Original Article

Need differences by treatment phases between patients with colorectal cancer and their caregivers: A text mining analysis

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ABSTRACT

Objective: To improve the quality of life and health outcomes of an increasing number of colorectal cancer patients and their caregivers, the specific needs of both should be understood across the cancer treatment trajectory. This study attempted to identify the supportive needs of patients and caregivers during each treatment phase.

Methods: Using text mining, posts from a South Korean internet self-help support group for colorectal cancer were classified by assigning labels to the terms extracted according to the poster, treatment phase, and support type. The extracted terms were then classified based on term frequency, with higher term frequency indicating higher need.

Results: Both caregivers and patients showed the highest term frequencies during the treatment phase. Caregivers had more high-ranking terms that were ranked higher than patients, indicating high support needs. In addition, the terms regarding treatments and diseases were ranked high. In the pre-treatment phase, test-related needs were ranked higher for both caregivers and patients. Meanwhile, patients had more highly ranked terms in the post-treatment phase, showing their high need in this phase, especially terms related to post-treatment symptoms. Caregivers had higher term frequencies of food intake during the post-treatment phase.

Conclusions: This study demonstrated that the needs of colorectal cancer patients and their caregivers were not always consistent in each treatment phase. Therefore, the needs of both patients and caregivers should be considered separately in each treatment phase and supportive interventions should be provided accordingly.

Introduction

The 5-year relative survival rate of colorectal cancer (CRC) has consistently increased in South Korea from 54.8% in the 1990s to 75.6% in 2012–2016 while in the US, more than 90% of CRC patients in the stable stage showed high 5-year survival rates. As the survival rate has increased, the number of CRC survivors that survived from diagnosis to post-treatment has risen. Further, the definition of cancer survivors also includes caregivers since cancer has various effects on both patients and their caregivers. As medical care has shifted from hospital-based to community-based treatments, caregivers have become the primary resources for patients' social and emotional support, playing a critical role by providing most of the patients' cancer management. Thus, the importance of caregivers in the management of CRC patients has become increasingly recognized.

Caregivers meet healthcare providers on behalf of patients when patients are unable to report their symptoms or management to healthcare providers because of their condition, treatment, and surgery. However, when caregivers represent patients, the caregivers' needs may differ from patients' practical needs, which can present notable challenges when the needs of patients and caregivers are diverse resulting in the unmet needs of patients.

CRC caregivers may experience various psychological problems, including anxiety, depression, and psychological distress comparable to that observed in patients and physical difficulties because of the burden of caregiving. Such challenges can negatively affect the quality of life and health outcomes of both patients and caregivers. Therefore, both patients' and caregivers' needs should be considered along with appropriate supportive help to support CRC survivors effectively.

Most studies have evaluated the needs of CRC survivors without distinguishing between patients and caregivers or have focused solely on either patients' or caregivers' needs. Further, the investigations have been fragmented as they have only examined needs at certain treatment...
stages, particularly in the treatment phase\textsuperscript{18} hindering a comprehensive understanding of the needs of patients with CRC and their caregivers throughout the entire cancer trajectory.

As a big data analysis method for unstructured data,\textsuperscript{19} a text-mining approach has mostly been used to analyze perceptions and trends of individuals using previously generated large-scale unstructured data. Text mining analysis has been shown to acquire useful information in medical research\textsuperscript{20,21} and posts on the internet can be a valuable source of data to understand patients and develop healthcare services. Specifically, many CRC survivors have utilized internet support groups to share experiences and information as a resource for social support.\textsuperscript{13} Therefore, text mining can provide an opportunity to analyze communications among CRC survivors naturally formed on the web,\textsuperscript{22} but only a few active studies have applied text mining to the CRC field, such using text mining for trend analysis\textsuperscript{23} or CRC experience analysis using descriptive and responsive data.\textsuperscript{24} In the current study, we analyzed posts freely written on a South Korean CRC internet self-help support group using a text-mining approach to identify the support needs of patients and caregivers in each phase of their cancer trajectory.

**Methods**

This descriptive study analyzed posts on an internet self-help support group using a text-mining approach to identify the support needs of patients with CRC and their caregivers. The data analysis involved a three-step process: preprocessing, operations, and postprocessing\textsuperscript{25,26} of text. The KoNLP and R word cloud packages (version 4.0.2) of the statistical program R were employed (http://cran.rproject.org, accessed on December 15, 2020).

