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# The needs of colorectal cancer patients/survivors: A narrative review

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## Abstract:

**BACKGROUND:** Identifying and addressing the needs of Colorectal cancer (CRC) patients/survivors' is important to improve patients/survivors' quality of life (QoL) and health. The present study aimed to review studies that have investigated CRC patients/survivors' needs.

**MATERIALS AND METHODS:** In this narrative review, databases including PubMed, Scopus, Web of Science, Iranmedex, ISC, SID, and Magiran were searched during 2011–2021 using keywords included need, CRC, colon cancer, rectal cancer.

**RESULTS:** The findings of the studies showed that the needs of the CRC patients/survivors' can be categorized into the 6 domains including informational, psychological, social, physical, financial, and spiritual needs.

**CONCLUSIONS:** By identifying CRC patients/survivors' needs, healthcare providers particularly nurses can develop and design comprehensive care programs tailored to the needs and priorities of these patients/survivors to improve their QoL and health.

## Keywords:

Colorectal cancer, narrative review, need, nursing, patient, survivor

## Introduction

Colorectal cancer (CRC) is the most common malignant disease in the gastrointestinal tract, the third most common cancer in men, and the second most common cancer in women.<sup>[1]</sup> According to the Glob can site, in 2018, 1.8 million new cases of CRC and 700,000 related death have been reported in the world.<sup>[2]</sup> Increasing 55% in the number of CRC survivors in recent decades poses new challenges for care providers, such as caring for the long-term effects of treatment and maintaining the Quality of Life (QoL) of survivors.<sup>[3]</sup> In addition, CRC and its treatment may cause significant physical, psychological, and emotional effects for patients, including pain, fatigue, anxiety, insomnia, neuropathy, cognitive impairment, and intestinal problems.<sup>[4]</sup> This in turn may lead to a variety of physical,

psychological, social, spiritual, and economic needs for patients.<sup>[5]</sup> Identifying and addressing the comprehensive needs of CRC patients/survivors is increasingly important to improve patients' reported outcomes such as QoL<sup>[7]</sup> and reduce patients' levels of depression and anxiety.<sup>[8]</sup> Conversely, lack of identification and inability to meet CRC patients/survivors' needs can reduce their QoL.<sup>[6,9]</sup>

Despite the importance of meeting CRC needs, research results indicate that CRC patients/survivors are still facing many unmet needs from the time of diagnosis to months following treatment.<sup>[10]</sup> By identifying CRC patients/survivors' needs, supporting programs, training, and decision-making models, caring guidelines, and follow-up packages can be developed to improve the quality of care and ongoing support for these patients/survivors.<sup>[11]</sup> Although many studies have been conducted to identify CRC patients/survivors' needs,

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these studies have been aimed at identifying such needs only during the treatment phase (not the survivorship period) or examined some aspects of patients/survivors' needs. Therefore, this study aimed to pull together all studies that have examined CRC patients/survivors' needs at different stages.

## Materials and Methods

This narrative review was conducted in 2021 to identify CRC patient's/survivors needs. At the beginning of this study, the related keywords were searched according to Mesh and Thesaurus. Keywords to be searched were included "need, colorectal cancer, colon cancer, rectal cancer". These keywords were searched separately in national and international databases including PubMed, Scopus, Web of Science, SID, Magiran, Iranmedex, and ISC. The results are then combined using "AND" or "OR" to generate several new findings. A manual search was also performed separately.

Retrieved articles were screened based on inclusion and exclusion criteria. Inclusion criteria included having the full text of the original articles (quantitative, qualitative, and mixed methods) and review articles published in English or Persian languages related to CRC patients/survivors' needs between 2011 and 2021. Articles related to advanced CRC patients/survivors' needs or those in which CRC patients/survivors' needs were assessed along with other cancers were excluded. Abstracts, short communications, letters to the editors, book reviews, and articles without having access to their full text were also excluded. After removing duplicates in the Endnote software, the title and abstract of the retrieved articles were reviewed by one of the researchers according to the inclusion criteria. In case of any disagreements about the relevance of the article, the article was reviewed by another researcher and a consensus was achieved. Then, the full texts of the remained articles were reviewed according to inclusion criteria leading to 25 articles for a final review. A reference list of selected articles was also searched, and as a result, 9 more articles were added for a final review (totally of 34 articles) [Figure 1].

