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Through the fog of disease: the challenges faced by and vision of medical staff and patients with regard to intermittent symptom management during colorectal cancer chemotherapy

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Abstract

Background Intermittent symptom management during colorectal cancer (CRC) chemotherapy entails challenges for both medical staff and patients. This study aims to explore the factors influencing and feelings associated with symptom management with the aim of providing a reference for clinical nursing practice.

Methods The researchers used a descriptive phenomenological method to conduct semistructured interviews with 19 medical professionals working in the field of oncology as well as 18 patients in April to July 2024. The interview data obtained from both parties were transcribed, coded, analysed with the aim of identifying themes and categories, described and interpreted; furthermore, the challenges entailed by and visions of symptom management extracted from the data were analysed from different perspectives.

Results Four themes were obtained from the medical staff: the brilliance of the lighthouse, the fog in the dark night, the challenge of the helmsman, and the drafting of the chart. Three themes were extracted from the patients: the perception of the beacon, the symptom coping strategy, and the star map of the helmsman.

Conclusions At present, intermittent symptom management during CRC chemotherapy does not meet patients' needs. In the process of symptom management, patients are more dependent on medical staff, and medical staff are more likely to advocate common decision-making with regard to patients. However, both parties believe that developing home symptom management schemes is highly important, and they highlight the needs to focus on the challenges encountered in the process of symptom management, to overcome information barriers, to enhance communication, to strengthen education and information provision, and to help the community jointly establish a vision for a home multiple support network.

Keywords Symptom management, Perspective, Qualitative research, Chemotherapy interval

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Background

Colorectal cancer (CRC) is currently one of the most common malignancies worldwide according to the most up-to-date statistics provided by the International Agency for Research on Cancer. CRC ranks third among all cancers in terms of global incidence, and it ranks second in terms of mortality rate, thus posing great challenges to the health system [1]. Among all malignant cancers in China, CRC ranks second and fifth in terms of incidence and mortality, respectively, and these figures are increasing; accordingly, this situation has attracted the attention of both domestic and foreign scholars in recent years [2]. At present, a combination of surgical treatment with chemo-radiotherapy is the main treatment mode for CRC; this approach can greatly improve efficacy of treatment and reduce rates of mortality and recurrence [3, 4].

Due to the toxic effects of chemotherapy drugs, chemotherapy patients often experience nausea, vomiting, fatigue, cognitive dysfunction, pain and other symptoms. Due to the cumulative toxic effects of chemotherapy drugs, patients often experience various therapeutic side effects during chemotherapy intervals, such as increased fatigue, nausea and vomiting, which can last for many days [5], accompanied by a loss of appetite, pain, abdominal distension, abdominal pain and other symptoms [6]. Patients with a stoma may also develop more intense intestinal symptoms and complications [7]. This disease is associated with fear, worry, pessimism, negative, loneliness, low self-esteem and a series of psychological problems. Previous studies have revealed that moderate and severe fatigue easily occurs in the process of cancer chemotherapy and continues to occur at home, with an incidence of 45–82.5% [8, 9]. Some studies have also investigated and analysed the symptoms of patients with colorectal cancer during postoperative chemotherapy and reported that the incidences of sleep disturbance, distress and fatigue were more than 90%; the incidences of poor appetite, sadness, nausea and vomiting, pain, shortness of breath, dry mouth, numbness and abdominal distension were between 80% and 90%; and the incidences of constipation and diarrhoea were between 60% and 70% [10]. At the clinical level [4], hospital bed turnover rates are high; accordingly, when chemotherapy patients are not receiving medication directly, the remainder of the chemotherapy interval [11, 12] is usually spent at home, and patients in this context require out-of-hospital management.

CRC patients exhibit a strong demand for symptom management at home because of the various physiological, psychological, social and cognitive problems they face during the chemotherapy interval. Additionally, effective symptom management at home is crucial to patients' recovery and treatment. However, the difficulty of symptom management often increases due to the lack of personnel and medical resources. Moreover, the cooperation mechanisms of multidisciplinary teams are not perfect, and there are obstacles in communication and coordination among various specialties, which affects symptom management [13]. There are two main barriers to symptom management during home care. On the one hand, from the perspective of medical staff, the plan for the management of cancer symptoms used in China is based on the best available clinical evidence, and the users of these guidelines [14] include medical institutions at all levels, as well as oncology nurses, doctors, physicians, rehabilitation personnel, psychological consultants, and other relevant users; the content covered includes dyspnoea, fatigue, anxiety, radiation dermatitis, depression, oral mucositis, anorexia, pain, nausea/vomiting, infection, cognitive impairment, sleep disorders, diarrhoea, and skin reactions, a total of 14 symptoms of assessment, nondrug management, and medication management. However, the management of home symptoms in chemotherapy patients is not standardized. The above guidelines cover all cancer types and lack symptom management guidance for different types of cancer. For example, patients with colorectal cancer may have more severe abdominal symptoms during chemotherapy than patients with lung cancer do, and some patients with rectal cancer may have stoma-associated complications [15]. Therefore, targeted analysis and exploration of symptom management during chemotherapy must be conducted for patients with a single carcinoma of colorectal cancer. In addition, medical staff pay attention to symptoms during hospital management; for home symptom management, more understanding is needed for consultation, follow-up and guidance. Studies also show that in the process of follow-up, medical staff rely only on patients' or patients' family descriptions, which are not good objective evaluations of patients' situations [16]. In addition, in China, the home care model is still in the initial stage [17], and there are no unified standards for home care providers, service objectives, content, and methods, and no effective referral system has been implemented during the hospital and discharge periods [17], thus leading to the absence of a perfect management model; in addition, out-of-hospital medical management is not in place, which has notable impacts on the effects of treatment, patient treatment choices and quality of life. On the other hand, from the perspective of patients, current ways of managing cancer symptoms do not take patients' subjective feelings fully into account. As the medical mode changes, patients' subjective feelings are also an important supplement to objective clinical indicators [18]. If an evaluation of adverse effects solely through observation or the results of objective examinations are insufficient, the patient himself or herself is most suitable person to evaluate his or her experience of symptoms [19]. Moreover, the modes of interaction and cooperation between medical staff and patients in the context of symptom management have not received sufficient exploration [16]. Less attention has been given to the views of CRC patients receiving chemotherapy in terms of their experiences of and suggestions for home symptom management from the perspective of medical staff, thus limiting efforts to improve symptom management. Therefore, it is necessary to explore the challenges entailed by and vision of intermittent symptom management during CRC chemotherapy from the perspectives of both medical staff and patients with the goal- of providing a foundation for overcoming the difficulties encountered during the intermittent symptom management of CRC chemotherapy and improving the out-of-hospital symptom management model used for CRC patients.

