



## Original Article

# A qualitative study about colorectal cancer patients and spousal caregivers' experience and needs during COVID-19: implications for self-efficacy intervention

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## ABSTRACT

**Objective:** This study aims to understand the experiences of colorectal cancer (CRC) patients and their spousal caregivers during the COVID-19 pandemic and to refine a self-efficacy (SE) intervention for these couples.

**Methods:** A descriptive phenomenological approach was used in this study. Data were collected from 11 CRC couples. All interviews were recorded, transcribed, and analyzed using the Colaizzi strategy.

**Results:** Three themes and eight subthemes emerged: (1) Get and contribute support, (2) Life's challenges, and (3) Journey of reconstruction. The CRC couples encountered escalating challenges in coping with cancer during COVID-19. At the same time, they have received considerable support and developed confidence in rebuilding themselves in the process. Healthcare providers are advised to focus on giving appropriate support to CRC couples, so they can go further.

**Conclusions:** This study gave insights into healthcare providers on the experiences of CRC couples and the development of SE intervention program to support these couples: (1) initially providing caregiving training for spousal caregivers and psychological support for patients, (2) encouraging self-care for CRC couples in the middle stage, (3) guiding them to view life positively in the later stage, and (4) assessing their situation in time to identify their needs and to provide support. Healthcare providers are recommended to increase flexibility in the SE intervention program delivery format to reduce the impact of COVID-19 on CRC couples.

## Introduction

Since January 2020, the COVID-19 pandemic has spread across the world. The Chinese government has developed a series of measures to control the spread of the virus, such as restricting unnecessary travel, reducing gatherings, and even locking down communities or cities if necessary.<sup>1</sup> According to statistics released by the National Health Commission of the People's Republic of China, there has been a cumulative total of 232,109 confirmed COVID-19 cases nationwide, of which 223,987 have been cured, 5226 have died, and nearly 3000 are still under treatment.<sup>2</sup> The disease and death rate has dropped from 4.19% in the early days to 2.25% now.<sup>3</sup> Although the spread of COVID-19 has been effectively controlled, it still affects people's lives, particularly hurting vulnerable groups, such as cancer patients and caregivers. Recent evidence suggests that the negative impacts of COVID-19 on cancer patients and caregivers are manifold and may be long-term.<sup>4-6</sup>

Colorectal cancer (CRC) is the world's third most common cancer, and in China, it has been increasing in incidence and mortality rates with each passing year.<sup>7</sup> Research has revealed that the pandemic will increase mortality in CRC patients, who will have an increased mortality rate of 15.3%–16.6% after 5 years.<sup>8</sup> Although the pandemic situation is ameliorating, it has already had an irreversible impact on CRC patients. We must admit that the COVID-19 pandemic is more challenging for cancer patients and cancer survivors who are not only at higher risk of contracting COVID-19 but are also affected by a lack of timely access to services and treatment.<sup>9</sup> Meanwhile, both treatment and rehabilitation also have an impact on family caregivers, the majority of whom are spousal caregivers (SCs).<sup>10,11</sup> SCs are required to not only meet the daily living, disease care, and emotional support needs of patients but also to assume more family and social responsibilities. Since the pandemic, individuals have been forced to implement rehabilitation programs at home, which has again increased the burden on SCs to some extent.<sup>12</sup>

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CRC patients and SCs can be viewed as a whole, suffering from a health crisis at the same time.<sup>11</sup> Therefore, we are supposed to adopt new evolutionary interventions for CRC couples in the context of the pandemic.

Self-efficacy (SE), first formulated by Bandura, is the idea that people can autonomously modify behavioral, environmental, and personal factors to promote health outcomes.<sup>13,14</sup> As a personal behavioral feature, SE is inextricably linked to personal traits, environment, and events, which means that this behavioral trait can be modified by external influences.<sup>15,16</sup> SE acts as a mediator of myriad positive outcomes, such as high self-management, and high quality of life, which play an important role for CRC couples.<sup>17-19</sup> Previous studies have shown that patients are encouraged to engage in rehabilitation programs at home during the COVID-19 pandemic, which requires a higher level of self-management.<sup>12,20</sup> Consequently, a commitment to enhancing SE in patients and SCs is appropriate in the context of COVID-19. In addition, high levels of SE imply better symptom control in cancer patients,<sup>21,22</sup> fewer complications of peripherally inserted central catheter in chemotherapy patients<sup>23</sup> and less emotional distress for SCs.<sup>16</sup> Thus, developing SE interventions would be beneficial for CRC couples.

Previous studies have been analyzed for SE interventions.<sup>24-28</sup> These studies used different approaches to improve the SE of CRC patients and/or SCs but obtained different outcomes. Studies that failed to produce positive outcomes had the following characteristics: SE was not considered the main intervention goal,<sup>24-28</sup> patient preference was barely considered in advance,<sup>25,26,28</sup> and the intervention approach was single (eg, online only).<sup>26</sup> Therefore, a multipath intervention that aims to improve SE based on CRC couples' preferences could be a positive future direction.

