

## Challenges of Meeting the Palliative Care Needs of Colorectal Cancer patients in Iran: A Qualitative Research

### Abstract

**Background:** Despite the high prevalence of Colorectal Cancer (CRC) in Iran and the need to pay more attention to the Palliative Care (PC) needs of patients with this disease, a few studies have previously examined the PC needs of them by gaining the patients', family members', and treatment team's views. This study aimed to investigate the challenges in the way of meeting the PC needs of CRC patients. **Materials and Methods:** This study was a qualitative content analysis study conducted on 43 participants (including 15 patients, 20 health care providers, and eight family members) through purposive sampling and semi-structured individual interviews in Omid Educational and Medical Center and Iranian Cancer "Control Center (MACSA) in Isfahan from May 2020 to December 2021. Data analysis was performed simultaneously with data collection using conventional qualitative content analysis with the Graneheim and Lundman approach. In order to assess the trustworthiness of the obtained data, credibility, dependability, confirmability, and transferability criteria were used. **Results:** Data analysis led to the production of 615 primary codes, 16 sub-categories, and five main categories. These five main categories included "Lack of facilities and equipment", "Lack of quality of services provided by the treatment team", "Insufficient financial support to the patient and family", "Insufficient psychological and emotional support from the patient and family", and "Inefficiency of the patient and community awareness process". **Conclusions:** To improve the quality of care and increase patients' satisfaction with the provided services, it is recommended that policymakers should meet the challenges of the PC.

**Keywords:** *Colorectal neoplasms, Iran, nursing, palliative care, challenges, qualitative research*

### Introduction

Colorectal Cancer (CRC) is the third most common cancer and the second deadliest cancer worldwide.<sup>[1]</sup> In Iran, CRC is the third most common cancer among men and the second most common cancer among women. Moreover, it is the third deadliest cancer in Iran.<sup>[2]</sup> CRC and its treatments lead to the development of various physical problems (including gastrointestinal obstruction, nausea, fatigue, diarrhea, neuropathy, and ostomy wound), psychological dysfunction (including anxiety, depression, body image disorder), social dysfunction (marital relationship disorder and leaving the job), and spiritual health disorder and also impose a lot of financial burden on the family and patient.<sup>[3]</sup> Therefore, diagnosis and treatment of CRC undoubtedly lead to irreversible effects on the Quality of Life (QOL) in these

patients.<sup>[4]</sup> Therefore, to improve the QOL in CRC patients, the World Health Organization (WHO) introduced Palliative Care (PC), intending to manage their symptoms, reduce the treatment-related side effects, and improve the QOL in cancer patients. PC is known as one of the main cancer control programs.<sup>[5]</sup> Various studies showed that providing PC in the form of specialized services may lead to better symptoms' control, pain management, reduced unwanted hospitalizations, provision of high-quality care, reduced anxiety and depression of CRC patients and families, improved QOL, and reduced economic burden resulting from cancer on the health system.<sup>[6,7]</sup>

Despite the importance and benefits of PC for CRC patients, because PC in Iran is relatively new care and the structure of PC delivery in the Iranian health system

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is not yet fully developed, in most cases, providing these services faces many challenges. Given that the challenges of meeting the PC needs of CRC patients have not been studied with the views of patients, family members, and the treatment team, this study aimed to investigate the challenges in the way of meeting the PC needs of CRC patients.

## Materials and Methods

This qualitative study was conducted from May 2020 to December 2021 using the conventional content analysis approach. This study is a part of a research entitled “Explaining the PC needs of CRC patients.” The research environment included Omid Educational and Medical Center affiliated with Isfahan University of Medical Sciences (IUMS) and Iranian Cancer Control Center (MACSA) as the main referral centers known for the treatment of cancer patients in Isfahan. In the present study, 43 participants [including 15 patients, 20 health care providers (HCPs), and eight family members] were selected through purposive and snowball sampling. The inclusion criterion for all the participants was the desire to participate in the study. The CRC patients included in this study have the diagnosis of colon and rectal cancer, being at stages 2 and 3 of the diseases and not at the metastasis stage, being under the treatment or in the follow-up stage of treatment. The inclusion criteria for the HCPs were having at least 6 months of work experience in adult cancer or PC wards. The criteria for family members were direct involvement in the continuous care of CRC patients and an age more than 18 years. Thereafter, the researcher explained the purpose of the study to the participants, and the time and place of the interviews were determined by the participants. Written informed consent was obtained from the participants as well. The main questions asked from the patients included “What problems and challenges did you face when receiving PC? The questions asked from HCPs included “What are the challenges of providing PC to CRC patients?” Moreover, CRC patients family members answered the following questions: “What are the challenges and problems faced your patient in receiving PC? (the subsequent questions were determined based on the participants’ prior responses), “What do you mean?”, and “Can you explain more?” The duration of interviews was between 30 and 60 min, with an average of 45 min. Accordingly, 46 in-depth semi-structured individual interviews were conducted with 43 participants. The interviews continued until data saturated, and no new data were generated.