## Ethical considerations

This review is a part of a bigger mixed methods research study. (Ethical code number is: IR.MUI.Research.Rec.1399.126).

## Results

From 34 included studies, 16 were conducted from 2011 to 2015, and 18 from 2016 to January 2021. The majority of studies had a quantitative approach including cross-sectional,<sup>[5,6,9,12-19]</sup> prospective cohort,<sup>[20,21]</sup> randomized controlled trial,<sup>[22]</sup> and descriptive.<sup>[10]</sup>

This was then followed by qualitative,<sup>[23-35]</sup> review articles,<sup>[11,36,37]</sup> and mixed methods<sup>[38,39]</sup> articles. 12 and 22 studies were performed with CRC survivors and CRC patients, respectively. These needs were categorized in the following sections.

## Spiritual needs

Only two studies stated spiritual needs. In the Jin *et al.* study, spiritual needs had the lowest score among all needs while in the Kim and Yoo study, spiritual and religious problems had the highest score after social support and information needs.<sup>[6,12]</sup>

## Physical needs

10 studies expressed the physical needs.<sup>1</sup> These needs raised in the articles included gastrointestinal dysfunction,<sup>[6,18,25]</sup> pain,<sup>[25]</sup> peripheral neuropathy,<sup>[6]</sup> limitation of activity and lack of energy or fatigue,<sup>[17,25]</sup> sexual problems,<sup>[10,13,17,18,25,31]</sup> sleep problems, adhesions, and infected wounds.<sup>[25]</sup>

## Educational and information needs

23 studies addressed educational and information needs. These needs had a focus on diet,<sup>[11,15,20,23,26-28,30]</sup> drugs and supplements,<sup>[28,32]</sup> lifestyle modification and physical activity,<sup>[20,23,27,30,32,38]</sup> sexual function,<sup>[6,10,30]</sup> control and self-management of symptoms and side effects of treatment,<sup>[9,11,15,20,22-24,26,30,32,33]</sup> support groups, return to work, potential health insurance and legal issues,<sup>[15]</sup> financial matters and life and travel insurance.<sup>[9]</sup> Many articles stated that CRC patients/survivors need information about the risk of recurrence, metastasis, the possibility of recurrence treatment,<sup>[15,30,32,39]</sup> prevention methods and measures in case of suspected recurrence<sup>[9,15]</sup>, and reducing the risk of recurrence.<sup>[20]</sup>

Other studies focused on CRC patients/survivors' information needs about the disease and its related cause, treatment, operation, and possible complications of having stoma,<sup>[6,26,29,30,32]</sup> prognosis,<sup>[6,32]</sup> body image,<sup>[6]</sup> postoperative expectations,<sup>[20,33]</sup> survival,<sup>[6,26]</sup> the risk of cancer for family members and the long-term effects of CRC diagnosis.<sup>[26]</sup> Several articles were related to patients/survivor's information needs about the role of heredity in cancer,<sup>[20]</sup> follow-up plans,<sup>[15,20,30]</sup> how to contact the hospital,<sup>[20]</sup> and credible sources of information.<sup>[15]</sup> CRC patients/survivors needed information as to how to access CRC nurse specialists,<sup>[11,25,26,28,35]</sup> experienced consultant,<sup>[14,32,38]</sup> or a person for providing sexual health care,<sup>[34]</sup> and educating patient's family.<sup>[9]</sup>

## Social needs

12 articles expressed the social needs of CRC patients/survivors. In the study of Wiljer *et al.*, social needs were the least important needs<sup>[19]</sup> while in the