Our previous study focused on summarizing existing intervention studies for CRC patients and caregivers to improve their SE. Based on the findings of this review, a preliminary SE intervention program was constructed.<sup>27</sup> This program is based on SE theory, with the primary goal of improving the SE of CRC couples. The intervention content targeted the four sources of SE as defined by SE theory, including performance achievement, vicarious experience, verbal persuasion, and emotional arousal, all of which contributes to SE development. For cancer patients and/or caregivers, performance achievement refers to the patients' and/or caregivers' successful experience in coping with cancer. The accumulated experience of coping with cancer will help diminish the negative effects of occasional failures in coping with cancer. Vicarious experience means that patients can encourage themselves to develop positive behaviors in coping with cancer by observing the positive behaviors of others in coping with cancer. Verbal persuasion is the process of persuading cancer patients and/or caregivers to be positive in dealing with the cancer challenge. The emotions evoked in each response to the task will also positively affect SE. The intervention content is as follows: Face-to-face sessions on skills training and knowledge strategies are provided, as well as web-based counseling and peer support services. The face-to-face sessions aim to enhance the performance accomplishments of CRC couples. The web-based sessions aim to provide vicarious experiences and verbal persuasion. Health providers attend to the emotional reactions of CRC couples at every session and guide them to positive emotions whenever possible. Skills training include stoma care, coping with relationship intimacy challenges and relaxation skills. Knowledge strategies include stoma, cancer symptoms, communication, and psychology. Each face-to-face session lasts less than 1 h, while a web-based meeting, like a consultation, lasts about 30 min. Evaluation of intervention outcomes included SE, anxiety, depression, and quality of life, which interacted with each other, with SE being the primary outcome.

However, the program details have not been adapted to the preferences and needs of CRC couples. For instance, how could the intervention delivery order be better adapted to a couple's experience of coping with cancer? What are the components that CRC couples value that we overlooked? There is a way to capture their experiences by conducting in-depth interviews. In this article, we are interested in learning about the

experiences of CRC couples coping with cancer during COVID-19, and what needs and preferences developed from these experiences to further modify the SE intervention.

## Methods

### Study design

This study used the descriptive phenomenological approach by Husserl,<sup>29</sup> which could gain insight into the essentials of human experiences.<sup>30</sup> This approach allowed CRC couples to narrate their own experiences of coping with cancer, to deepen the researchers' understanding of their lived experiences. To ensure rigor, we used the criteria established by Lincoln and Guba: credibility, transferability, dependability, and confirmability.<sup>31</sup> We ensured these four points by describing in detail the research environment, background, recruitment process, participants, and collection of data.

### Participants

We are extending an invitation to eligible CRC patients and SCs. The inclusion criteria were (1) patients diagnosed with pathologically confirmed CRC; (2) his or her spouse was the patient's principal caregiver; (3) all participants were older than 18 years; and (4) both CRC patients and SCs had comprehension and expression abilities and could clearly describe their experiences. If CRC patients and/or SCs had any mental, cognitive, or language disorders, they would be excluded. Participants were selected using the purposive sampling method, which is suitable for this study to obtain more information relevant to the research question.

The first (JG) and second (MC) authors are registered nurses with bachelor's degrees and are currently pursuing master's degrees. The third author (QC) is a registered nurse with 10 years of clinical experience. All researchers have been trained in qualitative research. When patients were identified as eligible, JG approached them face-to-face to establish a friendly relationship and provided them with information about the study purpose. Those who were interested in participating in the study were asked to sign a formal agreement that included consent to participate in the interview and be recorded.

### Ethical consideration

This study was conducted in accordance with the Declaration of Helsinki. We confirm that all methods were performed in accordance with the relevant guidelines and regulations. Ethical approval was provided by the Jiangnan University research ethics committee (Approval No. JNU20210918RB08). This study obtained verbal or written informed consent from participants who were told they may leave the research study at any moment without consequence. Participant names and admission numbers were replaced with code numbers to protect their privacy.

### Data collection

Data were collected through semi-structured interviews from September 2021 to November 2021 in the Affiliated Hospital of Jiangnan University. The participants decided upon the interview time. Interviews were conducted by JG, MC, and QC. The interviews were audio recorded and notes were taken to record the participants' body language and facial expressions. During each interview, only the participant and researcher were present. All interviews were completed with CRC couples (patient and SC present at the same time). Since there were traffic blockages during the pandemic, we used WeChat video or voice conferencing if face-to-face interviews were not possible.

The in-depth interview guide was jointly developed by all authors after discussion. The guidance consists of two sections. The first section

includes general information, including age, gender, education level, type of cancer, length of time as a caregiver, and so on. The second section consists of a list of open-ended questions used in the semi-structured interview. Two pilot interviews were conducted to test the semi-structured interview questions and train the researchers. The final interview guide was derived from discussions among all authors (one of whom is an expert in oncology nursing) and two pilot interviews and was found to be feasible through practice (see Table 1). The guidance was then applied to all participants. The interview questions included two aspects, namely “impact of CRC during the COVID-19 pandemic” and “reflecting on the meaning of the experience.” At the beginning of the interview, the participants were asked to describe either their experiences of the disease, or their experience caring for a patient, and elaborate on their experience with prompts such as, “Can you explain your answer in detail?” A total of 21 eligible CRC couples were screened. Two couples refused to participate because of illness and no interest in participating. At the time the 11th couple was included in this study, there were no new additional findings at that time and data were considered to have reached saturation. Eleven in-person interviews and one telephone interview were conducted (no repeat interviews). The reason for conducting the telephone interview was that one SC was unable to care for their spouse (CRC patient) in the hospital. The mean interview length was 43 min (range, 15–77 min). The recorded interview data were transcribed verbatim. To ensure accuracy, transcripts were compared to the audio and then returned to the participants for review.