In 1994, Larson [20] proposed symptom management theory (SMT), which, after further development and improvement, ultimately included four elements of nursing, namely, people, the environment, health and nursing. Furthermore, this theory gradually came to include three essential and interacting components, i.e., the symptom experience, the symptom management programme, and the symptom management effect evaluation, thus allowing it to form a systematic, theoretical whole. In this context, the symptom experience [21] consists of three dimensions: symptom perception, symptom assessment, and symptom response. SMT serves as a conceptual framework for the factors that affect symptom perception and the related factors that affect symptom management. Investigations of symptom management should first explore symptoms and then discuss their management. The management effect depends on the symptom management strategy, the implementation object and the patient's symptom experience [22]. Both medical staff and patients have different symptom management effects, and the symptom experience is thus a dynamic process. In practice, the symptom experience can be captured by longitudinal or qualitative studies [23], and SMT can guide descriptive, experimental and qualitative research [24].

This study uses a qualitative research method to improve our understanding of the patients involved in CRC chemotherapy in terms of home symptom management-related factors or feelings as well as to guide the construction of an interview outline based on the insights into symptom studies proposed by SMT. Accordingly, this research mainly involves in-depth interviews with medical staff and patients with the goal of provide ideas to support the subsequent construction of a home symptom management scheme.

Methods

Study design

The goal of the semistructured interviews conducted for this research was to obtain the perceptions, current statuses, experiences, and recommendations of both medical staff and patients who have a stake in the implementation of CRC symptom management with regard to home symptom management during the chemotherapy interval as well as the various problems they may encounter in this context. On the basis of a literature review, SMT was used to guide the construction of an outline for this research, after which the research group brainstorming method was used to modify this outline on the basis of preinterviews conducted with 1 doctor, 2 nurses and 2 patients. The interviews were repeated twice, the aspects of the validated interview outline that required revision were identified, and the final interview outline is as follows: Table 1 and 2.

Participants and setting

From April to July 2024, the researchers employed an intentional sampling method to select CRC patients undergoing chemotherapy at a Grade 3 A Oncology Specialist Hospital in Fujian Province, as well as the medical staff of a Grade 3 A Oncology Specialist Hospital and two Grade 3 A general hospitals in Fujian Province, for this research. In the symptom management process, the doctor is mainly responsible for making treatment plans and implementing treatment measures. Nurses are mainly responsible for health education, strengthening the follow-ups, providing different professional knowledge and skills, monitoring disease progress, curative effect evaluations, and meeting the needs of patients outside the hospital [25]; therefore, doctors and nurses were included in the study to explore different perspectives of symptom management.The medical staff were selected to be as diverse as possible in terms of age, sex, professional

Table 1 Interview outline for intermittent symptom management during CRC chemotherapy from a medical perspective

1. Do you believe that symptom management is important during chemotherapy at home? Why?
2. Do you know what symptoms the patient will develop during the chemotherapy interval? What symptom management measures do you currently use to treat your patient?
3. Based on your clinical work experience, how do you think patients should manage their symptoms at home?
4. What factors do you believe will affect the management of patient symptoms at home during the chemotherapy interval?
5. What do you believe that medical staff can do during the process of symptom management during the chemotherapy interval?
6. Do you have any supplements to suggest regarding the management of symptoms during the chemotherapy interval?

Table 2 Interview outline for CRC chemotherapy from a patient perspective

Symptom experience	Symptom perception	1. What symptoms have you experienced during your chemotherapy interval? 2. Have the symptoms you experienced during the chemotherapy interval affected you?
	Symptom reaction	1. How do you manage (deal with) related symptoms when they occur at home during the chemotherapy process? What problems and difficulties have you encountered? What solutions did you implement? 2. Do you believe that these measures have been effective?/Do you believe that you can manage the discomfort associated with these symptoms?
Symptom management needs	1. What do you believe that others have done to help you with your home-based symptom management during your chemotherapy interval? What other forms of help do you need? 2. What symptom management measures and management forms do you want to be provided by us?	
	Beyond the questions listed above, do you have any other opinions or comments regarding the self-management of symptoms during the chemotherapy interval?	

title, academic level, workplace and work experience with the aim of improving the heterogeneity of the sample, and patients were selected to be as diverse as possible in terms of age, sex, educational attainment, and number of chemotherapy sessions for the same reason. The inclusion criteria used for medical staff were as follows: (1) more than 3 years of oncology work experience; and (2) voluntary participation in this study. The exclusion criteria focused on medical staff on rotation and those engaged in further study. The inclusion criteria used for patients were as follows: (1) diagnosis with CRC on the basis of relevant diagnostic criteria and only received chemotherapy; (2) aged 18 years or older; and (3) understood the content of this interview and volunteered to participate in this research. The exclusion criteria focused on (1) patients with other malignancies or major organic diseases and (2) patients with mental illness or those who had recently used antipsychotic medication.

Data collection

Phenomenological research was conducted to collect data via face-to-face, individualized in-depth interviews. A quiet, comfortable, well-lit space in which no interference was anticipated was selected as the research site(The reception room in the hospital), and the interviews were conducted at agreed-upon times. Before the interviews, the purpose, method, and content of the study were introduced to the participants alongside the principle of confidentiality employed in this research; furthermore, the interviewees' comprehension and cooperation were determined, and signed informed consent forms regarding the recording of the interviews were collected.

Data analysis

The interview and data sorting processes were conducted simultaneously. In addition to the textual content, the body language and emotional language used by the interviewees were recorded. The audio recordings were transcribed into textual form within 24 h following the end of each interview, and the researcher sorted and classified the text, encoded recurring content, and integrated the course thus developed one by one with the assistance of NVivo 11.0 software and the Giorgi method of data analysis [23]. The data were analysed, and the results were summarized, following which the data were reconstructed and compared in light of certain themes, and the final themes were refined.

Quality control

① Semistructured interviews based on systematic qualitative research methods were conducted by the researcher before the study, and no references to similar studies were made prior to the study. The entire research process was conducted in the absence of the influence of the researchers' personal subjective judgement and understanding and without personal thought with the goal of making new discoveries. ② Before the interview, the researcher communicated with the interviewees on many occasions to establish good and trusting relationships with them, thereby ensuring the reliability and validity of the interviews. To obtain the opinions of the interviewees, an appropriate, quiet and comfortable environment was chosen for the interviews. The interviews were reviewed and compared after they were completed with the aim of determining the completeness of the content of the interview process. ③ After this transcription process, the researcher listened to the recorded interviews and checked them against the first draft of the text. According to the content of the recordings, the first draft was further checked and corrected, following which another research team member reviewed the data to ensure the accuracy of the transcribed information. All the results of this study were drawn from the interviews, and brief quotations pertaining to each topic are cited to support the themes revealed in this research. ④ During the process of data analysis, continuous and frequent communication through group discussion was used to ensure the reliability of the study and to mitigate the potential issues caused by researcher bias or subjective assumptions.

