

Priorities of Unmet Needs for Those Affected by Colorectal Cancer: Considerations From a Series of Nominal Group Technique Sessions

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ABSTRACT

Background: Colorectal cancer (CRC) is the third most common cancer among men and women in the United States. Patients and survivors experience a range of challenges, including anxiety, financial issues, long-term adverse effects, and more. The intent of this project was to assess the needs of the CRC community directly from survivors and their caregivers and to lay a foundation for ongoing support. **Methods:** Twelve nominal group technique sessions were facilitated. Participants were randomized and presented with the following questions: “What information do you wish you had at the time of diagnosis?” and “What information do you need now as a survivor?” After the nominal group technique process, each statement’s score was divided by the number of people in the session, providing the average to identify the top-ranked statements. Themes and subthemes were applied to statements. Results were compared between coders. **Results:** There was a total of 79 participants, 49 of whom self-identified as a patient with or survivor of cancer. Patient/survivor demographics were as follows: stage IV disease (n=20), stage III disease (n=22), stage II disease (n=5), stage I disease (n=2), caregiver/family member (n=30), male (n=16), female (n=63), White (n=50), Native Hawaiian/Pacific Islander (n=1), Hispanic/Latino (n=13), Black/African American (n=11), Asian (n=1), and more than one race/ethnicity (n=3). The most frequent themes among responses to the first question were communication and coordination with care team and access to CRC resources. The most frequent themes among responses to the second question were psychosocial support and family/caregiver support. Frequent themes among responses across both questions were understanding treatment options and adverse effects. **Conclusions:** These findings highlight gaps in support for individuals affected by CRC, and lay a foundation for ongoing assistance. Future studies exploring differences based on disease stage, race/ethnicity, age, gender identity, geographic location, and tumor location are needed to further tailor support for those experiencing CRC. Themes identified in this project require a multidisciplinary approach to ensure that the unmet needs of survivors are addressed.

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Background

Colorectal cancer (CRC) is the third most common cancer among men and women in the United States, with an estimated 147,950 new diagnoses in 2020.¹ Although the 5-year survival rate for patients with localized or regional disease is 90% and 71%, respectively, it is 14% for those with distant-stage disease.¹ Regardless of stage, survivors of CRC and their caregivers encounter a range of challenges that could be addressed by physicians, policy administrators, cancer centers, and nonprofit organizations.

The expanding body of literature on supportive care suggests that many survivors experience clinically significant anxiety and depression throughout their illness, which can persist years after treatment completion²⁻⁴; patients may be impacted financially by medical and basic living costs⁵; patients diagnosed at later stages, particularly those who are younger or with comorbidities, have an increased risk of more severe problems^{3,6}; and long-term care accentuates stress on family and caregivers.^{7,8} Nonprofit organizations, healthcare systems, policymakers, and providers are in a unique position to address gaps in care as described in the literature. However, before meaningful movement can be made in this space, these unmet needs must be identified and prioritized within the CRC population.

Although efforts to improve the patient and survivor experience have gained momentum over the past decade, it is essential to ensure that the CRC community has their needs met. The intent of this project was to lay a foundation for prioritizing these needs. Kotronoulas et al⁹ stated that “investing time to sensitively inquire about the supportive care needs of this patient population is key, whilst evaluating and re-shaping clinical interactions based on patients’ priorities is equally essential.” As a response to this call, we sought perspectives directly from the patient community (patients, survivors, and loved ones) to learn about gaps in care and challenges within the CRC experience that may not be adequately addressed. Based on this information, we suggest potential solutions to address these needs, supported by the current

literature and guidelines and recommendations from professional accrediting organizations. These solutions are intended to (1) create interventions and materials for support, (2) inform clinical care and interactions with healthcare teams, (3) propel current and future policy initiatives for survivors, and (4) further research endeavors.

Methods

Annual nominal group technique (NGT) sessions were hosted in 2016 through 2018 as a means of primary data collection. NGT is an efficient method for prioritizing topics and obtaining weighted group feedback while eliciting equal participation. This structured small-group discussion “results in a set of prioritized solutions or recommendations that represent the group’s preferences.”¹⁰ In 2015, a pilot session assessed NGT process feasibility.

The following questions were posed during all sessions: Question 1 (Q1) asked, “What information do you wish you had at the time of your CRC diagnosis?” and Question 2 (Q2) asked, “What information do you need now as a survivor of CRC?”

