life [46]. And this positive psychological feeling will stimulate the body to take positive actions through the stimulation of individual positive qualities, which will reduce the adverse effects of negative care reactions on caregivers. Medical workers can implement cognitive behavioral therapy by rebuilding caregivers' cognition of negative experiences, correcting incorrect cognition, reducing negative emotions and increasing the sense of benefit finding [34]. It is also possible to relieve care stress and increase the ability to discover benefits through low-cost, low-risk and easy-to-carry out activities such as music therapy, bibliotherapy and yoga [47]. At the same time, written emotional expression is also a convenient and low-cost psychological intervention method to promote personal physical and mental health [48].

4.1. Limitations

We used qualitative methods for data collection and enrolled a small purposive sample. Because of qualitative approach, there is not any statistical analyses, controls, sampling mechanism, and statistical reporting. Most participants in this study came from Jiangsu Province and its surrounding provinces, and the sample size was small, so it may not represent all the disease experience of the main caregivers of patients with CD enterostomy. The respondents recruited were caregivers caring for a diagnosed family member, but a longitudinal study would be necessary to understand more details inherent in the disease process. The data collected reflect the experience of caregivers in Jiangsu Province, China; therefore, they cannot be extrapolated to other populations that do not share similar characteristics. This geographic limitation should be addressed in future studies using similar methods in other provinces or similar cultures in China. A larger sample would provide a more comprehensive picture of family caregivers of patients with CD stoma. Nevertheless, this sample presented a variety of caregiving experiences at different stages of the disease and in different types of relationships, allowing the results presented to be transferable to other caregivers.

5. Conclusion

The results of this study showed that the caregivers of CD temporary enterostomy had heavy physical and mental burden and complex negative emotions. Therefore, while providing care for CD patients with temporary enterostomy, we should also pay attention

to the status of their caregivers, so as to avoid the negative care response of caregivers will have an adverse impact on the physical and mental health of CD patients. Medical staff should pay attention to caregivers' needs, reduce caregivers' care burden, teach them nursing skills, improve caregivers and patients' ability of nursing colostomy, timely evaluate caregivers' disease-related knowledge and skills, and understand caregivers' needs. This study also showed that the support system of CD temporary enterostomy patients and their families was relatively weak, reflected in economic, medical, life and other aspects. In China, social awareness of the disease is generally low. Health care professionals can regularly push publicity posts related to inflammatory bowel disease through official WeChat, make use of World inflammatory Bowel Disease Day to advocate social care for people with inflammatory bowel disease, appeal to the public to accept and treat CD stoma patients fairly in daily life and social communication, and reduce negative psychology such as shame, anxiety and depression of patients and their families. It is necessary to develop strategies to address caregivers' pain and perceived burden. Nurses and their main caregivers are the most frequent contacts and observation of patients with colostomy. Early identification and intervention of ostomy complications is also an effective line of defense to prevent recurrence of CD and perceive the risk of intestinal inflammatory activities.

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Data availability statement

Data included in article/supplementary material/referenced in article.

Additional information

No additional information is available for this paper.

CRediT authorship contribution statement

Sicong Liu: Conceptualization, Data curation, Formal analysis, Investigation, Writing – original draft, Writing – review & editing. **Bowei Sun:** Data curation, Investigation, Supervision, Writing – review & editing. **Wenjie Tian:** Data curation, Supervision, Validation, Visualization, Writing – review & editing. **Li Zhang:** Methodology, Project administration, Resources, Supervision, Writing – review & editing. **Fang Kong:** Conceptualization, Investigation, Project administration, Supervision, Visualization. **Mengmeng Wang:** Data curation, Investigation, Validation, Visualization. **Jing Yan:** Data curation, Investigation, Validation. **Ailing Zhang:** Investigation, Validation.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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