Results

Participant characteristics

According to the standard that the information appeared repeatedly and no new themes reached saturation, finally,19 medical interviewees were identified, for privacy purposes, their names are replaced by numbers N1-N19; 18 patient interviewees were interviewed and their names are replaced by numbers P1-P18,19 medical staff (5 males, 14 females) and 18 CRC patients (11 males, 7 females) were interviewed. The average age of medical staff was (37.67 ± 9.55) years, the age range was 26 to 59 years, the average working years was (15.42 ± 9.06) years, and the working years range was (3 to 32) years. The mean age of patients was (56 ± 10), ranging from 36 to 73 years. The remaining general information is shown in Tables 3 and 4.

We discuss symptom management during the CRC chemotherapy interval from the perspectives of both medical staff and patients, thereby revealing the unique insights and needs that characterize this context from different perspectives as well as revealing certain differences and commonalities. On the basis of the dimensions and research results obtained by reference to SMT, the specific themes and subthemes are as follows.

Part I: Views and suggestions concerning symptom management during CRC chemotherapy intervals from the perspective of medical staff

According to the analysis of data collected from 19 medical staff, data saturation was reached. Ultimately, 4 themes and 12 subthemes were obtained; the detailed themes and illustrative references are presented in Table 5.

Table 3 General information of the 19 medical interviewees

Number	Sex	Age /year	Record of formal schooling	Professional ranks and titles	Working life / year	Work department	Working hospital
N1	female	31	undergraduate course	primary nurse	9	Department of Gastrointestinal Oncology	Cancer specialist hospital
N2	female	25	undergraduate course	primary nurse	3	medical oncology	general hospital
N3	female	45	undergraduate course	nurse-in-charge	23	Department of Gastrointestinal Oncology	Cancer specialist hospital
N4	female	27	Master	chief physician	4	Department of Gastrointestinal Oncology	Cancer specialist hospital
N5	female	37	Master	nurse-in-charge	11	Department of Gastrointestinal Oncology	Cancer specialist hospital
N6	female	46	undergraduate course	associate chief physician	22	Department of Gastrointestinal Oncology	Cancer specialist hospital
N7	female	59	undergraduate course	chief superintendent nurse	28	stomach counterinsurgency	general hospital
N8	male	26	junior college education	chief physician	3	Department of Gastrointestinal Oncology	Cancer specialist hospital
N9	female	43	Master	chief superintendent nurse	20	Department of Gastrointestinal Oncology	Cancer specialist hospital
N10	female	50	undergraduate course	co-chief superintendent nurse	32	medical oncology	general hospital
N11	female	37	undergraduate course	nurse-in-charge	12	stomach counterinsurgency	general hospital
N12	female	48	undergraduate course	co-chief superintendent nurse	21	stomach counterinsurgency	general hospital
N13	male	36	Master	associate chief physician	11	Department of colorectal Surgery	Cancer specialist hospital
N14	male	47	Master	associate chief physician	21	Department of colorectal Surgery	Cancer specialist hospital
N15	female	49	undergraduate course	co-chief superintendent nurse	27	Day ward	Cancer specialist hospital
N16	male	28	junior college education	primary nurse	6	medical oncology	general hospital
N17	female	44	undergraduate course	nurse-in-charge	21	Department of Gastrointestinal Oncology	Cancer specialist hospital
N18	female	33	Master	nurse-in-charge	8	stomach counterinsurgency	general hospital
N19	male	37	Master	physician	11	Department of colorectal Surgery	Cancer specialist hospital

Table 4 General information of chemotherapy patients for CRC ($n = 18$)

Number	Sex	Age /year	Degree of education	Disease type	The number of chemotherapy
P1	male	55	Junior high school and below	carcinoma of colon	11
P2	female	58	Junior high school and below	rectal carcinoma	5
P3	female	46	Junior high school and below	rectal carcinoma	9
P4	male	71	Junior high school and below	rectal carcinoma	3
P5	male	73	Junior high school and below	rectal carcinoma	1
P6	male	60	Junior high school and below	rectal carcinoma	5
P7	female	64	Junior high school and below	carcinoma of colon	3
P8	male	64	senior middle school	carcinoma of colon	2
P9	male	51	senior middle school	rectal carcinoma	6
P10	male	61	senior middle school	carcinoma of colon	7
P11	male	61	senior middle school	carcinoma of colon	21
P12	male	59	special school	rectal carcinoma	3
P13	male	69	special school	carcinoma of colon	10
P14	female	47	junior college	carcinoma of colon	4
P15	female	50	junior college	carcinoma of colon	18
P16	female	48	undergraduate course	carcinoma of colon	23
P17	male	37	undergraduate course	carcinoma of colon	6
P18	female	36	Master	rectal carcinoma	8

Theme 1: The brilliance of the lighthouse

Patients' journey through illness is like a long and arduous voyage, where medical staff act as lighthouses, illuminating the path and guiding them through the fog to a harbor of hope, employing various methods to manage patients' symptoms, thus resemble a lighthouse that emits a warm light.

Subtheme 1: Symptom management during the hospitalization period

During chemotherapy hospitalization, there were existing symptom management measures, including patient education, pharmacological interventions, and guidance. These measures vary slightly among different hospitals and departments. However, only four respondents mentioned the provision of psychological support or counseling.

Subtheme 2: Symptomatic care after discharge

Twelve respondents reported that the time spent by patients in the hospital is brief and that symptom management requires more attention at home; At the time of discharge, patients receive education(symptom assessment, time of blood sampling, time to return to the hospital for chemotherapy, etc.), preventive medication and guidance and postdischarge follow-up, in the form of phone calls, WeChat group chats, and WeChat public accounts, etc.

Theme 2: The fog in the dark night

Although symptom management involves a series of guidelines and management measures, many problems and external challenges continue to present difficulties, resembling a "fog" in the dark night. These issues include the role overload of medical staff, information barriers, economic constraint symptom management, caregiver escape and life imbalance, and difficulties accessing medical services.

Subtheme 1: Role overload of medical staff

Fifteen respondents indicated that the role overload they faced as medical staff was reflected in heavy clinical work tasks and high levels of career development pressure (with regard to promotions, paper publication and participation in research).

Subtheme 2: Information barriers

In symptom management, information barriers are constituted by patients' and families' levels of knowledge, disease awareness, communication obstacles due to dialects, issues pertaining to confidentiality of illness, and varying effectiveness of education provided by different healthcare providers. Eleven respondents reported that issues pertaining to confidentiality of illness is common and hinders symptom management, making it difficult for patients to make optimal decisions.

Subtheme 3: Economic constraint symptom management

The vast majority of respondents reported that economic issues limit symptom management and that high treatment or drug costs may lead to patient withdrawal or the interruption of treatment, which can, in turn, impact the efficacy of symptom control and treatment. If the formulation of symptom management programmes, rehabilitation therapists, nutritionists and other resources entail costs, patients may not pay.