**Data analysis**

**Step 1. Text preprocessing**

The data collection process yielded 2825 posts written from 2011 to 2022 from the largest (approximately 15,000 members) and most active internet self-help support group for CRC survivors in Republic of Korea. Two research assistants read posts and classified them by assigning a label based on the poster (ie, patient or caregiver) and treatment phase (ie, pre-treatment, treatment, and post-treatment). According to House’s social support definition,\textsuperscript{27} the identified support needs on the posts were labeled as Informational Support Need (ie, asking or sharing information), Emotional Support Need (ie, sharing emotional challenges or expressed emotion), and Appraisal Support Need (ie, relating to information that is useful for self-evaluation). The two research assistants independently assigned labels after reading each post multiple times. Single labels were assigned to each post for the posters, treatment phases, and support needs, whereas multiple labels were assigned when a post corresponded to one or more labels in each category. The two research assistants independently classified 2825 posts, of which 2597 were consistently classified. For the 228 posts with inconsistencies, discussions and decisions were made by all authors on the final labels.

During the data cleaning process, 11,927 nouns and adjectives were extracted from the text of the posts. Following a cleaning process that comprised noise removal and term unification, 4882 terms were included in the final analysis. Noise was defined as a term that was incompletely extracted with a difficult to understand meaning and of low importance (eg, size, body part, quantity and number, age, country, region, hospital, greetings, title). For text transformation and feature selection, the terms extracted through the cleaning process were converted into a matrix based on the term frequency (TF) for each label.

**Step 2. Text operations**

Classification analysis was performed based on term frequency (TF). High TF indicated an important term,\textsuperscript{28} which was interpreted as a high social support need in this study. For each label, the 20 most frequent terms were analyzed, and supervised labeled latent Dirichlet allocation (SL-LDA) was applied to analyze data with single and multiple labels. The 20 most frequent terms used by the patients and caregivers were visualized using word clouds, where a more frequently appearing word is visualized using a larger font size.\textsuperscript{29}

**Step 3. Postprocessing**

The results were interpreted to determine what they meant statistically, discussed, and compared to previous studies.

**Results**

A total of 13,695 terms written by caregivers were ranked in the top 20 terms on the internet self-help support group for CRC survivors compared to the 9035 terms written by patients (Table 1). Fig. 1 shows that both caregivers and patients frequently used terms related to treatments and tests, including “surgery,” “chemotherapy,” “treatment,” and “examination.” For patients, terms related to defecation and pain, such as “anus,” “stool,” “colostomy,” and “pain,” appeared with higher ranks. For caregivers, terms related to the disease itself and hospitals such as “colorectal,” “cancer,” “metastasis,” and “hospital” had higher ranks.

Table 2 shows TFs for caregivers and patients by the treatment phases. Both groups had the highest TFs in the treatment phase, followed by the post-treatment and pre-treatment phases. In the pre-treatment phase, patients and caregivers showed similar TFs. However, in the treatment phase, caregivers’ had greater TF being twice more than patients. In contrast, patients had greater TF in the post-treatment phase compared to caregivers.

In the pre-treatment phase, patients and caregivers posted test-related terms most frequently, including “level,” “white blood,” “endoscopy,” and “result.” The terms mostly used by patients were “radiotherapy” and “anus,” while “surgery” was the highest-ranked for caregivers. In the pre-treatment phase, the terms that were high ranks for patients were those for negative emotions such as “anxiety” and “stress,” which was not observed among caregivers.

The top 20 terms in the treatment phase were those related to CRC treatments and adverse effects, including “chemotherapy,” “surgery,” “treatment,” “side effect,” “take medicine,” and “injection.” The term “pain” was ranked high for both patients and caregivers; however, patients posted the term more than caregivers. Meanwhile, “concern” was posted more by caregivers than by patients. Finally, “recurrence” was highly ranked only for the patients.

In the post-treatment phase, “surgery,” “examination,” and “recurrence” were ranked high for both patients and caregivers. For patients,
terms related to pain and defecation, including “pain,” “symptoms,” “stool,” and “defecation,” were in higher ranks. While the term “exercise” was ranked high for patients, food intake-related terms such as “food,” “diet,” and “intake” intake were ranked higher for caregivers.

Table 3 presents the TF ranks according to social support. Both patients and caregivers used the high-frequency terms in reference to informational support the most, followed by appraisal and emotional support. For informational and emotional support, caregivers had greater TF than patients. In contrast, for appraisal support, patients had greater TF than caregivers. For both patients and caregivers, the highly ranked terms for informational support were related to CRC treatment, tests, and the disease itself, including “surgery,” “chemotherapy,” “examination,” “treatment,” and “colorectal cancer.” “Pain” was more highly ranked for patients than caregivers. The terms “symptoms” and “recurrence” were only identified in the higher ranks for patients.