Sessions began with an introduction of Q1. Participants were randomly assigned to 2 groups. During a silent idea generation period, participants wrote down as many statements as possible in response to the question based on their experience. Participants shared one statement at a time from their list until all statements were exhausted and recorded. Duplicate ideas were not repeated. Participants ranked their top 5 statements from most to least important. The process was repeated for Q2.

Sessions were analyzed individually. Each statement’s total score, determined by the NGT ranking process, was divided by the total number of people in the group,

providing the average to identify top-ranked statements. Themes and subthemes were applied to statements in Q1 and Q2. Results were compared between coders and discrepancies were discussed until consensus was reached.

Participants in the NGT sessions met in person at an annual conference hosted for those affected by CRC. These participants had self-selected to engage in work related to advocacy and awareness, including a variety of focus groups and discussions, and had traveled to the conference from around the country.

Results

Demographics

Twelve NGT sessions took place. In total, 79 individuals participated. More than half of the participants (62%) were cancer survivors, and the remainder self-identified as caregivers or family. The following demographics were collected from survivors, although these were not confirmed with medical records: stage IV disease (n=20), stage III disease (n=22), stage II disease (n=5), stage I disease (n=2), caregiver/family member (n=30), male (n=16), female (n=63), White (n=50), Native Hawaiian/Pacific Islander (n=1), Hispanic/Latino (n=13), Black/African American (n=11), Asian (n=1), and more than one race/ethnicity (n=3).

Themes

There were 15 themes that arose for Q1 and 16 for Q2. Figure 1 identifies the most frequent themes each year. Tables 1 and 2 list the highest-ranked statements during the sessions for Q1 and Q2, respectively. The most prevalent theme for Q1 was communication and

Theme Frequency	Themes Question 1: What information do you wish you had at the time of your CRC diagnosis?			Themes Question 2: What information do you need now as a survivor of CRC		
	2016	2017	2018	2016	2017	2018
1 (most frequent)	Treatment options	Communication coordination with care team	Communication coordination with care team	Psychosocial support	Psychosocial support	Psychosocial support
2	Adverse effects	Psychosocial support	Treatment options	Support for families and caregivers	Long-term adverse effects	Treatment options Legal support and employment
3 (least frequent)	Communication coordination with care team	Adverse effects Access to CRC resources	Access to CRC resources	Treatment options Advocacy Genetics	Treatment options	Support for families and caregivers End of life

Figure 1. The most frequent themes identified by year.

Abbreviation: CRC, colorectal cancer.

coordination with the care team, which suggested that coordination and communication at the time of diagnosis was not optimal and that methods of improving patient understanding about the intricacies of cancer care should be considered. The next most-prevalent theme for Q1 highlighted the lack of CRC-specific resources. For Q2, the most prevalent theme was psychosocial health, emphasizing the unmet need for mental and behavioral health support for survivors. The next most-prevalent theme was support for family and caregivers. Common themes seen across both questions included adverse effects, referring to the apprehension regarding adverse effects and adverse effect management, and understanding treatment options, specifically palliative care, medication adherence, maintenance therapy, and ending curative treatment. Many themes noted throughout were tied intimately to the communication theme seen in the responses to Q1.

Discussion

This project identified pressing issues for survivors of CRC and their loved ones and has the potential to support future research, interventions, and policy initiatives. Current guidelines and recommendations put forth by professional organizations are aimed at improving the patient experience.

Our findings indicate a need for stronger implementation and support of the current recommendations and gaps in care to better serve the CRC community.

Although prominent themes based on frequency and consistency within the sessions should be prioritized, specific statements that ranked highly, such as financial concerns, genetic testing, and others, should be considered for future research and program planning as well.

Q1 Most Frequent Themes

Communication and Coordination With Care Team

The saliency of this theme suggested that coordination and communication between patient and provider at the time of diagnosis was not optimal and that information may not be adequately delivered to and/or understood by patients. Many statements during the sessions were explicit about the need for navigators, whereas other statements described challenges and frustration with understanding treatment expectations, coordinating second opinions, accessing medical records, and obtaining meaningful guidance from doctors.