Table 5 Themes, subthemes and illustrative references from the perspective of medical staff

Themes	Subthemes	Illustrative quotations
Theme 1: The brilliance of the lighthouse	Subtheme 1: Symptom management during the hospitalization period	Quotation 1: "General symptom management. In addition to the role of our nurse as a guide, there is a healthy prescription, that the doctor may be more standardized to implement early interventions with medication, some antiemetic drugs or antidiarrheal agents." (N11) Quotation 2: "We are enhancing our focus on symptom management by introducing a standardized no-vomiting ward and utilizing informational boards to promote standardized cancer treatments." (N17) Quotation 3: "Because chemotherapy drugs chemotherapy will help educate him, there is some psychological support, and we may communicate with the family, let them give more support… We should not only pay attention to the patient's psychological counselling; we may also want to pay attention to the psychological counselling of the family members." (N7)
	Subtheme 2: Symptomatic care after discharge	Quotation 4: "We now have a follow-up system, and our department also has a special follow-up mechanism… Just ask about some medication, some adverse reactions, telephone follow-ups, and their own doctors and patients; he has a doctor–patient WeChat group, and they will also have a reaction in it. For example, if he has any discomfort, he will contact the doctor and the nurses." (N5) Quotation 5: "Maybe some of the doctor's discharge instructions are a little more comprehensive than our nurses, including the time he draws blood and the time he returns to chemotherapy." (N11) Quotation 6: "There are many WeChat public accounts in our department. We push some disease-related knowledge, all kinds of… But only knowledge of tweets… There is a medical assistant in our department, some other questions without a chemotherapy plan; she is responsible for the one-to-one communication via WeChat." (N19)
Theme 2: The fog in the dark night	Subtheme 1: Role overload of medical staff	Quotation 7: "Just like now, we should not only publish papers but also perform clinical work; we need to do research." (N9) Quotation 8: "Because the time of the director and the doctor is very limited, there are also contact, but there are more operations, and there may not be timely communication; the current clinical work task is still very heavy." (N19) Quotation 9: "Because for the time being, our medical resources in China are not so sufficient, and the clinical work pressure associated with medical care is quite high; now, there is still the pressure of scientific research." (N16)
	Subtheme 2: Information barriers	Quotation 10: "We often have a lot of nurses, when we go to do the mission of the hospital, not all by the same person." (N12) Quotation 11: "Of course, some are inevitable. For example, some elderly people face language barriers; they cannot understand what we say, and we can speak only Mandarin, so we have to communicate with their families." (N17) Quotation 12: "The education level of patients and their family members affects his communication with doctors and nurses. He has difficulty understanding what doctors and nurses tell him,…. The understanding of their disease is not enough, or the information, maybe there are a lot of us Chinese people like protective treatment, Even some people don't know they have cancer. They may not be aware of the disease itself…" (N11)
	Subtheme 3: Economic constraint symptom management	Quotation 13: "Some patients feel that they don't want to take that much medicine, that it costs a lot of money, and they will stop it." (N4) Quotation 14: "And patients aren't necessarily willing to pay if you charge them. Yes, you said, I want to get a recipe, you want to let him spend a dozens of dollars; he may think, I can spend dozens of dollars to eat a meal, why should I spend dozens of dollars to give you a recipe home." (N12) Quotation 15: "Or feel that some people are afraid of spending money; they do not want that (prescribed medicine)… They may face some economic problems, chemotherapy is uncomfortable, the economy is not good… Otherwise, there is no money, no money, you don't want to do it (chemotherapy)." (N13)
	Subtheme 4: Caregiver escape and life imbalance	Quotation 16: "With the importance of the patient, with the family members, with the degree of support, possible care. Some people are some people for various reasons; children have to go to work or something; he said that he may have a difference in care. For example, with regard to her mother, sometimes she cannot take care of her; after all, she is old." (N14) Quotation 17: "For example, many of them are only children; children are very busy, plus the lack of manpower at home; he (the patient) will overcome (symptoms) by himself, which may be a big factor affecting home management." (N7) Quotation 18: "It is a more costly one; because they are at home, sometimes when the symptoms are more serious, the family may not have a way that at any time, send someone to take care of, or the family does not care about." (N2)

Table 5 (continued)

Themes	Subthemes	Illustrative quotations
	Subtheme 5: Difficulties accessing medical services	Quotation 19: "His resources are not enough, he is very remote, he cannot live in… Even if he felt very anxious to know that he wants to seek medical treatment, it is far away from the county seat to the place where it can be solved. Your half-day's drive will also affect the symptom management." (N9) Quotation 20: "In fact, the chemotherapy patients in our department are very fast, and the time they spend in the hospital is very short… His psychological symptoms above, actually, we also do not understand; namely, we do not have a lot of time and energy, unless he has serious mental illness, but generally very few… So, in fact, to him in fact, the psychological contact above is not much." (N18) Quotation 21: "Because every time he has to draw blood and prescribe medicine, it may not be very convenient for them to seek medical treatment; it is still a bit like a medical environment. Some people live far away; it may not be convenient for them to draw blood and review." (N11)
Theme 3: The challenge of the helmsman	Subtheme 1: Multiple symptoms at home	Quotation 22: "Because now the surgery is more than the 3-week plan; the 3-week plan is here, and he only does half a day of treatment, go back to take 14 days of medicine, in fact, his discomfort is at home… At home, we should look at the side effects of our drug and the disease itself, which will affect each other, leading to a lot of symptoms." (N14) Quotation 23: "Because we have some of the side effects of chemotherapy, it may appear a few days after returning, especially the first five days of chemotherapy, and it may have some chemotherapy-related side effects… Gastrointestinal reactions and abdominal pain, these symptoms may appear, and some patients with a stoma, if they have stoma problems, they are very troubled." (N4)
	Subtheme 2: Internal conflicts of faith	Quotation 24: "… Therefore, what the doctor thinks is important, but what patients think is not necessarily important. With regard to the patient's own feeling and the importance of medical judgement, subjective and objective indicators may be combined with symptom management." (N9) Quotation 25: "Some of his consciousness, we have explained that we need to draw blood, but he said that there has been such serious anaemia, we cannot draw blood; it is such a situation, in fact, that their whole consciousness is a problem, with regard to their lack of awareness of the disease." (N17)
Theme 4: Drafting a nautical chart	Subtheme 1: Establishment of a home support system for patients	Quotation 26: "I think that you can make good contact with the community, because many people, like patients who want to draw blood, can go to the community hospital without having to go to our hospital, if you can make better contact in the community. The main thing is education and communication to make it easier for patients." (N19) Quotation 27: "That is, he may pay more attention to the doctor, because sometimes the nurse repeatedly stressed that he may not listen carefully or may not pay attention to it, that he may not necessarily have it in mind; it is more possible for the medical care team to unite, to let patients pay attention to these aspects." (N3) Quotation 28: "That is to say, in-depth follow-up, maybe with enough human resources, can perform regular family follow-up like the community; it is more recommended to mobilize the resources of community medical treatment, ah." (N2)
	Subtheme 2: Patient education and information provision	Quotation 29: "This kind of home for every family, to ask him to solve this problem. Because many of the patients are either thin or vomiting. Like, this is not what our hospital can solve for him… We must rely on the patient and the family member to cooperate together, you can do it… Diet is one piece, exercise is one piece, and symptom assessment is one piece." (N12) Quotation 30: "Food is the life of the people; diet, of course, also includes eating more fresh vegetables, fruits… The effects of drugs, side effects, etc., or some other aspects, such as possible exercise… Some people are very afraid of pain; you do not want to move the people, you have to encourage him; the emotional value is very important." (N7) Quotation 31: "you give him a plan, you must urge, track, evaluate, even use some encouraging measures to let him to do it, to see if he has no effect… Still, you can use a few therapies from Chinese medicine, such as Chinese medicine conditioning and so on." (N18)