Data analysis

The study results were concluded using the Consolidated Criteria for Reporting Qualitative Research criteria.<sup>32</sup> The authors 1–3 used NVivo version 12 software to manage and analyze the data in accordance with the Colaizzi method.<sup>33</sup> This is a common method of data analysis in phenomenological research. The text was first analyzed by multiple close readings, which were broken down into units of meaning and then condensed to make it shorter without sacrificing any important information. These meaning units were given a code. The codes were recombined to find themes and subthemes based on the differences and similarities. After the initial identification of themes and subthemes, the inspection results were returned and redundant parts were subtracted to make the results more concise. In this process, JG and MC worked on the initial codes, and then the themes were refined and named by JG and QC. When disagreements in analysis occurred, the authorship team would resolve the matter by discussion. Coding was finalized and returned to

**Table 1**  
Interview guide for CRC patients and caregivers.

Participants	CRC patients	Spousal caregivers
Warming up	Can you talk about your disease with me?	Can you talk about your experience as a caregiver taking care of your spouse?
<b>Impact of CRC during the COVID-19 pandemic</b>		
Question 1	Has the disease impacted you?	Has caring for the patient impacted you?
Question 2	How do you think the COVID-19 pandemic has affected your treatment?	How do you think that the COVID-19 pandemic has affected your caring for your spouse?
Question 3	As a CRC patient during this pandemic, what stands out to you as the most important?	As a CRC caregiver during this pandemic, what stands out to you as the most important?
Question 4	What do you get from coping with cancer? (both)	
Question 5	What is your mental state usually like when dealing with these effects? Has your mental well-being changed while coping with cancer? If so, what are the reasons for these changes? If not, what motivates you to maintain your mindset? (both)	
<b>Reflecting on the meaning of the experience</b>		
Question 6	What do you think is most important to you from these findings? (both)	
Question 7	What advice do you have for other patients/caregivers or health providers? (both)	

the participants to ensure that the results truly reflected their feelings and experiences.

Results

Overall, 11 CRC couples participated in this study. The patients' age was 61.45 ± 13.27 years, while the SCs' age was 60.82 ± 11.79 years. Participants' demographic characteristics are reported in Table 2.

Three main themes emerged from the content analysis: (1) Get and contribute support, (2) Life's challenges, and (3) Journey of reconstruction. The themes and subthemes are presented in Table 3.

Get and contribute support

The overwhelming majority of participants reported that all kinds of support are important in coping with cancer. As a couple, they usually support each other, even if one member of the couple is ill. Moreover, other types of support will also be sought, such as support from other family members, medical support, and so on. As stated by SC11:

*When she was diagnosed with cancer, I directed my son to call a doctor and make an appointment for a hospital bed and prepare for surgery. She (patient) didn't need extra care before the operation. Since we came here, I have always been with her. We are getting old, and always take care of each other at home. We would be happy if our son came to visit us.*

In the early stages of CRC diagnosis, couples tend to actively seek support. They are willing to share their experiences with others in the same situation and give others support in the process. These supports include the three aspects described in Table 4.

Caregivers become primary agents

Some CRC patients reported they were usually with their SC, and living together made them dependent on each other. As one participant said, “The doctors are talking to my wife about my illness, she knows more about it than myself (P6).” Patients prefer to stay behind their SC during rehabilitation. Indeed, the caregiver role is that of an agent of patient self-management. When SCs have difficulty caring for patients, it is often up to them to proactively seek support from health providers, with most of the support sought being related to disease knowledge and care strategies.

Emotional support from others on the cancer ward

There are also special moments when patients tend to seek comfort from strangers, such as friends met in the hospital. Since the caregiver has already taken on the caregiving task, the patient might be too embarrassed to again express his or her emotional needs to the SC and would turn to strangers instead. As one participant put it: “Getting support from strangers makes me less burdened in my mind (P5).” Furthermore, it is a positive sign that wardmates, who are in the same situation, encourage and comfort each other during hospitalization. Participants indicated that they kept in touch with their wardmates, and encouraged each other, which gave them the confidence to cope with cancer. SCs also communicate with other caregivers, but the topic is usually related to caring for the patient.

Making a contribution can lead to a sense of value

Once the CRC patient has improved, they can also be freed up to help their SC and take care of each other in their daily lives. Several participants expressed a desire to contribute to their families after they were feeling better. For instance, some participants indicated they wanted to continue to work and earn money to support their family, while others said that they wished to help their spouse take on household chores. Living with CRC leaves them temporarily incapable of working or even taking care of themselves. To some extent, it blocks the source of SE for CRC patients, which affects the accumulation of performance