Data analysis was then performed simultaneously with data collection using the conventional qualitative content analysis method with Graneheim *et al.*'s approach.<sup>[8]</sup> In the first step, the researchers listened to interviews several times, and the interviews were then transcribed verbatim in Microsoft Word Office. The researcher read the transcribed

text and identified and coded important words and phrases. Subsequently, similar codes were merged and summarized, which appeared under similar sub-categories. Finally, the sub-categories were grouped into the main category. Both data management and analysis were performed using MAXQDA 10 software.

In this study, Lincoln and Guba's criteria were used to examine the trustworthiness of the obtained data.<sup>[9]</sup> Credibility improved through continuous and prolonged engagement with participants, the participants' selection with a maximum variation in terms of the demographic characteristics, peer check, and checks by the participants. For dependability, the summary of the interviews and the extracted codes were returned to the participants for their review and comments. For confirmability, the data analysis process, coding, and results were clearly and concisely stated (research audit). A full description of the research methodology and context was provided to be used in subsequent research in order to increase the transferability.

## Ethical considerations

This study was extracted from a Ph.D. dissertation in nursing which has been approved by the Ethics Committee of Isfahan University of Medical Sciences, Iran (code: IR.MUI.Research.Rec. 1399.126). All participants read and signed the informed written consent form. They were assured that their information was confidential. The participants' recorded voices were stored in a safe place. A code was assigned to each participant to maintain confidentiality.

## Results

In this study, 15 patients were included, of whom 5 were women and 10 were men with a mean (SD) age of 54 (9.81) years. Correspondingly, 11 cases had colon cancer, 10 were without a colostomy bag, and 13 cases had a diagnosis time less than 2 years. A total of 20 HCP participants, including 10 females and 10 males with a mean (SD) age of 43(13.65) years, were also selected. The majority of HCPs had a master's degree and a work experience between 5 and 10 years in the cancer ward. Also, eight family members participating in the study had a mean (SD) age of 43 (13.65) years, and the majority of them were patient spouses and with education levels less than a diploma and were colostomy patients' caregiver. The HCPs included four nurses, four clinical psychologists, one cancer psychiatrist, two social workers, three general practitioners, three spiritual caregivers, two oncologists, and one geneticist. Data analysis led to the production of 615 primary codes, 16 sub-categories, and five main categories. The main categories and sub-categories are described in detail below.

### **Lack of facilities and equipment**

Problems in providing colostomy bags and colostomy accessories because of sanction conditions, the lack of diagnostic equipment, and the lack of use of new technologies were mentioned by the participants. This category consists of three sub-categories.

#### *Lack of use of information technology and new technologies*

Knowledge-based companies must produce high-quality colostomy bags in Iran using new technologies. A participant remarked that *“Knowledge-based companies in Iran should be able to use new technologies to produce disposable colostomy bags that can be easily entered into the machine and crushed and so that they can subsequently enter the municipal sewage system”* (Doctor 2).

#### *Lack of adequate resources and facilities*

Sanctions have diminished the availability of colostomy bags and radiopharmaceuticals essential for the diagnosis, treatment, and follow-up of CRC patients. A participant stated that *“They constantly declare that the basic cancer treatment drugs and colostomy bags are not due to sanctions.”* (Nurse 2).

#### *Lack of integration of diagnostic services in one center*

The lack of diagnostic services in one center leads patients to travel to different medical centers, and this confuses them. A respondent stated that *“One problem is that many of these diagnostic services (such as CT scan and MRI) are not available at this center and the patients have to go to other treatment centers”* (Doctor 3).

### **Lack of quality of services provided by the treatment team**

The quality of PC diminished because of inadequate communication of HCPs with patients, the lack of inter-professional collaboration, and incompetence of HCPs in providing PC. This category consisted of six sub-categories.

#### *Poor communication of HCPs with the patient and caregiver*

The lack of effective communication between the physicians and the patients imposed a big barrier for patient confidence in HCPs. A patient stated that *“Doctor trains the assistant without paying any attention to the patients, while they have to talk to the patient and justify his/her companion, but that does not happen at all”* (Patient 9).

#### *Challenges of bad news*

The participants stated that the bad news of cancer is not given by trained people and properly to patients. A doctor remarked that *“bad news must be given in the right setting and by a trained person, but the protocol of giving bad news to the patient is not done appropriately by the doctors”* (Doctor 5).