In 2017, ASCO released guidelines on effective communication for physicians treating adult patients with cancer. The recommendations encourage providers to check for patient understanding after discussing goals

Table 1. Highest Ranked Statements by Year and Group for Question 1

Question 1: What Information Do You Wish You Had at the Time of Your CRC Diagnosis?						
Rank Order	2016		2017		2018	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
1	Patient navigation	Financial concerns – paying for treatment	Counseling to manage the psychological impact of the cancer diagnosis	Information about all treatment options before choosing a treatment	Information about physical adverse effects of chemotherapy	Access to a nurse navigator
2	Genetic testing for myself and family (prevention)	Long-term effects of chemotherapy	Up-to-date resources specific to CRC	Financial advice for patients	Financial support for caregivers	Checklist of things to do before making treatment decisions
3	Mental health support	Support for how to talk to children (adult and young) about my cancer diagnosis	Information about adverse effects which could result from each treatment type	Support for children of all ages; resources to help them cope	Information on biomarkers and how this could affect current and future treatment options	More information about standard treatment options
4	Specific information about how nutrition affects the body during and after treatment Information about all treatment options, including clinical trials	Clear expectations for treatment before it begins	Care coordination and continuity of care	Information about family history and genetics	Family support	Emotional care
5		Information for caregivers on how to help patient in active treatment	Information about family history risk and risk prior to treatment Knowing that a second opinion is an option and information on how to obtain one	Information about integrative medicine for adverse effect management and primary treatment Information about and support for sexual side effects—for patients and sexual partners	Lay patient navigator	Information on treatment options being studied in clinical trials

These statements, made by participants, clarified and edited using the nominal group technique approach, were reported as needs at the time of diagnosis. Abbreviation: CRC, colorectal cancer.

Table 2. Highest Ranked Statements by Year and Group for Question 2

Question 2: What Information Do You Need Now as a Survivor of CRC?						
Rank Order	2016		2017		2018	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
1	Support for current financial strain after active treatment	Information on where the science is heading	Provider discussing and offering genetic testing	Education for patients and their family about increased risk and early screening	Long-term adverse effect management support	A cure
2	Future treatments and maintenance options that may be available for survivors of stage IV CRC living with disease	Information and support for posttraumatic stress disorder	Management of posttraumatic stress disorder for caregivers/family members after death of cancer survivor	Support for anxiety and posttraumatic stress disorder	Survivorship care plan	Survivorship care plan
3	General survivorship mental health support	Clear information for how to navigate clinical trials	Fear of recurrence Support in managing anxiety about getting CRC (high-risk family member)	Support to cope with loss and end of life	Clear information and direction for routine screening guidelines once no evidence of disease	Identification of family risk and family screening schedule
4	Continued family support post diagnosis and beyond into survivorship	General and easy access to mental health care	Tips for adjusting to new normal Managing relationships after the death of a spouse	Resources for adjusting to life after cancer	Coping with anxiety and fear of the unknown	CRC-specific support group (colon vs rectal) to raise awareness and connect
5	Family and genetic testing offered Tips on managing cancer and career	Information about long-term effects of chemotherapy on the body	Medically sound advice for building a stronger immune system Support for when and how to talk to adult children about a patient's end-of-life choices Long-term distress monitoring of children who have lost parents to CRC	Detailed and easy-to-read information about health insurance policies	Managing survivor guilt and remorse	Avenue to share story and help others

These statements, made by participants, clarified and edited using the nominal group technique approach, were reported as needs at the time of diagnosis. Abbreviation: CRC, colorectal cancer.

of care and prognosis, treatment selection, end-of-life care, and family involvement.¹¹ Although empathy is widely considered to improve patient satisfaction and reduce distress,¹² “good interpersonal skills are not a substitute for strong healthcare communication skills.”¹¹ Interventions to ensure patient understanding should be implemented to achieve adherence to the ASCO guidelines.

Patient navigators have been shown to play a key role in closing the gap of communication and coordination. They provide individualized assistance, directing patients to services such as psychosocial, educational, and family support in a timely manner. Studies have indicated that patients who receive navigation services have decreased barriers to care and increased satisfaction.¹³ Patient navigation can improve care coordination and communication between patients and their care teams. A review by Gorin et al¹⁴ found that coordinated approaches, including patient navigation, telehealth, and nurse case management, among others, led to improvements in 81%

of outcomes, including measures of patient experience with care. Some organizations, such as the American College of Surgeons Commission on Cancer, have implemented standards to ensure patient-centered care by requiring that all cancer programs seeking accreditation include patient navigation.¹⁵

Based on our findings from the NGT, we support the development, evaluation, and use of care coordination programs; the incorporation of nurse or lay navigators; and effective patient-provider communication to optimize relationships and the care experience. Payers play a key role in ensuring that navigation services are available to patients with cancer, and patient advocacy organizations are positioned to participate in training lay navigators to help patients through the healthcare maze. Implementing care coordination programs and encouraging meaningful, consistent communication with healthcare teams are essential to helping the patient community understand a convoluted healthcare system.