**Table 2**  
CRC patients and caregivers' characteristics.

		Age (years)	Gender	Marriage length (years)	Education level	Work or not	Place of residence	Types of cancer	Stoma	Length of time as a SC
P	P1	63	Male	42	Middle school	No	City	RC	No	N/A
	P2	62	Female	40	Primary school	No	Village	CC	Yes	
	P3	74	Male	47	Middle school	No	City	RC	No	
	P4	71	Male	45	Primary school	No	Village	CC	No	
	P5	33	Female	9	College	Yes	City	RC	No	
	P6	52	Male	26	Primary school	Yes	City	RC	Yes	
	P7	68	Male	38	College	No	City	CC	No	
	P8	75	Male	46	Primary school	No	City	CC	Yes	
	P9	64	Male	35	Primary school	No	City	RC	Yes	
	P10	44	Female	25	Middle school	No	City	CC	No	
	P11	70	Female	47	No education	No	City	CC	Yes	
SC	SC1	67	Female	42	Middle school	No	City	N/A	N/A	1–2 years
	SC2	66	Male	40	Middle school	No	Village			1–2 years
	SC3	68	Female	47	Middle school	No	City			< 1 year
	SC4	70	Female	45	Primary school	Yes	Village			< 1 year
	SC5	37	Male	9	University	Yes	City			< 1 year
	SC6	45	Female	26	Primary school	Yes	City			< 1 year
	SC7	65	Female	38	High school	No	City			> 2 years
	SC8	71	Female	46	Primary school	No	City			< 1 year
	SC9	58	Female	35	High school	Yes	City			> 2 years
	SC10	50	Male	25	Middle school	Yes	City			1–2 years
	SC11	72	Male	47	High school	No	City			< 1 year

CC, colon cancer; N/A, not available; P, patient; RC, rectal cancer; SC, spousal caregiver.

**Table 3**  
Themes and subthemes.

Themes	Subthemes
Get and contribute support	Caregivers become primary agents Emotional support from others on the cancer ward Making a contribution can lead to a sense of value
Life's challenges	Bodily discomfort causes discrepancies with others Caregivers into crisis Strained spousal relationship
Journey of reconstruction	Adjustment of reflections Rebuild yourself

achievements. They hoped to reintegrate into society if possible. This altruism can give patients a sense of value and perhaps allow SCs to gradually step down from the role of agent.

In the beginning, the SCs assumed the role of the patient's agent, with the patient passively receiving care and working with the SC to promote recovery outcomes. Later, as the patients adjust and regain strength, they take on some of the responsibility for self-care while expressing a willingness to help others, but this takes some time.

*Life's challenges*

The CRC couples mentioned the challenges they have faced in dealing with cancer. Since a cancer diagnosis, CRC couples face a spectrum of challenges that have emerged gradually over time. Even though they have become accustomed to living with cancer, there are still inevitable negative effects, such as maintaining relationships. As a patient who had completed an ileostomy closure said,

*He didn't take care of our shared home when he was young, but he wants me to take care of him when he's old. My heart died a long time ago. He was selfish and never cared about my feelings. Maybe he will only be good to me when he is dead. (SC4)*

Thus, there are many life challenges in coping with CRC. These impacts include the three aspects as described in Table 5.

*Bodily discomfort causes discrepancies with others*

With cancer treatment, patients were changed physiologically, creating differences compared to the general population. Patients

who undergo surgical treatment usually need to live with their stoma for a period of time or even the rest of their lives. Patients feel more anxious and disturbed if they are different from others. Meanwhile, the SC experiences this sense of difference together with them. Some SCs said they kept track of patient visits and helped them carry tissues to facilitate stoma care. When asked about their spouse's stoma, they would answer along with the patient and even talk more, displaying the same conversational tone and attitude as the patient did. Even as they adjust to such a life, they never regard cancer treatment as a positive event and feel exhausted and helpless. There are reports of CRC patients whose weight continues to decline. They usually look miserable when surgery, chemotherapy, or stoma issues are discussed.

*Caregivers in crisis*

SCs were also plagued by illness, expressing they had no time to take care of their physical needs. Not only that, the COVID-19 pandemic also increased the complexity of their care work. SCs said that it's not easy to get into the hospital, they needed to go through layers of formalities, and there was no end in sight. Although the SC initially assumes the role of the patient's agent, he or she is unable to sustain it all of the time. They may complain or even want to escape from the SC role once they have been in the proxy role for too long, or their physical condition is in crisis. Also, CRC patients were aware of this situation but were helpless to make changes.

*Strained spousal relationship*

Some patients and their SCs also lack the desire to communicate, over time, which may make it difficult for couples to develop a mutual understanding. This may lead to the patient lacking knowledge about the SC, resulting in their ignoring the SC's feelings. For instance, a CRC couple reported that they could not find the right time to communicate: one wants to communicate, but the other refuses to say how they feel (P4, SC4). In an interview, the SC expected the patient to express himself more, but the patient did not have the desire to talk about his thoughts. The SC said that her spouse's refusal to communicate is a regular part of daily life, so she has no more appetite to express herself (SC7).

*Journey of reconstruction*

Interviews showed that CRC patients and SCs develop ideas in the course of coping with cancer. For example, some participants expressed