Regarding emotional support, the highly ranked terms differed between patients and caregivers. For patients, highly ranked terms were related to recovery and health management, such as “exercise,” “health care,” “complete recovery,” “living,” “vitamin,” “food,” and “nutritional,” and a term related to emotion, “afraid,” was observed. In contrast, for caregivers, highly ranked terms were related to treatments and adverse effects, such as “chemotherapy,” “surgery,” “colorectal cancer,” “vomit,” and “side effect,” and the emotion-related terms were “concern” and “stuffy.”

There were differences in the high-ranking terms used in relation to appraisal support between patients and caregivers. For patients, the highly ranked terms were those related to defecation, such as “stool,” “anus,” “colostomy,” “toilet,” “urge for defecation,” “gas,” and “bloody stool.” Caregiver's highly ranked terms were those related to treatment, food intake, and test values, including “injection,” “take medicine,” “food,” “intake,” “eat,” “level,” and “white blood cell.”

**Discussion**

Differences between patients' and caregivers' desired and provided needs may lead to negative outcomes, making it important to provide tailored support resources during treatment.30 This study provides insights into the support needs of patients and caregivers across different cancer trajectories.

We found that information support needs were ranked highest for both patients and caregivers, similar to the results of a study that analyzed an online community of cancer patients.22 Terms related to CRC treatment, tests, and diseases were also highly ranked, similar to research showing a high need for treatment-related resources, treatment, unmet needs related to the cancer itself, and information.23,24 Notably, there were some differences between caregivers and patients, with terms related to defecation and pain appearing in the higher ranks for patients. Such symptoms have significant implications for patients regarding the fear of recurrence and functional loss.32 Thus, supportive interventions for patients' symptoms should be actively provided.

While the term “recurrence” was posted by caregivers in the post-treatment phase, it was first used by patients in the treatment phase. Fear of recurrence does not persist for CRC patients but is induced by various events that are reminders of the possibility of cancer recurrence, such as symptom onset and hospital visits.33 Treatment procedures involving various invasive treatments and symptoms may play a role in reminding patients of recurrence, which could be interpreted as patients' recognition of treatments as active responses to reduce the risk of recurrence.33 These findings suggest that supportive interventions to address fears related to cancer recurrence should be provided to patients in the early stages of their cancer treatment trajectory.

The need for cancer information has been shown to change across a patient's cancer trajectory.34,35 Similarly, we found a difference in the support needs of caregivers and patients across cancer trajectories.

In the pre-treatment phase, there were similar numbers of high-frequency terms for patients and caregivers, with test-related terms appearing mostly in high ranks. This may be because when patients undergo various tests in the diagnostic phase, both patients and caregivers seek additional information to understand the cancer diagnosis and make the best decision.37

Cancer patients manage the uncertainties that they commonly experience by obtaining information, helping them feel a sense of control over their lives.36,37 Information-seeking behavior can be interpreted not only as a problem-focused coping strategy but also as an emotion-focused coping function.30 In the diagnostic phase, cancer patients experience emotional challenges.30,33 In this study, “anxiety” and “stress” were high-frequency terms used by patients, which might be interpreted as survivors’ emotion-focused coping to control their uncertainty. Thus, healthcare providers should provide sufficient information about various tests to caregivers and patients to mitigate the emotional challenges of CRC survivors.

It has been reported that patients experience many unmet needs in the treatment phase,38,39 which was supported by the current finding that showed the highest term frequencies were found in the treatment phase.
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Table 2
Term frequency ranks by information providers and treatment phases.