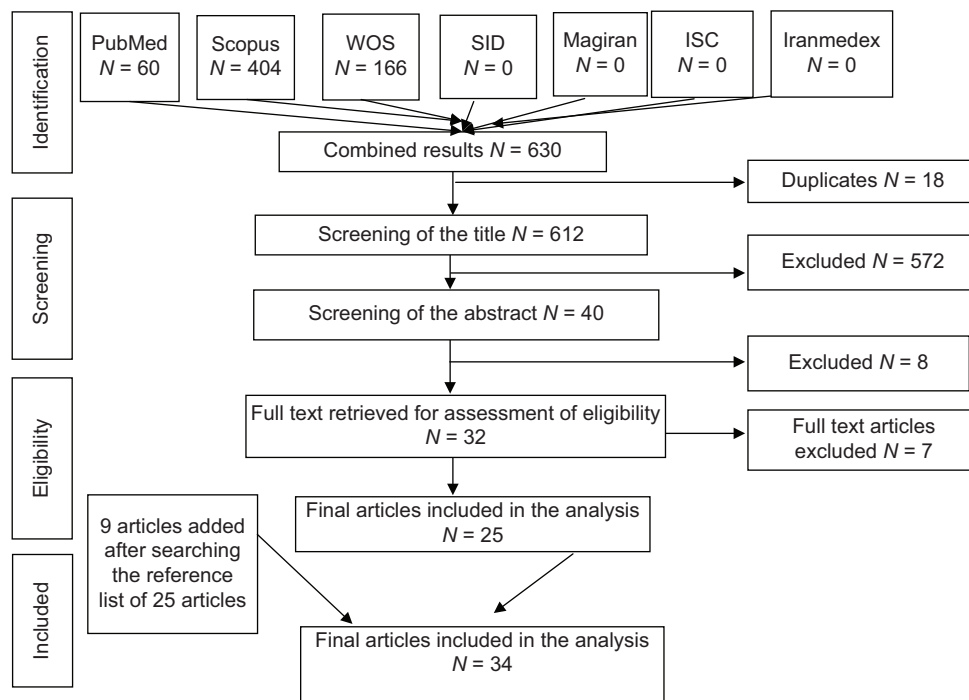


Figure 1: Flowchart of studies selection process

study of Kim and Yoo, social support needs had the highest score.<sup>[6]</sup> Communication with similar patients during treatment,<sup>[24,26,30,31,35,36]</sup> receiving support from friends and peers,<sup>[24,30,35]</sup> attending support groups,<sup>[24,33]</sup> receiving social support from family, friends or community members,<sup>[31]</sup> facilitating communication with family,<sup>[6,18,30]</sup> and need counseling to increase social participation,<sup>[12,22]</sup> unemployment and travel problems<sup>[26]</sup> were the other social needs of CRC patients/survivors expressed in the articles.

### Psychological and emotional needs

Twenty-four studies were related to psychological needs. In two studies, the greatest need of CRC patients was related to emotional needs.<sup>[18,19]</sup> In the study by Lithner *et al.*, it was found that CRC patients/survivors needed physical, practical, and emotional support.<sup>[32]</sup> Supporting by friends or family<sup>[10,24,28,33]</sup> to deal with the consequences of illness and treatment,<sup>[26]</sup> making changes in their health behaviors,<sup>[27]</sup> practical and emotional support by their spouses<sup>[25]</sup> including the participation of family members in care tasks,<sup>[29]</sup> the preparation of meals, transportation to visit and help with housework,<sup>[31]</sup> diet support,<sup>[38]</sup> and emotional support to deal with the fear of recurrence of the disease<sup>[11,12,29-31]</sup> were among the psychological needs expressed in these articles. Other issues in this dimension were patients' uncertainty about the effectiveness of treatment,<sup>[16,22,25]</sup> need continuous assurance,<sup>[28,32]</sup> receive the best medical care,<sup>[25]</sup> fear of the future,<sup>[25]</sup> cancer recurrence,<sup>[22,25,37]</sup> spread of cancer,<sup>[16,17]</sup> and the impact of the disease on the

family members. The need to have self-worth and relationship,<sup>[18,38]</sup> love, belonging and self-esteem,<sup>[12]</sup> receiving psychological treatment,<sup>[30]</sup> emotional support and empathy, positive and respectful relationship between patients and caregiver team,<sup>[11,29,31,32,40]</sup> improve inter-professional collaboration between HCPs,<sup>[9,15,32,33,37,40]</sup> involvement patients in treatment decisions,<sup>[24,26,32,39]</sup> improve disclosing bad news to the patient<sup>[30]</sup> were also mentioned in the articles.