Table 5 (continued)

Themes	Subthemes	Illustrative quotations
	Subtheme 3: The construction of the scheme should be based on the "Tri-Dimensional and Tri-Attribute" model -The "Tri-Dimensional" construction: Scientific, systematic, and individualized -The"Tri-Attribute" construction: Operability, innovativeness, and sustainability	Quotation 32: "Currently many guidelines feature symptom management, but they focus on a single form of management, not a systematic one… According to his symptoms, you must choose focus symptoms; you cannot build the programme for all systems. For this kind of patient, the most common thing, the most important, is the most troubling for them to intervene; I think that it is still very necessary… I think that it is to have characteristics, if it is innovative, and really can be landed, meaningful, this may be better. It should not be too complex but rather more grounded, and equability is relatively high… It is more important for you to evaluate whether this scheme is effective or not and to determine where its feasibility, its penetrability, its significance are, whether it still has some deficiencies, whether it can be improved in this way." (N18) Quotation 33: "How do you guide these, to have individual, targeted care; we listed the things that have we can take, the market we can get to absorb the things… We also said that the movement must be step by step, to see. Of course, when we guide to see is to see the individualized… How to deal with home, to what extent; you must go to seek help, medical treatment, time spent with them to give some doctors and nurses contact information; let him have someone contact for the first time…" (N7) Quotation 34: "In fact, home care should be based on the needs of patients as the most important guide to care… I think that WeChat is very convenient, both voice and text; it can also have video, and it is actually more convenient than the phone. Now, WeChat is more square than that; this is an app that they have mastered, based on this mature platform; it is better for them, rather than to make them learn to use an app…." (N3) Quotation 35: "I think that the paper is paper after all; it features a lot of a dynamic feedback, and the whole family together, we should intervene according to the actual situation of the patient; how to make personalized treatment for him, this is the most critical… I suggest that you make these precautions or measures more detailed and more operational. Instead of taking some generic ones such as a literature class before, but you actually you can't use it… It's a bit like a critical value, how far do you seek medical attention… Grading management, how is the initial stage of pain, how is the later stage, how to deal with different symptoms…" (N17) Quotation 36: "A prior precaution before the onset of symptoms or some treatment for the onset of symptoms… On the other hand, you must remind them, for example, through follow-up; it may be this kind of reminder, a kind of urge…Actually I think less a little older they don't go to turn, suggest that health education lecture hall, you can also qr code, and then his class and code, or WeChat introduced to me, let them open, or TikTok that may brush, open point open see that, short video way and then the kind of public… We have no way to identify one of its core symptoms" (N1)

Table 6 Topics, subthemes, and illustrative references from the perspective of patients

Themes	Subthemes	Illustrative quotations	
Theme 1: Perception of waypoints	Subtheme 1: Multidimensional distress due to symptoms		Quotation 1: "The front at the beginning is okay; the back is to vomit, vomit, nausea, the front and hair, the back of the medicine; at home, there is no energy, which is uncomfortable, sick, all uncomfortable." (P4) Quotation 2: "I want to sleep after chemotherapy. My mouth is dry, as if I am a little tired; I want to sleep, and I do not want to eat." (P8) Quotation 3: "Now is the hand numbness, and when I have just finished, I do not want to eat; I am very tired, and once diarrhoea was very serious; there is abdominal pain behind, and then I lost a lot of weight; sometimes I have little spirit." (P11)
Theme 2: Symptom response strategy	Subtheme 1: Polarity of disease-adaptive behaviour	Active and adaptive coping behaviour	Quotation 4: "Because I found some online small red books or something; I have their search summary. The patients themselves summed it up, and I integrated it again and found that there are indeed some rules. I just follow it myself." (P18) Quotation 5: "After, I bought protein powder but also through or to consult others or the internet, use the internet to check others, I will do this." (P8)
		Nonconstructive coping behaviour	Quotation 6: "at the beginning of chemotherapy, the early reaction is very big, nausea, vomiting, that I am myself am boiling, ah; also, I have no way to deal with the result of dehydration, or I go to the hospital to get a drip." (P6) Quotation 7: "the doctor had said what I cannot eat; I think that it does not matter, as usual, but from that day, I do not know to eat what causes the stomach to distend, behind the pain, to the hospital to say intestinal obstruction, and they also inserted a gastric tube." (P13) Quotation 8: "I have always been in good health; it's a little uncomfortable and nothing, but I do not take it to heart." (P16)
Theme 3: Star charts of the helmsman	Subtheme 1: Requirements for information acquisition and the corresponding pathway	Lack of relevant knowledge and access channels	Quotation 9: "For the side effects of this piece, of course, there is a drug, but now are all added to the doctor's WeChat; we can timely address uncomfortable situations or receive timely feedback, and he suggested what we need to do… In fact, more information acquisition is needed." (P9) Quotation 10: "For a while you do not know how far I had to go to see a doctor, so I talked to him about my WeChat with the attending doctor. But sometimes, he will certainly be busy, and he will not necessarily reply immediately." (P11) Quotation 11: "I think the most needed help is during the early stage, because I was confused during the early stage about the information I obtained. Yeah, it's not clear how to get the information, what's diarrhoea." (P15)
		Advice regarding ways of obtaining information	Quotation 12: "But it may be specific; for example, diarrhoea may be related to the diet, but our diet is specific to the real thing. I cannot, say, eat the apple; can I eat rice, can I eat this kind of dish? You only judge it by yourself. There are also some experiences accumulated, such as with the previous vegetable stem, or beans, what, Dutch beans, I see may have crude fibre; I dare not eat what, it can only be this kind." (P14) Quotation 13: " She thought that we could get some of these cancer friends. Yes, in fact, I found that there is an anticancer association, some, but I found that it did not fall into the field; it felt a little lofty… But it is best not to simply say that patients should have some professional personnel, such as nurses, doctors and so on to do some guidance. Such as when you see what tumour markers are abnormal and try some explanation; sometimes, our patients don't know and grow more worried, so we emphasize scientific things as much as possible, such as by explaining the meaning of some tumour markers and what to focus on, what this patient knows; thus, he will not experience anxiety."(P18) Quotation 14: "With regard to diet, I think I can give a very specific guidance, a list; you don't say it's easy to digest, you can, and I have a summary, such as fruit for a kind of cancer, patients you can eat some things such as apples, grapes, bananas, strawberries, blueberries… You can directly write out as such, so the patient is not so confused, or you can indicate specific measures, what cannot be eaten or must be limited."(P12)
	Subtheme 2: Exercise, diet and lifestyle errors		Quotation 15: "Our diet is basically light. Of course, I hope to have personal tutoring, such as more protein or what, this is with us. I had green cabbage, but the doctor told me I couldn't." (P9) Quotation 16: "In terms of sports, it is true that I also have no such part; I may not know how to move, I dare not move, ah, or just walk, walk, go for a walk." (P17) Quotation 17: "the doctor said to buy protein powder and nutrition solution, but I think that it is not necessary to buy; malnutrition due to chemotherapy is uncomfortable, beyond what index is too low, so I stopped for a period of time." (P6) Quotation 18: "I heard that Chinese medicine has a paste and smear; it was said that it can treat cancer, and then I did not come to chemotherapy. I later found that it had no use and was scolded by the children." (P5)

