

Responding to Priorities of Unmet Needs for Those Affected by Colorectal Cancer (CRC)

Considerations from a Series of Nominal Group Technique Sessions

INTRODUCTION

Fight CRC puts our patient community first. Over the past four years, we surveyed our network to find out more information on the unmet needs of those affected by colorectal cancer. Based on the results, it's evident that care teams, nonprofit organizations, and policymakers can greatly reduce the stress of colorectal cancer on the patient and their support system once key priorities and concerns are identified.

By seeking perspectives directly from the patient community, this study has established the foundation necessary for supporting future research, programmatic interventions, and policy initiatives to improve the experience of those affected by CRC.



STUDY METHOD

- Annual Nominal Group Technique (NGT) sessions were hosted between 2016 and 2018 at annual conferences for those who've been affected by CRC
- 79 advocates participated, with 62% representing survivors and 38% representing caregivers or family members
- The following questions were posed during all sessions:
 - » Question one (Q1): What information do you wish you had at the time of diagnosis?
 - » Question two (Q2): What information do you need now as a survivor?
- Participants ranked their top 5 answers from most to least important and then discussed their results until a consensus was reached and top themes were identified.

RESULTS

TOP THEMES

Question 1: What information and support did patients wish they had at the time of diagnosis?

- Increased communication and coordination with care teams
- Patient navigators to help close the gap between physicians and patients
- A more thorough explanation of the intricacies of a cancer diagnosis
- Better access to colorectal cancer resources

Question 2: What information and support do patients need now?

- Mental and behavioral support, specifically for survivors
- Support for patients and caregivers through programs tailored to independent needs and unique aspects of caring for colorectal cancer patients
 - » Caregivers and family members are an integral part of the care team, and need support, along with patients, through these types of programs

Patients indicated needing the following support and resources at the time of diagnosis and throughout their survivorship journeys:

- A better understanding of palliative care, medication adherence, maintenance therapy, and ending curative treatment
- A better understanding of side effects and side effect management, such as chemotherapy side effects, medical marijuana, medication interactions, and ostomy support

WHAT DOES THIS MEAN FOR FUTURE PRACTICE?

- The development, evaluation, and use of care coordination programs, the incorporation of nurse or lay navigators, and supportive patient-provider communication would optimize relationships and the care experience
- Collaboration between healthcare providers and advocacy and patient organizations at the time of diagnosis would improve patient access to cancer-specific resources and peer-to-peer support
- Providers are encouraged to screen for psychological stress associated with cancer survivorship and to quickly triage survivors who need support
- Patient organizations should develop materials to support caregivers that are culturally sensitive and cancer specific
- Easy-to-read resources should be developed and disseminated to better explain topics such as:
 - » Palliative care
 - » Integrative medicine
 - » Family planning
 - » Clinical trials
- Conversation-starters should be provided to help initiate complicated discussions between providers and patients
- Education of side effects should be provided to patients and caregivers at multiple points along the cancer continuum

CONCLUSION

In addition to the major themes, this study identified patient and caregiver concerns such as finances, genetic testing, and a lack of resources specific to cancer stage and location (rectal or color), race/ethnicity, age, gender identity, and geographic location.

Movements to improve the patient and survivor experience have been gaining momentum over the past decade, and it's essential to the Fight CRC mission to ensure the CRC community has their needs met. Studies like this help us focus our efforts on the concerns most important to patients and caregivers and raise awareness of these issues within the provider and research communities. » [Read the full report here: *FightCRC.org/UnmetNeeds*](#)



Fight Colorectal Cancer (Fight CRC) is the leading patient-empowerment and advocacy organization in the United States, providing balanced and objective information on colon and rectal cancer research, treatment, and policy. We are relentless champions of hope, focused on funding promising, high-impact research endeavors, while equipping advocates to influence legislation and policy for the collective good.

We are Relentless Champions of Hope in the Fight Against Colorectal Cancer.

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