Access to CRC Resources

Limited access to CRC materials and survivor or caregiver networks at the time of diagnosis was described in NGT sessions. Participants reported receiving materials that were difficult to read and comprehend. Some received cancer-agnostic resources, and others received breast cancer resources. The consensus was that printed and digital resources specific to the individual's cancer (ie, location of the cancer and biomarkers) would have supported their understanding of diagnosis, treatment decision-making, and next steps. Participants agreed that having a support network to turn to might have improved their diagnosis experience, because connecting with peers can help patients and loved ones navigate their disease and feel less isolated by learning from others' experiences.

Linking patients to meaningful information across the cancer continuum can help them advocate for value-based care. Informed patients may find it easier to make important treatment decisions. Patient organizations can encourage providers to recommend resources written using the patient voice to reduce the sense of isolation. Organizing in-person and virtual CRC-specific support groups in which those affected by CRC can discuss unique challenges and share experiences is worth exploring. Many organizations offer peer support and programs to connect patients and caregivers with others who can share similar experiences and resources they have found useful. We encourage collaboration between healthcare providers and advocacy and patient organizations so that patients can access cancer-specific resources and peer-to-peer support at the time of diagnosis.

Q2 Most Frequent Themes

Psychosocial Support

The most frequent theme for Q2 was psychosocial support, highlighting the unmet need for mental and behavioral health resources for survivors and their loved ones. Participants discussed posttraumatic stress disorder, coping with end of life, lack of access to mental health support, adapting to a new normal, and managing relationships.

A 2008 Institute of Medicine report¹⁶ identified gaps in psychosocial care for patients with cancer, models for delivering psychosocial care, and recommendations for research, policy, and education. The report suggested that patients' psychosocial health needs were not being adequately met, despite robust evidence displaying the benefits of meeting these needs. A 2006 Institute of Medicine report recommended that cancer survivors receive an individualized survivorship care plan that would include guidelines for monitoring and maintaining their health and that was developed to meet a patient's diverse needs as they change over time.¹⁷ Because of these reports, the early 2000s saw an increased awareness and screening for

psychosocial distress in patients with cancer.¹⁸ Unfortunately, substantial barriers and insufficient program use remain, and survivors of cancer face a range of challenges, including pain, problems with sexual functioning, fear of recurrence, financial difficulties, and poor sleep.^{19,20} Additional barriers include limited reimbursement and complex billing for behavioral health providers, differences among specific population needs (young people vs older adults), and mental health stigma.¹⁹ An insufficient number of clinical trials has been conducted to address the complex psychosocial needs of patients, resulting in minimal evidence-based interventions for long-term survivors.¹⁹

Many survivors of CRC experience clinically significant anxiety and depression across the trajectory of illness.³ Attention should be directed toward psychosocial health across the cancer continuum, including survivorship. Distress screening is a critical aspect of care, and tools such as those from NCCN²¹ and the Cancer Support Community, and surveys such as the Patient Health Questionnaire (PHQ-9) and customized surveys addressing distress should be used throughout the cancer course. The American Cancer Society and other cancer support agencies have also provided great guidance for patients about how to report their distress and provide an opportunity to talk about emotional health and well-being as a standard part of care. For patients who have completed active treatment, survivorship care plans can ensure that any referral needs for mental health services after treatment are identified and fulfilled. Based on a systematic review, evidence supporting the efficacy of psychosocial interventions is limited, and therefore large-scale trials are needed before definitive conclusions can be made.^{3,19} We urge policymakers and researchers to advocate for additional research funding for psychosocial interventions to identify which practices have the greatest benefit for survivors of CRC. In addition, we urge providers to not overlook the psychological stress associated with cancer survivorship and to quickly triage survivors who need support.

Support for Families and Caregivers

The family and caregiver support theme included statements reflecting a wide range of needs. One caregiver statement highlighted the difficulty of managing personal medical appointments while caring for a loved one. One patient perceived that her partner did not know how to help or be supportive. Many caregiver participants described feelings of burnout, and many survivors reported concern over their caregiver's wellness.

Informal caregivers play a vital role in supporting patients and survivors. They face challenges such as coping with uncertainty of prognosis, processing emotions, burnout, stress from observing treatment toxicities and adaptations such as ostomy support, and social challenges—all of which change throughout the disease course.^{22,23}

In addition, a recent study by Sasaki et al²⁴ suggests that it is not just the caregivers who are worried, but also patients and survivors themselves who report concern over how their cancer affects their families.