**Table 4**  
Interview excerpts of the subtheme of get and contribute support.

Subtheme	Interview excerpts
Caregivers become primary agents	
◆ From caregivers	<i>He (SC) is always there, although he occasionally fights with me. I rely on him a lot, he's the only one who cares for my stoma. (P10)</i> <i>Usually, I need to help him to expand the anus (every four or five days) and observe his stoma. Sometimes it gets a little red. I would help to disinfect, and apply a little gin paste. (SC9)</i>
◆ From health providers	<i>During the disease period, we have kept communicating with a doctor to help my recovering better. (P3)</i> <i>After the operation, he needs to turn his body once every 2 h. The nurses did a great job taking care of my husband, particularly during that special period. They kept helping my husband turn his body once every 2 h, and observing his condition now and then. I would say they are very responsible and kindly help us a lot. (SC6)</i>
◆ Support from relatives	<i>We are from the countryside. Relatives sometimes comfort me. We often talk to and give advice to each other, such as eating well, having a good rest, and not worrying about the disease. (P2)</i> <i>My nephew was very kind to us, and when he found out his uncle was ill, he sent us ten thousand dollars overnight. (SC6)</i>
Emotional support from others on the cancer ward	
◆ Support from network	<i>Sometimes I think online friends give more encouragement. They don't want anything in return. There are many patients on websites who share their lives, and I can chat with them freely. (P5)</i>
◆ Support from wardmates	<i>We're in the same ward, we talk to each other about the illness and recovery. After being discharged from the hospital, we will add WeChat and communicate with each other. Due to having the same disease and experience, it is easy to communicate and understand each other, and we have more common language. (SC11)</i>
Making a contribution can lead to a sense of value	
◆ Couples support each other	<i>I feel better now that she (SC) can go play mahjong in the afternoon. As long as we are in a good frame of mind, life will be better. (P8)</i> <i>We both got used to supporting each other and the whole family. Before the disease, we were at work, we have tried our best to support each other and balance work and life, eg, we cook together, take care of our children and grandchildren, and now it is basically him to do this work. I'm relaxed now, you see I'm so fat, haha. (SC9)</i>
◆ Give back to family	<i>They're so nice to me, and I'm still wondering how to pay them back. One is that I take good care of myself, after which I continue to make money to repay them. (P6)</i>
◆ Support companions	<i>A 49-year-old friend was very sad. She wonders why I got the disease when I was so young. Then I said to her, you are 49 years old. You see how old I am, I am like this. You do not have to compare yourself with older people. In the end I succeeded in comforting her. (P5)</i>
◆ Contribute to social development	<i>We also want to see some miracles. If he recovers well, it will not only be a continuation of his life, but also a contribution to the medical treatment cause. (SC1)</i> <i>Alipay can choose to donate the remains. I want to donate organs, but unfortunately, I can't donate my organs after chemotherapy. (P5)</i>

their appreciation for time spent with their family and planned to travel together when they were feeling better. They also actively considered the implications of the disease and then developed some experiences to rebuild themselves. They reflected on their previous life with cancer before adjusting their behavior, so as to complete the process of self-rebuilding. As a patient said,

*Over the years, it seems to me that the goal of my life has been to work and make money. However, after being diagnosed with cancer, I felt it was time to make a change. I felt that I could not just focus on working and making money - I also needed to take care of myself and try to enjoy life. (P5)*

The theme of Journey of reconstruction emerged from the data with two subthemes (Table 6).

**Table 5**  
Interview excerpts of the subtheme of life's challenges.

Subtheme	Interview excerpts
Bodily discomfort causes discrepancies with others	
◆ Stress of surgery	<i>When I was to sign the consent form for the operation, the doctor told me that I may not be able to protect the anus, then I collapsed. (P5)</i>
◆ Care burden of stoma	<i>It is always inconvenient with this stoma, particularly for going out, which limits my social activities indeed. I took care of the stoma for him every time when we went out. I had more say in the matter. (SC9)</i>
◆ Side effect of chemotherapy	<i>My tongue becomes painful and red as soon as I eat. (P7);</i> <i>She had just finished chemotherapy and was feeling nauseous a lot at that time, and I couldn't handle the situation. We went to the hospital and the doctor was able to prescribe that antiemetic. I told the doctor that I didn't care how much it cost, as long as it made her feel better. (SC10)</i>
Caregivers into crisis	
◆ Disease	<i>Diabetes and numb legs have caused my poor health. I feel uncomfortable all over and in severe situations, I called 120 for help because of dizziness. (SC4)</i>
◆ Multiple burden	<i>Due to the COVID-19 pandemic, we need to come to the hospital for nucleic acid tests one day before the official admission. Only a negative nucleic acid test makes us eligible for hospitalisation. (P7, SC7)</i> <i>In addition to taking care of the sick, I also need to take care of our elderly parents. To be honest, sometimes I feel tired. (P9, SC9)</i> <i>There was no such thing before. Due to our aging legs, it is inconvenient for us to go to the hospital. Moreover, it is depressing that we need to shuttle back and forth to the hospital on a hot day with our luggage, and I think we're going to die. (P4, SC4)</i>
◆ Like being on a circle and not stopping	<i>The treatment process seems to be endless. After the operation, I have been receiving chemotherapy, and now we still cannot see the end. (P7, SC7)</i>
Strained spousal relationship	
◆ Lack of "we" consciousness	<i>I often fight with him and he rarely considers my feelings or opinions when it comes to changing the ostomy bag. He could not get it right, he said, then you do yourself. (P10)</i> <i>Before he (the patient) got sick, he liked to play and never took care of our family. Now he is ill and depends on me. Don't we quarrel? (SC4)</i>
◆ Lack of proactive communication	<i>She (SC) is so grumpy that she never considers the other person's feelings when she speaks. (P4)</i> <i>To be honest, I'm sadder than him (the patient). To prevent our brothers and sisters from laughing at us, I tend to avoid communicating with them, and I need to be strong. (SC6)</i>

**Adjustment of reflections**

Over time, the state of recovery from illness will replace the previous state of life as the new normal. Suffering from CRC becomes a booster for couples to continue to grow. Participants indicated they would look back on their lives when they were alone. They have more time for solitude, thanks to the pandemic. They are relatively calm and do not feel regret about their lives even though they are sick. They have realized the importance of self-regulation of the mind, so even if they have negative emotions, they will make adjustments to become more positive. In the recovery process, each successful act of care inspires more positive emotions, such as confidence, in both the patient and SC.