Table 6 (continued)

Themes	Subthemes	Illustrative quotations	
	Subtheme 3: Moderate construction of social support networks	Alienation from social support	Quotation 19: "A little not like normal people, say this, like seeing normal people is a little embarrassing. For example, if you have cancer, you go home; outside, the people dare not ask, are so, and many children will avoid the question, no." (P16) Quotation 20: "outside, some people say, you have chemotherapy, have what, radiation ah, what is very taboo; they specifically avoid it, that we also don't matter, ah; you feel very speechless." (P15)
		Compassion pressure	Quotation 21: "People in the family know that you have this cancer, and they often send this to send that; holiday dinner is also a variety of ask me about the body; it makes very uncomfortable, like they are always saying to me, I am not like normal people, and they always tell me that I have this disease." (P2) Quotation 22: "my wife is really good to me; since I have suffered from this disease, she has been taking care of me, she does not let me do things, but I am very guilty, and I feel suffering due to this disease; it hits her very hard, and I seems to become a waste person; nothing can be done." (N17)
	Subtheme 4: Enhance the self-efficacy of treatment	Quotation 23: "I now, now, we get sick; we just want to get better day by day, just want to get better; other things are nothing, not uncomfortable." (P5) Quotation 24: "Now I just don't want to do anything; I just want to get better quickly, uncomfortable, not uncomfortable, with what medicine if I listen to the doctor—as long as it is effective, I can recover; this is what I am most concerned about." (P14)	

Subtheme 4: Caregiver escape and life imbalance

Eighteen respondents reported that caregiver support for patients is an important external factor that affects symptom management, that the establishment of a caregiver support network is a complex process, and that caregivers may resort to avoidance because of difficulties they face in coping with the pressures of the role, a lack of availability due to other responsibilities or work, and their unwillingness or inability to take on caregiving responsibilities for a variety of reasons.

Subtheme 5: Difficulties accessing medical services

The short duration of hospital stays and the medical environment that focuses less on psychosomatic symptoms create difficulties for patients in accessing medical services. Moreover, symptom management is further complicated by cumbersome medical procedures and inconvenient transportation for urban medical visits.

Theme 3: The challenge of the helmsman

In the journey of coping with illness and symptoms, medical staff act as lighthouses offering stable guidance. However, patients, operating as helmsmen, must not only find their way through the turbulent "seas" but also face internal and personal challenges.

Subtheme 1: Multiple symptoms at home

During hospitalization, chemotherapy patients can receive timely interventions from healthcare providers. However, during the intermission period at home, due to the cumulative toxicity of chemotherapy drugs, underlying diseases, or complications, patients are prone to multiple symptoms. The majority of respondents reported that gastrointestinal symptoms are particularly prominent during the patients's home period, and patients with stomas need to pay more attention to related symptoms.

Subtheme 2: Internal conflicts of faith

Most respondents claimed that in their clinical work experience, there are often conflicts between patients' treatment beliefs, adherence, and their levels of knowledge and education. Patients' beliefs about treatment and their psychological states further impact symptom management and treatment adherence.

Theme 4: Drafting a nautical chart

With regard to ways of managing symptoms and reaching the "other side of victory" more effectively, as part of the construction scheme and its implementation, the respondents proposed various expectations and suggestions regarding the drafting of a nautical chart.

Subtheme 1: Establishment of a home support system for patients

In the context of symptom management at home, the importance of patients' home support systems should be emphasized, including not only the participation of family members and caregivers but also social support and the integration of community resources, the potential role of community hospitals and family physicians, and medical cooperation. A total of 17 respondents reported that cooperation among doctors, nurses and patients was the core requirement for establishing such a home support system.

Subtheme 2: Patient education and information provision

Emphasize the importance of providing patients with disease knowledge and symptom management guidance, including diet and nutrition, exercise, and medication, to enhance patients' self-management capabilities, and adopt incentive mechanisms. As two respondents mentioned, this approach can be combined with traditional Chinese medicine interventions.

Subtheme 3: The construction of the scheme should be based on the "Tri-Dimensional and Tri-Attribute" model

The "Tri-Dimensional" construction: Scientific, systematic, and individualized. Respondents suggested that the construction of the scheme should be based on a theoretical framework, comprehensively follow guidelines, and integrate elements such as symptom monitoring, assessment, early warning, and tiered interventions. By combining these elements with patients' needs and individual characteristics, also should efficiently target core symptoms.The "Tri-Attribute" construction: Operability, innovativeness, and sustainability. The proposed measures should be specific and feasible, with a diversified format, such as paper manuals, videos, mobile apps, public accounts on WeChat, small programs, lecture halls, and logs or diaries. Regular follow-ups and dynamic tracking should be implemented to ensure continuous feedback and adjustment of the scheme.

Part II: Needs and opinions pertaining to home symptom management for CRC from the perspective of patients.

Data saturation was reached after the content of interviews with 18 patients was analysed. Ultimately, 3 themes and 6 subthemes were obtained. The detailed themes and illustrative references are presented in Table 6.

Theme 1: Perception of waypoints

In symptom management, patients act as helmsmen, using symptoms as navigational markers to sense and adjust their treatment and lifestyle, thereby ensuring that the boat that represents their health does not deviate from the intended course.

Subtheme 1: Multidimensional distress due to symptoms

The ability of chemotherapy drugs to kill tumour cells can simultaneously also affect normal tissues and cells and cause different degrees of toxic effects. During the chemotherapy interval, the degree of difficulty varies among different people, but all patients experience multidimensional symptoms; nonetheless, it is worth noting that most patients report nausea, poor appetite, and other gastrointestinal reactions, which differ in terms of degree.

Theme 2: Symptom response strategy

Patients adapt to their perceptions of the symptoms of the disease by employing positive or negative coping strategies that are polarized, including active adaptive coping behaviours and nonconstructive coping behaviours that involve negative coping or avoidance.

Subtheme 1: Polarity of disease-adaptive behaviour

The bipolarity of disease adaptation behaviors is manifested in the starkly different reactions and psychological states that patients exhibit when facing symptoms.**Active and adaptive coping behaviour** In the face of symptom distress, patients actively seek disease-related knowledge, treatment options, and methods for symptom management. They maintain a positive psychological state and proactively seek advice and assistance from their physicians.**Nonconstructive coping behaviour** Some patients adopt negative or avoidant non-constructive coping behaviors, ignoring symptoms or failing to take action, which can lead to symptom exacerbation, endangering their health and subsequent treatment.