### Financial needs

These needs were expressed in 6 articles. In the study Vu, 24% of CRC patients' needs were financial.<sup>[18]</sup> In this study, the cost of chemotherapy drugs, lack of subsidies for stoma appliances, and inadequate coverage of medical insurance were CRC patients' financial problems.<sup>[35]</sup> Financial and insurance advice,<sup>[37]</sup> financial issues,<sup>[22]</sup> employment problems, and financial support by insurance companies,<sup>[38]</sup> and financial support<sup>[31]</sup> were also expressed in some articles.

### Discussion

This review study was conducted to identify the needs of CRC patients/survivors. Several studies emphasized, informational needs are the most persistent and critical need throughout the disease continuum.<sup>[6,10-12,16,19]</sup> Benefits of having sufficient information include more patient involvement in decision making, translating to greater satisfaction with treatment choices, improved coping mechanisms during the diagnosis, treatment, and posttreatment phases, reductions in anxiety and mood

disturbances, and improved communication with family members.<sup>[5,19,37]</sup> and ultimately a better quality of life for the patients/survivors.<sup>[5,19,20,37]</sup>

Indeed, both cancer and its treatment might result in psychological damage to CRC patients/survivors.<sup>[41]</sup> The most important psychological problem reported in most studies was fear or worry about cancer recurrence or progress. Similarly, in a systematic review, Fear of Cancer Recurrence was rated as one of CRC survivors' greatest concerns.<sup>[42]</sup> Psychological problems negatively impact a variety of treatment outcomes such as adherence to treatment, motivation, ability to cope with the diagnosis and prognosis.<sup>[41]</sup> Thus, identifying psychological needs is important to develop and perform psychological care to improve rehabilitation outcomes and the psychological wellbeing of CRC patients/survivors.

The most-reported challenge in the social domain was communication with similar patients. Yoon *et al.*'s study expressed that other patients with similar conditions were an excellent source of support for people diagnosed with CRC.<sup>[35]</sup> Similar patients could tell them what to expect in terms of mobility, pain, recovery and what was "normal" in terms of physiological signs and symptoms. Social support has been identified as a helpful strategy and has a good impact on treatment outcomes, QoL, and mental health outcomes for patients with CRC.<sup>[24]</sup>

Beyond the clinical consequences, many patients with cancer also suffer significant economic hardship caused by the disease and its treatment.<sup>[43]</sup> It is important that patients with these issues are identified as early as possible and given advice and access to appropriate benefits also policymakers should further consider some financial protection strategies and support for cancer treatment because cancer is a very costly and chronic disease.

Limited studies have pointed to spiritual needs in CRC patients/survivors. While spiritual needs are found to be key in improving psycho-spiritual well-being in other research but spiritual needs in cancer care are often neglected.<sup>[44,45]</sup>

Studies suggested that persistent physical and functional symptoms caused by the disease and its treatment have a negative effect on the psychological well-being and QoL of the CRC patients/survivors.<sup>[35]</sup> HCPs' attention to physical problems, reduces the risk of worsening symptoms and the cost burden of the symptoms and finally leads to maintaining or enhancing QoL and increasing survival of these patients/survivors. Findings of this review must be considered along with its limitations, especially in using standard search terms in national databases. To overcome this problem, we

used all synonyms of search terms separately in English languages and despite efforts to locate all relevant extant studies, some were missed. The language restriction to English and Persian was also a limitation.

## Conclusions

CRC patients/survivors similar to other cancer patients have different needs including informational, psychological, social, physical, financial, and spiritual. Among these needs, psychological and informational issues were identified as the most important needs reported in these articles. So identifying different needs of CRC patients/survivors can help HCPs tailor treatment plans more effectively for providing comprehensive care to these patients/survivors. The unique needs experienced by CRC patients/survivors provide insight for re-shaping and developing clinical actions, practices, care programs, and support for these patients/survivors throughout their treatment and survivorship. Findings from this review can also be used by health team members in their everyday interactions with CRC patients/survivors to facilitate safe, effective, and person-centered care.

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## Conflicts of interest

There are no conflicts of interest.

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