Participants agreed with the statement that they obtain experience by practising. Some SCs who assist patients with stoma care said that they had tried several types of ostomy products and then chose the right model for patients, based on their preferences. In addition, CRC patients have found ways to divert their attention away from the negative consequences of cancer treatment, such as postoperative pain or loss of appetite after chemotherapy. The CRC couple has continued to adapt their thoughts and behaviors as they struggle with living with cancer on a daily basis.

**Table 6**  
Interview excerpts of the subtheme of journey of reconstruction.

Subtheme	Interview excerpts
Adjustment of reflections	
◆ Understand each other	<i>Nurses often come to change the dressing, and they are very kind and gentle. (SC11)</i> <i>It is good for all of us to do a good job in the prevention and control of the epidemic. (P8)</i>
◆ Remain calm and positive	<i>I have actually accepted the truth and do not think about how to live long. No matter what you think, it's already like this. (P5)</i> <i>Basically, he takes care of himself without my care, and apart from being at home, he usually goes fishing to relax. (SC9)</i>
◆ Sum up experiences	<i>I perceived that you have to undergo chemotherapy when you have cancer. The capital for having chemotherapy is the quality of one's body. (SC1)</i> <i>At first, I was not used to the stoma in my stomach, but now I am used to it. Compared with the original troublesome ostomy bag, which requires handwashing before each use, there are now convenient disposable ostomy bags that can be thrown away after use. Moreover, this disposable ostomy bag is very cheap. (P9)</i>
Rebuild yourself	
◆ Change multiple plans	<i>Before the cancer metastasised, we could play cards with our friends or travel. Now there is no way, we can only actively cooperate with the treatment. (P7)</i> <i>My daughter was supposed to be a graduate student, but she gave that up after knowing her dad was sick, with an intention to relieve the economic burden of the family. (SC6)</i>
◆ Gradually adapt to epidemic prevention and treatment	<i>The doctors in this hospital are very responsible and come to the ward every day to give us nucleic acid tests. We are all at ease. (P8)</i> <i>Before going out, we have to think about what to bring in order to prepare for the stoma that needs our attention. Wherever we planned to go, he (the patient) kept asking me if we had something ready, eg, a wet wipe ... These preparations are common now. (SC9)</i>
◆ Keep healthy with knowledge and skills	<i>Now I've learned how to care for my stoma by myself. I don't need my wife to help me since I learned how to handle it. As a carpenter, I think I do learn things quickly. (P6)</i> <i>When we are in the hospital, we will listen to the doctors. .... They tell us what we should do. (SC2)</i> <i>I follow the instructions of doctors to take care of him (the patient). In some ways, I might be doing better than the doctor asked. As long as the doctor gives me some advice, I will do better. (SC1)</i>

**Rebuild yourself**

The CRC couple who had rebuilt themselves was able to easily deal with day-to-day events involving cancer, which became a new life. First, they changed their plans, eg, family plans and social plans. Cancer has affected the whole family. Almost all family members made dealing with cancer together with a priority, believing that only in this way can they better cope with cancer. However, due to the pandemic, the SC assumes the role of the primary agent and is difficult to transfer out.

As time went by, CRC patients and SCs adapted both to cancer treatment and COVID-19 pandemic prevention, thanks to multiple supports. Regarding the impact of the COVID-19 pandemic on their lives over time, participants stated that they were accustomed to monitoring their body temperature every day and to wearing masks in public. But staffing constraints limit types of family support. Caregiving tasks continue to be a priority for CRC couples. Keeping healthy has become a major goal for CRC patients and SCs. Participants stated that they put a lot of effort into this, such as by learning self-care methods and practising the rehabilitation advice received from doctors, which also reflected their strong willpower and determination to take care of themselves.

**Discussion**

To the best of our knowledge, this is the first in-depth study to explore CRC couples' experiences during the COVID-19 pandemic. The findings have revealed that CRC couples are adapting to cope with the impact of CRC and the COVID-19 pandemic, but challenges continue to emerge one after another and in rapid succession. The interviews revealed that CRC couples mobilize their own SE in coping with cancer. The SE theory explains which supports CRC couples need in their journey of coping with cancer together. A total of three themes were identified in this study: Get and contribute support, Life's challenges, and Journey of reconstruction.