Theme 3: Star charts of the helmsman

The needs for symptom management serve as a key "star chart" for patients to guide symptom management plans or health management programs.

Subtheme 1: Requirements for information acquisition and the corresponding pathway

Lack of relevant knowledge and access channels A total of 16 patients expressed a lack of symptom assessment and coping knowledge; moreover, in terms of information access, patients felt that being able to communicate regarding health care is one of the most effective approaches in real time.**Advice regarding ways of obtaining information** Patients expressed the hope that the suggestions or management measures communicated to them would be accessible, real-time, concise, specific and clear, and they proposed the use of a WeChat group (such as a patient group or medical communication group) or the release of educational videos. Three patients with different online information transmission preferences mentioned specific advice: interpretation of the review indicators can help alleviate their feelings of anxiety and uncertainty regarding their illness.

Subtheme 2: Exercise, diet and lifestyle errors

The vast majority of patients focus on the management of exercise, diet, and lifestyle. However, there are common misconceptions regarding bland diets and nutritional supplements such as protein powders, as well as misunderstandings about exercise and treatment modalities. These misconceptions can lead to malnutrition, lack of exercise, and over-reliance on traditional Chinese medicine techniques. Notably, patients with colorectal cancer have particularly strong needs regarding diet and nutrition.

Subtheme 3: Moderate construction of social support networks

Based on patient needs, a social support network composed of caregivers, family and friends, neighbors, community members, and healthcare professionals should be constructed. However, the construction of such a network needs to be moderate; both overly dense and overly sparse networks may fail to provide the necessary support.**Alienation from social support** Alienation from relatives and friends, as well as caregivers shirking their responsibilities or deliberately distancing themselves from patients due to chemotherapy, can lead to an overly loose social support network.**Compassion pressure** When family members, friends, or caregivers exhibit excessive concern, patients may feel overemphasized in their illness status, leading to increased stress and the formation of an overly dense social support network.

Subtheme 4: Enhancing the self-efficacy of treatment

The vast majority of patients focus more closely on whether they can recover from the disease or how effective the treatment is, and one important demand of patients pertains to the self-efficacy of the treatment.

Part III: Similarities and differences in the intermittent symptom management of patients receiving CRC chemotherapy from different perspectives.

This study explores the management of symptoms associated with CRC chemotherapy from the perspectives of both medical staff and patients, thereby revealing unique insights and needs from different perspectives. Certain differences and commonalities were revealed by this research, which are presented in Table 7.

Therefore, medical staff must pay more attention to individuals' needs and psychological states, and patients need more support and educational resources to improve their symptom management ability. Future research and practice should focus on bridging these differences as well as jointly developing a patient-centred approach, facilitating medical staff support and providing social resources that can integrate symptom management plans completely.

Discussion

Overcoming the challenges associated with the roles of medical staff and improving the effectiveness of symptom management

Both the role overload faced by medical staff, who should serve as guides for symptom management, and the existence of information barriers between medical staff and patients have important impacts on the effectiveness of symptom management. Several domestic and foreign studies [26–28] have reported that medical staff generally face moderate to high levels of occupational stress and that occupational stress affects the physical and mental health of healthcare workers in several ways. Furthermore, some scholars [28, 29] have conducted qualitative interviews that have revealed that the role overload faced by medical staff is now characterized by occupational pressures such as those pertaining to promotions and appraisals, excessive workloads, and the difficulties encountered in doctor−patient relationships; these findings are consistent with the results of this study. Previous studies have also reported [30] that nurses face high levels of pressure and challenges in their work, which may decrease their work input and thus cause them to consider leaving their jobs. Therefore, medical staff must establish a balance between their demanding clinical work and the career development pressures that they face while simultaneously overcoming the communication barriers that separate them from patients, thus enabling them to provide effective symptom management. Future efforts in this context should focus on reducing the work stress experienced by medical staff and minimizing unnecessary workloads; strengthening multidisciplinary team collaboration and optimizing workflows; providing professional development opportunities for medical staff with the goal of alleviating the promotion pressures they face; and providing symptom management training to increase staff members' professional competence. Medical staff themselves must also improve their research and medical skills continuously, maintain a balance between work and life, and learn to seek help when necessary.

Responding to the needs of and challenges faced by patients and improving their self-management ability

Self-management behaviour has been identified as an important component of the intermittent management of cancer patients. The impact of knowledge on the self-management behaviours of cancer patients is the most direct effect observed in this context, and it facilitates

Table 7 Similarities and differences in intermittent symptom management of patients receiving CRC chemotherapy from different perspectives

Perspective SMT dimension	Medical staff	Patients	Differences	Commonalities
Role and positioning	Serving as a beacon for symptom management, thereby providing direction and support.	As a helmsman for symptom management, expressing feelings regarding the symptomatic response.	Medical staff focus more closely on guidance and support, while patients focus more closely on symptom perception and real-time feedback.	Both parties share an emphasis on the importance of symptom management.
Symptoms of perception and assessment	Evaluation and assessment based on medical standards and clinical experience.	Identifying and understanding the situation in line with their personal experience and feelings.	Medical staff focus more closely on objective assessment, while patients focus more closely on subjective experience.	Both parties perceive the symptoms to facilitate effective management.
Symptomatic reaction	Implement various interventions, such as by adjusting treatment programmes or providing psychological support.	Emotional responses, behavioural changes, and adaptability to treatment.	The responses of medical staff are more biased towards professional interventions, while patients' responses are more personal.	Both parties must respond to symptoms with the goal of optimizing management strategies.
Symptom management strategy	Establish a home support system for patients, develop a home symptom management programme based on the "Tri-Dimensional and Tri-Attribute" model, and strengthen patient education.	Real-time, specific, and clear information and advice.	Medical staff emphasize active adaptive coping behaviours, while patients are more willing to listen to physicians but emphasize the accessibility and utility of information.	Both parties agree regarding the importance of information needs, but the details and real-time characteristics of their demands differ.
Symptom management effect	Patients actively participate in the process of symptom management and the formulation of a treatment plan, help establish a comprehensive support system, and seek to reduce clinical work pressure.	Participation in the symptom management process can enhance the self-efficacy of the treatment and focus on the actual feelings that occur in the process of symptom management.	Medical staff focus more closely on the formulation and implementation of programmes, while patients focus more closely on symptom relief and the improvement of their quality of life.	Both parties agree regarding the importance of symptom management with respect to improving patients' quality of life and treatment outcomes
Challenges associated with symptom management	Role overload, information barriers, caregiver avoidance, etc.	Multidimensional symptom distress, diverse coping strategies, lack of knowledge and skills pertaining to symptom management, etc.	The challenges faced by medical staff are more likely to result from occupational stress and resource constraints, while those faced by patients are more likely to result from personal experiences and support needs.	Both parties face challenges, but their specific performance and needs differ.