Caregivers and family members are an integral part of the care team, requiring programs tailored to their independent needs that also consider the unique aspects affecting many patients with and survivors of CRC, such as living with an ostomy or bowel incontinence. Steps should be taken to meet the ASCO patient–clinician communication guideline recommendations:

Clinicians should suggest family and/or caregiver involvement in discussions (with patient consent) early in the course of the illness for support and discussion about goals of care [and] determine if a formal family meeting in a hospital or outpatient setting is indicated at important junctures in care. When possible, ensure that patients, their designated surrogates, and desired medical professionals are present.¹¹

In addition, patient organizations should consider developing caregiver materials that are culturally sensitive and cancer-specific to ensure that caregivers have resources for support and can learn the stories of others in similar circumstances, which may reduce feelings of isolation.

Themes Across Q1 and Q2

Understanding Treatment Options at Diagnosis and Beyond

Understanding treatment options was a prevalent theme among responses to both questions, consisting of statements about palliative care, medication adherence, maintenance therapy, and ending curative treatment. As these issues are intimately tied to communication and coordination, steps toward helping patients and caregivers understand treatment options could include improved resource access and patient–provider communication.

Shared treatment decision-making has been shown to improve the patient experience and can only be achieved when patients understand what treatments are available to them and why.^{25,26} As referenced in the ASCO patient–clinician communication guideline,¹¹ clinicians should make patients aware of all treatment options, including clinical trials and palliative care. We recommend developing and disseminating easy-to-read resources detailing treatment options for patients with CRC, including palliative care, integrative medicine, family planning, and clinical trials, and methods to initiate complicated discussions between provider and patient.

Adverse Effects at Diagnosis and Beyond

Concern about adverse effects was a prominent theme across both questions. At the time of diagnosis, patient

statements were about chemotherapy adverse effects, medical marijuana, medication interactions, and ostomy support. Statements in response to Q2 included concern about long-term adverse effects, menopause and hormonal changes, and managing bowel incontinence and pain. Across both questions, participants noted that palliative care was something they wished they had been offered at treatment initiation.

Patients with cancer experience adverse effects based on treatment type. Improved treatment and outcomes have the potential for late and long-term adverse effects, which can decrease quality of life. Short- and long-term follow-up, health maintenance, and lifestyle modifications remain important components of CRC survivor care. Passik et al²⁷ stated that at the time of diagnosis and throughout the course of treatment, levels of distress and fear related to treatment, specifically chemotherapy, are ever-changing, and therefore increasing awareness of adverse effects at diagnosis and continuing through the duration of care could help patients adapt to current and future treatments. Toxicity education at the time of diagnosis could (1) help patients understand adverse effects, (2) support patients and caregivers in preparing practically for adverse effects, (3) reduce stress stemming from the patient–caregiver relationship, and (4) support patients and caregivers in shared decision-making by enabling risks and benefits to be discussed and patient values to be incorporated into treatment decisions.²⁴

We recommend providing education regarding CRC adverse effects to patients and caregivers at multiple points along the cancer continuum, including palliative care information at the time of diagnosis. Many organizations offer free, patient-facing materials about treatment-related adverse effects and management that can be easily found and distributed by healthcare teams. Access to care coordination could provide patients and survivors with supportive care for adverse effects through the trajectory of illness and into survivorship.

Limitations

If a given statement in the NGT is ranked highly, it does not necessarily mean that many participants voted for it as a top priority. Therefore, we focused on the frequency of themes and the average weight given to themes. Although it is important to identify the strength of a given statement (based on total votes), voting frequency was deemed more useful for these purposes. NGT thrives on the diversity of a group, and therefore participants were not stratified by demographics such as age or disease stage. Stratifying participants in the future may yield useful results. The NGT is limited to a single purpose and single topic and requires all participants to agree to using the same structure, limiting discussion.

The data were collected over multiple years, leaving the potential for changes over time. There was a limited sample size with varying times from diagnosis for participants, making analysis challenging for accurate examination across the continuum. The patient population was heterogeneous in disease stage, making it difficult to identify which priorities were the most meaningful for patients with later-stage versus early-stage disease.

Conclusions

The intent of this project was to garner input from the CRC community to assess needs and lay a foundation for ongoing support. Given the robust heterogeneity and rich process of the NGT, this effort has strong potential to help inform and improve interventions and materials for those affected by CRC, inform clinical care and interaction with healthcare teams, provide insight for current and future policy initiatives for survivors, and inspire future research endeavors.

More research is needed to ensure that patients have essential resources from diagnosis through survivorship. Future studies exploring differences based on stage, race/ethnicity, age, gender identity, geographic location, and tumor location are needed to further tailor support for all those experiencing CRC. The themes identified in this project require a multidisciplinary approach to ensure that the unmet needs of survivors are addressed.

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