| Rank | Patient (n = 2142) | Caregiver (n = 2468) | Treatment phase | Patient (n = 4478) | Caregiver (n = 10,281) | Post-treatment phase | Patient (n = 3893) | Caregiver (n = 2638) |
|------|-------------------|---------------------|----------------|-------------------|-----------------------|---------------------|-------------------|---------------------|
| 1    | Radiotherapy      | 487                 | Colon          | 276               | Chemotherapy          | 988                 | Chemotherapy      | 2171                | Surgery             |
| 2    | Anus              | 450                 | Endoscopy      | 271               | Surgery               | 817                 | Surgery           | 1977                | Examination         |
| 3    | Level             | 359                 | Examination    | 204               | Treatment             | 519                 | Treatment         | 1379                | Exercise            |
| 4    | Normal            | 107                 | Tissue         | 190               | Pain                  | 192                 | metastasis        | 446                 | Concern             |
| 5    | White blood cell | 92                   | Surgery        | 184               | Good                  | 172                 | Good              | 440                 | Fine                |
| 6    | Hemorrhoids       | 66                   | Result         | 133               | Medication            | 150                 | Hospital          | 408                 | Pain                |
| 7    | Visit hospital    | 65                   | Colorectal cancer | 128             | Examination            | 148                 | Colorectal cancer | 390                 | Symptoms            |
| 8    | Red ginseng       | 62                   | Abdominal pain | 118               | Colectomy             | 135                 | Concern           | 316                 | Abnormal            |
| 9    | Urine             | 54                   | Emergency room | 118               | Result                | 130                 | Colostomy         | 310                 | Abnormal            |
| 10   | CT (Computer tomography) | 53                | Polyp          | 113               | Take medicine         | 126                 | Examination       | 309                 | Concern             |
|      |                   |                      |                |                   |                       |                     |                   |                     | Diet                |
| 11   | Strain            | 53                   | Removal        | 107               | Colorectal cancer     | 121                 | Medication        | 305                 | Stool               |
| 12   | Stage             | 48                   | Detection      | 93                | Side effect           | 117                 | Condition         | 260                 | Rectal cancer       |
| 13   | Bleeding          | 43                   | Vomit          | 82                | Severe                | 115                 | Result            | 244                 | Chemotherapy         |
| 14   | Permanent         | 40                   | Treatment      | 73                | Concern               | 110                 | Pain              | 240                 | Endoscopy           |
| 15   | Laparotomy        | 37                   | Advanced       | 68                | Rectal cancer         | 109                 | Stage III        | 193                 | Recurrence          |
| 16   | Anxiety           | 32                   | Sleep          | 65                | Injection             | 109                 | Take medicine     | 193                 | Defecation           |
| 17   | Belly button      | 31                   | Digestion      | 64                | Metastasis            | 108                 | Side effect       | 183                 | Defecation           |
| 18   | Anastomotic site  | 29                   | Lymph node     | 63                | Hospital              | 105                 | Severe           | 180                 | Medication           |
| 19   | Stage I           | 27                   | Hospital       | 59                | Stage III             | 105                 | Possibility       | 170                 | Care               |
| 20   | Stress            | 27                   | Sound          | 59                | Recurrence            | 102                 | Stage IV         | 167                 | Home                |

Interestingly, caregivers had more than twice the number of terms in the treatment phase than patients, indicating that caregivers might have higher support needs. Similarly, another study revealed that 78% of caregivers showed behavior that searched for information besides that provided by healthcare providers. Thus, one notable behavior patterns for CRC caregivers is information seeking. Furthermore, this finding indicates that caregivers recognize that information is critical to help patients make the best decisions without compromising their autonomy. Caregivers recognize coping with patients' physical and emotional pain as a key challenge in the treatment phase. As caregiving burdens greatly increase in the treatment phase, they want sufficient information to effectively support patients. However, despite this increase in their need for information, caregivers may not receive sufficient information from healthcare providers or understand the provided...
information. Caregivers prefer information provided by healthcare providers but tend to be passive in asking for desired information.

In contrast to caregivers, patients have more support needs during the treatment process, and CRC treatment-related information needs are met within the healthcare system. Caregivers may have easier access to an internet self-help support group than patients that face challenges related to hospitalization, treatment, and adverse treatment effects. Furthermore, they may lack the opportunity to actively find information in internet self-help support groups. Therefore, strategies to improve information accessibility in the healthcare system should be developed to meet caregivers’ informational needs since caregivers are the primary source of support for CRC patients and play a central role in helping patients integrate and digest information.

The post-treatment phase was the only phase in which patients had more frequent terms than caregivers. These results differed from those of Ehemann et al that reported patients stopped actively seeking cancer information after treatment. Since unmet needs were cancer-specific in the post-treatment phase, this difference might be attributed to CRC-specific support needs. Unlike other cancer patients, CRC patients experience various adverse effects, such as changes in their bowel function after treatment and challenges adapting to daily life. Such challenges can lead to unmet needs, resulting in behaviors like actively seeking information in online self-help support groups.

In addition, the terms related to delayed symptoms were highly frequent terms for patients, showing that patients with CRC have high support needs related to various post-treatment symptoms. This is consistent with research reporting that many CRC patients feel abandoned because they lacked satisfactory supportive care from healthcare providers in the post-treatment phase. Moreover, most negative experiences of CRC patients are due to a lack of post-treatment care. Thus, supportive interventions that manage delayed symptoms of CRC patients in the post-treatment phase should be actively provided to help patients adapt to their changed circumstances.