#### *Lack of inter-professional collaboration of the treatment team*

Because of the lack of inter-professional collaboration, the patient’s needs are not comprehensively assessed, so the patient is not supported. *“When a person is diagnosed with cancer, if there is a team, they justify the patient and the team fully supports the patient, but there is no inter-professional collaboration in our hospitals”* (Nurse 2).

#### *Insufficient adequacy of the specialized treatment team*

Insufficient knowledge and skills regarding HCPs in providing PC led to the decreased quality of care. A nurse stated that *“Newly graduated nurses may not have seen a cancer patient at all as a student or have not worked with a patient with colostomy, so they may not be able to work with cancer patients or those with colostomy when they are employed in a hospital”* (Nurse 3).

#### *Patients’ inadequate participation in treatment decisions*

Another challenge is the lack of patients’ participation in treatment decisions. A participant said that *“In treatment decisions, most patients tell the specialist that whatever you say, patients do not give themselves the right to decide on their treatment process”* (Doctor 1).

#### *Lack of sexual counseling*

The participants reported that the sexual problems are taboo; they do not receive sexual counseling from HCPs. A doctor stated that *“In addition to psychological counseling, patients need sexual counseling. Because patients themselves do not ask about sex at all, the patient feels that the sexual problem is his/her problem and he/she can no longer do it”* (Psychologist 6).

### **Insufficient financial support of the patient and family**

CRC patients receive inadequate financial support from the government and Non-Governmental Organizations (NGOs). This category consisted of two sub-categories.

#### *Insufficient financial support by the government and NGOs*

Most participants complained of the lack of government and NGO funding for the treatment and colostomy bag costs. A participant stated that *“Who has contributed one Rial to cancer patients? NGO does not come to the aid of cancer patients who are themselves ill and need a colostomy bag”* (Patient 1).

#### *Insufficient coverage of health services by insurance companies*

Another major concern was the insufficient coverage of medical expenses by insurance companies as one of the participants stated that *“You buy a medicine, then you go for supplementary insurance, and the insurance company says that this drug needs confirmation and this medicine does not need a confirmation, and you stop taking the cost of medicine and say leave it at all”* (Patient 4).

### **Insufficient psychological and emotional support from the patient and family**

CRC patients and their family members may suffer from many psychological problems that require receiving psychological services in medical centers. This category consisted of three sub-categories that are explained below.

#### *Insufficient psychological and emotional support by relatives of the patient*

Many patients stated that their condition was not understood by their family members. A patient stated that *“Patients need to be comprehended by relatives. At some points, I want to be alone so that I can easily get rid of my bloating, or I do not want to go on a group trip because I have diarrhea, I have a hard time and I cancel many of our group trips and the others mutter to me why you do not fit in and why you are not with the group”* (Patient 5).

#### *Insufficient psychological support of the patient’s family to accept the disease*

In addition to the patient himself/herself, family members also require psychological and emotional supports. A participant stated that *“My wife is very obsessive and because I have a colostomy bag, she rinses everything and consumes half of Isfahan water; and this torments me so much that my wife has not yet accepted the condition of my illness”* (Patient 6).

#### *Providing inadequate psychological services to patients*

There is a lack of psychological services for CRC patients. One of the participants remarked that *“The first and most important thing is lack of the psychological team. The psychological team should follow up the mental and psychological problems of the patients and people involved in the disease”* (Nurse 3).

### **Inefficiency of the patient and community awareness process**

Many participants stated that insufficient information is provided on how to treat cancer patients and colostomy bag patients and the need for genetic counseling for family members in the radio and television media. This category consists of two sub-categories.

#### *Insufficient awareness to people in the community*

It is necessary to inform the public about cancer patients and patients with colostomy bags through the public media. A doctor stated that *“A lady or a gentleman got on a bus and opened his colostomy bag. The society must know how to treat this patient and this culture must be created in the society and people by radio and television”* (Doctor 6).

#### *Lack of genetic counseling*

Because of a lack of knowledge of doctors and patients or the high cost of genetic counseling, genetic counseling is not performed for family members. A geneticist remarked

that *“At least 30 to 40 percent of these patients should be referred for genetic counseling because of family history, but because doctors do not know this fact, this is not happening, and this is very worrying”* (Doctor 4).