easy identification and intervention through education, training, dissemination and counselling services [31]. This situation is consistent with the results of the analysis conducted for this study, which highlighted strong patient needs at the level of symptom management knowledge. In addition, this study revealed that patients exhibit obvious demands with respect to information acquisition, exercise and diet, and social support. This finding applies to an expert consensus concerning the management of tumour integration and rehabilitation (2024) that has been proposed [32] regarding the tumour recovery and maintenance period. Namely, patients must continue to focus on physical training, nutrition and weight management, daily life skills training and psychological and social support goals. This consensus also suggests that the self-management ability of tumour patients should be cultivated and that patients must be encouraged to promote disease rehabilitation via their health behaviour. Accordingly, in the future, patients' education and self-management ability should be improved, efficient interventions should be implemented to address the core symptoms associated with the chemotherapy interval, and personalized education plans should be develop to meet patients' needs. Moreover, a peer support system (which may involve, e.g., patient exchange meetings) should be established to help patients and caregivers master disease knowledge and symptom management methods as well as to obtain empirical support.

A study has reported that economic toxicity [33] has gradually become an important factor pertaining to the diagnosis and treatment of the disease; in particular, this factor is related to the difficulties or suffering experienced by patients and their families as a result of the persistent high costs of cancer treatment. This study also revealed that financial constraints and caregiver avoidance represent challenges with regard to symptom management; namely, most respondents noted that persistently high treatment costs may lead to patient treatment interruption, thus making it difficult for families to balance the financial burdens they face with their care responsibilities. Medical staff can help patients apply for health insurance, government subsidies, or clinical trial opportunities to ease their financial stress or establish caregiver support groups and provide relevant training to help them develop symptom management skills and stress management strategies that can enable them to cope with caregiver emotional management problems. By reference to patients who were subjected to a chemotherapy interval protocol [13], the interviews revealed that patients' symptom burden, self-coping ability, psychological stress and role conflict can address problems with their self-esteem and image, among other issues. Ultimately, future researchers and practitioners should strive to develop and implement more comprehensive and personalized symptom management programmes with the goal of improving patients' quality of life and treatment outcomes.

Establishing an appropriate social support network and taking full advantage of community resources

Research has reported that during the home-based care phase, cancer patients experience not only physiological discomfort but also psychological distress and social isolation [34], a view which is in line with the findings of this study indicating that patients exhibit a strong need for social support but also experience social alienation. Social support can enhance patients' ability to cope with stress, maintain their physical and mental balance, increase their understanding of the disease, enhance their participation in decision-making, reduce their uncertainty regarding the illness, and improve their quality of life [35, 36]. Such support typically includes support from family, friends, and other individuals. However, this study revealed that excessive sympathy or concern may lead patients to feel anxious and stressed and may even result in "compassion fatigue" [37]. Therefore, social support should moderately integrate the power of family, caregivers, community resources and medical professionals with the aim of providing comprehensive support for patients rather than relying on the view that the stronger, the better.

Furthermore, this study revealed that patients with CRC at different treatment stages exhibit different types of needs for social support [38]. Therefore, personalized social support plans, which may include regular follow-ups, psychological assessments, and necessary interventions, should be developed on the basis of patients' needs. As primary healthcare institutions, community hospitals can strengthen the patient support network by helping dedicated individuals or teams within the community provide follow-ups [39]. Moreover, family doctors can connect with patients' attending physicians directly via mobile platforms, intelligent software, and other means and provide patients with platforms for information exchange and experience sharing by participating in online science popularization seminars and other activities.

Developing a home-based symptom management scheme and focusing on model innovation

Future efforts in this regard should focus on the development of home-based symptom management programs, which is a dynamic, scientific, systematic, and personalized process. The interviews conducted as part of this study revealed that such a programme must encompass a comprehensive home-based support system, continuous assessment, education, support, and adjustment; furthermore, it must provide specific measures that are tailored to the peculiarities of colorectal cancer (such as management for patients with stomas). In addition, an effective communication mechanism between healthcare providers and patients should be established by improving the medical treatment platform and strengthening the training in communication skills provided to healthcare professionals, thus helping relevant actors overcome information barriers and helping patients understand their condition correctly and participate actively in the process of home-based symptom management. Additionally, some interviewees noted that the development of innovative symptom management models on the basis of mobile internet technology (such as online platforms, mobile apps, and telemedicine) also represents an important direction for future research. These models can offer real-time symptom monitoring, health education, online follow-ups, and symptom management guidance, thereby improving patients' adherence to management as well as the efficiency of doctor–patient interactions [40].

Moreover, as an emerging research method, symptom network analysis can help researchers identify core symptoms and highly correlated symptoms by analysing the relationships between these factors, thereby providing a scientific basis for symptom management. Studies have revealed that management programmes that are based on core symptoms can improve the efficiency of symptom management and are superior to the management of other symptoms [41–42]. Therefore, the rational use of the method of network analysis to provide insights that can support symptom management is also an important direction for future research.

Limitations

First, the selection of patients was limited to specific hospitals in Fujian Province, which may limit the general applicability of the study results, as there may be differences in medical resources, cultural background, and patient characteristics across different regions. Second, since the study was conducted at specific points in time, dynamic changes in symptom management and patient needs may not have been captured over time.

Future studies should consider different regional and cultural settings and longitudinal research methods using multiple interviews or observations of the same group of patients or health care staff at different time points to track changes in symptom management needs over time and improve the generalizability and applicability of the findings.

Conclusions

This study revealed many challenges in the management of chemotherapy for colorectal cancer, including staff overload, information barriers, economic constraints, caregiver escape and life imbalance, medical service access problems, multidimensional symptom management in patients, internal belief conflicts, and an exercise diet. Effective home-based symptom management is crucial for improving the quality of life and treatment beliefs of patients receiving chemotherapy for colorectal cancer and can provide more comprehensive and personalized care through professional guidance from medical staff, patient education, the integration of community resources and innovative management models. In future work, we should focus on overcoming the challenges faced by medical staff; breaking information barriers; improving communication skills of both doctors and patients through typical case analysis, scenario simulation training and special lectures; establishing a multilevel support network for family, peer groups, professional medical staff and communities; providing comprehensive support and services for patients; building a moderate social support network; and further studying and building a scientific, systematic and personalized symptom management scheme that combines patients' needs.

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Author contributions

All authors conceptualized and designed the study. XCL, XZ and XK organized data collection. XCL carried out the interviews. DL contributed to the analysis and writing of the manuscript. XCL wrote the manuscript and all authors read and approved the manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study follows the Helsinki Declaration, and was performed in accordance with relevant guidelines and regulations. This study has been approved by the school Ethics Committee (approval number: Fujian Medical university Ethics Review [2024] No. 11),and the study has been registered with the National Medical Research Registration and Filing Information System (Project number: [226294]). Participants' identity information was anonymized to protect their personal information. Informed consent was obtained from all subjects.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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