In the post-treatment phase, there were clear differences in the types of high-frequency terms used by patients and caregivers. Nutrition, diet, and bowel activity have been reported as major unmet information needs for CRC patients. In this study, “bowel activity” was a high-frequency term for patients, while “nutrition” and “diet” were high-frequency terms for caregivers. For appraisal support, indicating the information needed to evaluate health conditions, the highly ranked terms were related to bowel activity for patients and to nutrition and diet for caregivers. These results indicate that patients and caregivers have different support needs in the post-treatment phase. Patients may experience defecation symptoms, primarily in the post-treatment phase. They consider these symptoms as the standard for evaluating their health status, which increases patients’ support needs to manage and cope with such symptoms in the post-treatment phase. While CRC patients either lose appetite or feel uncomfortable with food intake due to intestinal stomas or changes in colonic function, caregivers also recognize higher appetite as a sign of recovery. Therefore, increases in caregivers’ support needs may be owed to their desire to provide healthy food to patients. These differences suggest that CRC patients and caregivers should have access to different supportive interventions in the post-treatment phase. Patients with CRC should be supported with programs that manage and adapt to their changes in bowel function, while CRC caregivers could benefit from programs that address preparing or providing healthy and easy-to-eat foods for patients with CRC.

Limitations

This study had some limitations. First, we focused on frequently used terms in the social media posts of CRC survivors to analyze the supportive needs of patients and caregivers, which cannot provide an in-depth understanding of the experiences of the patients and caregivers. In addition, interviewing CRC patients and caregivers about the results of text mining in the postprocessing step is needed to strengthen the validity. Further studies that used methods such as focus group interviews are needed to better understand the needs of patients with CRC and their caregivers. Second, the posts written by caregivers were not identified according to their relationship to the patient (eg, spouse, child, other family members), and there may be differences in needs between the patients’ spouses/partners and other family members. For instance, the spouses of patients with breast cancer have been found to lack the necessary information about sexual attractiveness, but family members, such as daughters, were more concerned about their mother losing hair and breast loss during the treatment. Identifying the differences between the spouses/partners of CRC patients and family members’ needs would be valuable for providing more tailored interventions in the future. Third, this study could not identify the ages of the patients or their caregivers that posted in the self-help group. Given the finding that internet use and the age of cancer survivors are related, additional research is needed to determine whether there are significant differences in supportive needs based on the age of the posters. Finally, selection bias may exist in the study’s data because the individuals that posted on this internet self-help group may be more motivated than those not engaged in this group, limiting the generalizability of the results to other CRC patients and caregivers.

Conclusions

Supportive interventions based on the needs of CRC survivors can efficiently help improve their quality of life. However, few studies have examined the differences and similarities in patients’ and caregivers’ needs across cancer trajectories. The significance of this study is that it provided a comprehensive understanding of the specific needs of CRC patients and caregivers across cancer trajectories. In particular, this study uses a novel approach of using the internet posts written by CRC survivors to needs analysis. The posts were recently, naturally, and increasingly formed on the Internet and were considered important for investigation.

We found that the needs of patients and caregivers were not always similar, depending on the treatment phase, thereby, highlighting the importance of distinguishing the needs of both parties and providing supportive interventions accordingly. In particular, these data suggest the necessity of supportive interventions in which healthcare systems actively provide caregivers with satisfactory levels of information about disease treatment and the disease itself, as shown by the high support needs of the Internet self-help support group. Finally, programs that address the management of delayed symptoms for patients and help caregivers prepare food for patients in the post-treatment phase.

Moreover, these results can be used as fundamental data to provide supportive interventions tailored to the needs of patients and caregivers in each treatment phase. The similarities and differences in the caregivers’ and patients’ needs demonstrate the necessity of analyzing the specific needs of both groups across the cancer treatment trajectory. Future studies should investigate these needs using methods such as surveys and interviews and compare them with the results of this study.

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Declaration of competing interest

None declared.

Authors’ contributions

Conceived and designed the analysis: Jaehee Yoon and Heesook Son; Collected the data: Jaehee Yoon and Heesook Son; Contributed data or...
analyses: Jaeehee Yoon; Performed the analysis: Jaeehee Yoon and Heesook Son; Wrote the paper: Jaeehee Yoon and Heesook Son.

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