### **Discussion**

The finding of this study depicted a picture of the challenges of the meeting the PC needs of CRC patients in Iran. The findings showed that these challenges could be evaluated in five main categories including “Lack of facilities and equipment”, “Lack of quality of services provided by the treatment team”, “Insufficient financial support to the patient and family”, “Insufficient psychological and emotional support from the patient and family”, and “Inefficiency of the patient and community awareness process”. PC in Iran is relatively new, and its establishment as one of the goals of the health system requires identifying and addressing the challenges of providing PC considering that providing high-quality and comprehensive PC services to CRC patients requires significant resources; unfortunately, with the current financial turmoil in Iran, resources have shifted to other priorities and besides, sanctions against Iran have made essential infrastructure, including information technology, adequate resources (basic cancer drugs and colostomy bags), and equipment unavailable or too expensive. All these conditions caused a painful period of illness and treatment and reduced QOL in CRC patients.<sup>[10]</sup>

Insufficient knowledge and expertise of HCPs on PC are considered as other barriers to the implementation of PC. In other studies, the lack of knowledge, attitude, and skills of HCPs regarding PC have been mentioned because of the lack of PC training in physicians’ and nurses’ academic and clinical training programs.<sup>[5,11,12]</sup> Because of the establishment of PC centers in different cities of Iran and responding to this challenge (both academically and clinically), inter-disciplinary curriculum related to PC in academic courses of physicians and nurses at all levels can be effective on training specialized staff.<sup>[5]</sup> Inappropriate communication between HCPs with patients is another factor effective on reducing the quality of PC. Although HCPs’ good communication with patients could bring a positive effect on physical and mental health patients, such as improving adaptation and controlling physical symptoms, controlling pain, and increasing the patient’s active participation in his/her treatment decisions.<sup>[7]</sup> Therefore, the treatment team needs to be empowered in communication skills with CRC patients and colostomy patients.

The lack of inter-professional collaboration in providing PC is another challenge. Considering that PC should cover all aspects of health problems and such care requires a team and an inter-professional approach, the development of inter-professional training programs is emphasized to enhance the knowledge, attitude, and skills required by professional staff and to improve services to

CRC patients.<sup>[11,13]</sup> Another challenge is the lack of the patient's participation in his/her treatment decisions. In a previous study, patients who played an active role in treatment decision-making showed a greater increase in understanding of prognosis, treatment options, and benefits of treatments.<sup>[14]</sup> Therefore, it is better to encourage and empower patients to play an active role in their health decisions as well as promote the culture of patients' involvement in treatment decisions among the treatment team. One of the challenges mentioned in this study was the lack of sexual counseling by HCPs. The impaired sexual health of CRC patients can lead to lower QOL and higher anxiety in patients.<sup>[15]</sup> Some studies have previously shown that HCPs do not usually discuss the effects of illness and treatment on sexual health with patients.<sup>[16,17]</sup> Therefore, it is necessary to upgrade the knowledge and skills of the HCPs in the field of sexual health counseling.

The lack of financial support by the government and NGOs is another barrier in the way of providing PC services. Other studies have confirmed this finding as well.<sup>[5,12,18]</sup> Therefore, the NGOs can raise public funds for CRC patients through advertising in public and social media.

Insufficient insurance coverage is known as one of the most frequent concerns of CRC patients. High costs can reduce patients' access to essential treatments, effective drugs, and ultimately the health status and QOL of patients, especially among low-income patients.<sup>[19]</sup> Therefore, new policies for cost coverage by medical insurance organizations might help them to manage cancers efficiently.

Another challenge is receiving insufficient psychological and emotional support from the patients and their families. Other studies have also stated that CRC patients need physical, practical, and emotional support.<sup>[20,21]</sup> The International Psycho-Oncology Society (IPOS) has set a standard of care that includes monitoring psychological distress as the "sixth vital sign." Therefore, CRC patients should be screened for psychological disorders at the time of diagnosis as well as the key points during the course of their disease and survival period. Psychosocial care for CRC patients reduces the length of hospital stay and anxiety and depression, improves colostomy acceptance, and improves patients' quality of life.<sup>[22]</sup> Because caregivers' problems in the family environment and the continuation of patients' treatment consequently cause a negative effect, health care systems must provide the necessary psychological support to caregivers to provide better quality care to the patient.

A challenge stated by the participants was insufficient awareness to people in the community toward cancer patients. Overcoming this challenge is possible through providing valid and proper training in the form of social trends and awareness posters and community-based free discussions by health care staff and caregivers.<sup>[5]</sup> On the other hand, regarding the necessity of genetic counseling for family members of CRC patients, health policymakers

should adopt a policy to cover genetic testing and counseling by insurance organizations and also provide sufficient information to the public about the necessity and importance of genetic counseling. The limitation of this study was the generalizability of the findings to other environments. The present study attempted to increase the generalizability using maximum variation in selecting the participants.

## Conclusion

PC is currently a relatively new and fledgling care in Iran. The results of this study show that providing PC to Iranian CRC patients faces several challenges. Overcoming these challenges requires health policymakers to pay more attention to the use of facilities, adequate equipment and information technology, and financial support; increase the coverage of health insurance, community awareness, and empowerment of the treatment team in providing PC and sexual counseling; and psychologically support the patient and his/her family members.

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## Conflicts of interest

Nothing to declare.

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