Participants indicated that they would actively seek support to cope with cancer after being diagnosed with CRC subtheme 'Get and contribute support'. At first, the patient seems to be hidden behind the SC, with the SC taking on spousal care at the outset. This is a challenge to the SCs' *performance accomplishment*. According to the previous SE programs, it seems appropriate to add caregiving skills such as stoma care, cancer symptom care to SCs' role at the onset of diagnosis as the first stage of the SE program. Through the guidance provided by healthcare providers, SCs can better help patients cope with cancer. In addition, other family members may provide support, such as financial support, to CRC couples, while healthcare providers providing psychological counseling (*verbal persuasion*) to patients to courageously face the challenges of cancer alongside their SCs. During COVID-19, the cancer care content set for SCs should be available in both booklet and online versions for CRC couples. Access to psychological support for patients has also changed to both an online and face-to-face format. Some stated that they hid their feelings from their spouses and turned to peers (wardmates or friends on a social media network) for comfort. On the one hand, their psychological needs may have been ignored by healthcare providers and spouses,<sup>34</sup> possibly due to reduced contact with relatives as a result of the pandemic.<sup>35</sup> On the other hand, seeking support from strangers may alleviate the guilt they feel toward their relatives due to their illness.<sup>36</sup> This situation reflected the fact that support from peers rather than relatives was more acceptable to patients.<sup>37,38</sup> Peer support seems to work more easily for patients who do not interact directly with their healthcare providers, as they lack confidence in understanding the instructions of their healthcare providers. Therefore, it seems possible to set patients as the primary recipients of peer support in our previous preliminary SE program. Peer support enables patient-to-patient transmission of health or illness-related experiences (*vicarious experiences*). This kind of giving can also make them feel satisfied and become more confident.<sup>15,39</sup> Corresponding to SE theory, the main goal of the first session is to enhance SC *performance achievement* and help patients stimulate positive coping emotions. Previous studies have provided psychosexual support for prostate cancer couples with the aim of improving intimacy impaired by cancer side effects (urinary, prostate function),<sup>40</sup> while the SE intervention provided peer-given psychological support with content focused on adapting to cancer and restoring health, rather than on improving intimacy.

Since surgery, CRC couples have officially begun their struggle with cancer (subtheme 'Life's challenges'). In addition to surgery, chemotherapy, and carrying a stoma are the main events that affect life. Moreover, the COVID-19 pandemic has prevented them from alleviating the discomfort of treatment. Recovery challenges will be ongoing for CRC couples. Therefore, the main goal of the second stage may be to support patients in improving skills and knowledge relevant to self-care (*performance accomplishment*). As coping with cancer has become the normalization, a better outcome can only be achieved if patients and SCs work together. Otherwise, the SCs may be in a health crisis, and even intimate relationships may suffer as a result.<sup>41,42</sup> Some participants in our study overlooked the importance of communication, leading to a number of problems in which they communicated less or had difficulty communicating effectively with their spouse. As in other cases, there will always be quarrels between husband and wife, which can lead to

misunderstandings or resentments that are difficult to solve effectively. This ultimately leads to a lower quality of intimacy. SCs often put their health aside, even if they also suffer from chronic conditions.<sup>43</sup> This sense of crisis seems to be stronger compared to before the pandemic.<sup>11,44</sup> Prior to the pandemic, it was easier for couples to obtain more support, such as when one partner was tired and the other sought support elsewhere.<sup>44</sup> However, SCs now need to care for their spouses alone and it is difficult to receive a break by alternating with others. In the SE program's second stage, it might be a suitable time to consider incorporating SC health education to improve their health.<sup>45</sup> Moreover, intimacy promotion courses should be considered at this stage, to help CRC couples enhance their happiness and maintain a good relationship.<sup>24,46</sup> The aim of this SE program's intimacy promotion component is to help both partners reach a consensus and rapport when coping with cancer. Previous cancer couple coping interventions have focused more on addressing couples' cancer-related sexual problems and improving intimacy.<sup>40</sup> It is worth noting that by this stage, the patient has been suffering from the disease for a period of time, causing the SC to gradually run out of energy, and CRC couples were in the grip of negative emotions. This is evident from the comments of some participants, who expressed concerns about their health, lives, and future. Health providers and peers remain sensitive to the patient's withdrawal and the SC's resistant attitude. Positive guidance should be given to CRC couples to be optimistic about the challenges that arise in their lives (*Emotional Arousal*). COVID-19 amplifies CRC couples' feelings of helplessness, and we may need to increase our contact with CRC couples to support them online or by phone. We no longer mandate that all content be provided to CRC couples in one session. Corresponding to the SE theory, the main goal of the second session was to enhance the *performance achievement* of patients coping with cancer and to help SCs improve their own health to *relieve the negative emotions* of both parties as a result of coping with cancer.

Over time, participants have practical experiences, whether experiences of failure or success, that have allowed them to adjust (subtheme 'Journey of reconstruction'). This can be seen as a cognitive adjustment process.<sup>15</sup> They evaluated their past lives. If given a positive self-evaluation, it may bring benefits and encourage participants to face life positively.<sup>47,48</sup> If the self-evaluation was negative, it could lead them to fall into negative emotions with a low SE level.<sup>49</sup> Therefore, in the SE program's third stage, health providers are expected to focus on guiding CRC couples by making positive evaluations of their previous lives and directing them to focus on happy, pleasurable moments to motivate themselves to move forward (*verbal persuasion*). This positive guidance may bring comfort to both patients and SCs. In contrast to palliative psychotherapy for couples with advanced cancer, the SE program targets cancer patients who are likely to survive in the long term alongside their SCs. Healthcare providers could guide and inspire them to feel confidence in living a longer life together, while interventions for patients with advanced cancer were aimed at soothing emotions, alleviating discomfort, and achieving calmness and tranquility.<sup>50</sup> In the final, fourth stage, the healthcare providers review the CRC couple's self-rebuilding efforts. This review helps us discover what needs CRC couples still have that remain unmet.<sup>51</sup> Corresponding to SE theory, the main task of the third and fourth sessions was to *verbally persuade* the CRC couple, provide counseling services to identify their unmet needs, and awaken positive emotions. To accommodate the impact of COVID-19, the third and fourth course delivery format, which is primarily counseling-based persuasion, can be adapted to telephone or online.

In summary, by understanding the experiences of CRC couples coping with cancer during the COVID-19 pandemic, we clarified the specific content and sequence of the previous SE program. In the first session, SCs are taught CRC caregiving knowledge and skills to help them feel confident in becoming a caregiver. Patients need psychological support at this time. Healthcare providers identify their avoidant attitudes and encourage patients to face reality to gradually work with their SCs to overcome the challenges of cancer. During this period, patients can be encouraged to interact with their peers if they avoid contact with

healthcare providers. As CRC couples progress toward recovery, patients should be encouraged to complete self-care to the best of their ability. The core of the second session is to teach both CRC patients and SCs the knowledge and skills of self-care and intimate relationships. The patient no longer hides behind the SC to truly ease the SC's burden, whether it be psychological or physical. The emotions of couples, especially SCs, need to be noticed during this period. When they feel overwhelmed, it may exacerbate the effects of negative emotions. In the third session, CRC couples are guided to make positive comments about their previous recovery experiences. As of the third session, all of the main content has been provided to CRC couples. In the fourth session, there is no longer set content. Prior to the fourth session, the healthcare providers check the CRC couples' mastery of the content of the previous sessions and determine the content of the fourth session based on individual couples' needs. At the same time, researchers cannot ignore the impact of COVID-19 and adapting the delivery format of the above content to be more flexible is in line with the trend.

Overall, previous couples coping interventions have been more comprehensive, helping patients and caregivers to reduce distress, improve coping, adapt to cancer, and promote intimacy.<sup>52</sup> The present SE program is guided by SE theory with the primary goal of enhancing couples' SE. SE is a mediator of multiple factors such as quality of life, anxiety, and depression.<sup>53</sup> It appears that SE interventions can be a mediating intervention to help cancer couples achieve additional benefits in other areas. Meanwhile, there are many commonalities between the present and previous studies. The SE program also focuses on the psychological needs of cancer couples by considering the cancer patient and SC as a dyad with simultaneous interventions. The SE program may enable couples to successfully resist stressful events as a result of cancer and reduce negative emotions by improving SE levels. It is worth noting that the majority of study participants had received a junior or senior high school education, which may have influenced their attitudes toward cancer. Moreover, most were from urban areas, so future studies could be conducted in rural areas.

#### Strengths and limitations

Several strengths and limitations exist in this study. First, we paint a general portrait of what CRC couples feel when coping with cancer. According to their experiences, we have made a specific design for the SE program. The SE program will be divided into four sessions to teach a variety of content. It may be able to increase SE program acceptance to some extent, so that CRC couples benefit from the program.

There are several limitations in this study. The CRC couples were interviewed at the same time, which may have encouraged them to say what they believed the other person wanted to hear. Future studies could consider interviewing patients and SCs separately. In addition, because we performed the interviews and analyzed the content in Chinese and then translated it into English, language differences can be considered a study limitation. The interview guide was validated by nursing experts and preinterviewed participants, but no other studies have been conducted using this interview guide, which may be a limitation of this study.

#### Implications for practice

The study findings suggest that COVID-19 measures appear to reduce ease of access to support for couples coping with cancer. SC helplessness may be amplified during a pandemic, which in turn may lead to faster and more pronounced exposure of problems in CRC couples. Therefore, professional guidance may still be needed for CRC patients and SCs. In the future, we would encourage researchers to develop easily accessible interventions, such as web-based interventions, to help cancer couples. In addition, it is suggested to help cancer couples identify problems in their intimate relationships and actively guide them to view setbacks with optimism. Moreover, the situation of cancer couples is assessed on time to ensure that interventions can match the reality of the situation.

## Conclusions

The CRC patients, with their SCs, described several disruptions caused by cancer and the COVID-19 pandemic. The challenges faced by CRC couples are continuing and even increasing during the pandemic. The study findings will contribute to the improvement of the SE program, which will offer four sessions to CRC couples. The first session provides counseling to patients and caregiving skills to caregivers, which was neglected before this study. The second course provides self-care knowledge and intimacy-related content. The third session provides positive guidance to help CRC couples discover the positive aspects of their lives. The self-reconstruction of CRC couples was done in the last session. The content of the fourth session is decided according to the actual situation of the individual CRC couple. To accommodate the pandemic, it is considered of great importance to offer booklet copies of course content delivered to CRC couples and provide timely telephone instruction.

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## Author contributions

**Jiali Gong:** Conceptualization, Methodology, Investigation, Writing – Original Draft. **Meizhen Chen:** Investigation, Writing – Original Draft. **Qian Cao:** Investigation, Writing – Original Draft. **Yi Lin:** Investigation, Writing – Original Draft. **Alice Yuen Loke:** Writing – Review and Editing, Supervision. **Qiuping Li:** Writing – Review and Editing, Supervision. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit for publication. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

## Declaration of competing interest

The authors declare that they have no conflicts of interest. The corresponding author, Prof. Qiuping Li, is an editorial board member of Asia-Pacific Journal of Oncology Nursing. The article was subject to the journal's standard procedures, with peer review handled independently of Prof. Li and their research groups.

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## Ethics statement

This study was approved by the Jiangnan University Research Ethics Committee (Approval No. JNU20210918RB08). This study obtained verbal or written informed consent from participants, who were told they may leave the research study at any moment without consequence.

## Data availability statement

The data presented in this study are available on request from the corresponding author. The data are not publicly available due to Participant's personal information.

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