SURVEY OF THE COLORECTAL CANCER COMMUNITY DURING COVID-19

COVID-19 RESPONSE
In April 2020, Fight Colorectal Cancer (Fight CRC) conducted an online survey to the colorectal cancer community. The survey was distributed through social media channels and targeted emails from April 24-May 5, 2020. Virtual focus groups were also conducted to gather rich qualitative data from cancer patients about their experiences during the novel coronavirus pandemic.

In total, 10 participants participated in the focus groups:

- **FEMALE = 7**
- **MALE = 3**
- **STAGE III = 3**
- **STAGE IV = 7**

In total, 222 individuals responded to the survey:

- **68%** • Colorectal Cancer Survivor/Patient
- **12%** • Caregiver
- **8%** • First-degree Family Member
- **3%** • Medical Professional
- **3%** • Family Member (not first-degree)
- **2%** • Friend

**COVID-19 Diagnosis amongst patients:**

- **87%** • Have NOT had COVID-19 symptoms, not been tested
- **4%** • HAVE had symptoms, wanted test, but COULDN’T receive test
- **4%** • HAVE had symptoms and HAVEN’T been tested
- **2%** • Have been tested and were NEGATIVE
- **0%** • Tested positive

**CHANGES IN COLORECTAL CANCER CARE**

Fight CRC’s patient survey also collected information about changes in care among the colorectal cancer community. Thirty-seven percent of respondents indicated that COVID-19 has caused disruption in their or a loved one’s colorectal cancer care.

For many, care has been delayed by 2+ weeks, and others don’t know when their care will be rescheduled:

- **34%** • In-person visits changed to telehealth
- **26%** • Care or treatment delayed by more than 2 weeks
- **23%** • Care or treatment delayed and don’t know when it will be rescheduled
- **20%** • Minimal impact
- **<10%** • Supplies/prescriptions
- • Care or treatment delayed by less than 2 weeks
- • Cancer care/treatment completely cancelled
- • Cancer care/treatment cancelled and no plan on rescheduling

Two of the ten focus group participants reported having genetic colorectal cancer (Lynch and JPS). Both had their routine colonoscopies delayed. Additionally, one of these participants has children who are also living with a genetic mutation known to cause colorectal cancer, and their screenings have also been postponed.

“I wasn’t sure what to make of all of it. It didn’t seem real until it hit in the U.S. My biggest concern was if it would impact my treatment.”

Statements reflected a notion that the human aspect of cancer care had been removed – couldn’t see no more smiles from infusion nurses (due to masks and full personal protective equipment), no chatter in the infusion room (due to regulations keeping visitors from joining patients), no chairs or brochures in the waiting room, use of telemedicine, and the inability to have caregivers at appointments. Additionally, one participant referenced anxiety about their nurse who had also been treating COVID-19 patients in the ER. However, even with these changes, patients felt that the infusion room was a safe place to be.

“Last week when I was there I sent a message to my mother telling her I felt like at this very moment, sitting here at chemo, I’m in the safest place I can be—safer than walking around among a bunch of people.”

Focus group participants agreed that there was frustration with those in their community not following recommendations for mask-wearing and social distancing. Almost all participants were scared about states opening up sooner than the science recommends, and those who were not scared noted that they feel confident in managing their own safety.

- “I want to get outside, but I can’t trust others to practice safe social distancing and/or wear masks.”
- “I am anxious but hopeful [about lifting restrictions]. I am worried about complacency of others.”

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**Primary Residence:**

- **51%** • Suburban
- **32%** • Urban
- **15%** • Rural

**Minimal impact**

- Supplies/prescriptions
- • Care or treatment delayed by less than 2 weeks
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**The top 5 types of medical visits have been the most affected include:**

- **73%** • In-person Visits
- **34%** • Imaging
- **25%** • Supportive Services (OT, PT, Mental Health)
- **25%** • Active Treatment (Not Including CT)
- **13%** • Clinical Trials
MAJOR THEMES
Several major findings and themes emerged from this survey including the impact of COVID-19 on the medically underserved, and the burden on mental health and finances.

DISPARITIES FOR THE MEDICALLY UNDERSERVED

 Patients on Medicare were more likely than patients on private insurance:
• To report that they do not have good communication with their health care team
• To have difficulties affording basic supplies (such as food) due to COVID-19
• To feel unable to stop worrying nearly every day and feel as though they are struggling (and not doing well)

People living in rural areas were more likely:
• To be on Medicaid
• To be between the ages of 55-64 compared to other age groups (25-44, 45-54, 65-74)
• To have disruptions in active treatment for cancer care compared to those in suburban/urban areas
• To feel as though they can’t stop worrying on more than half the days compared to those living in suburban areas
• To have greater concerns about maintaining a supportive network than those living in suburban areas
• To need financial support more than those in suburban and urban areas

FINANCIAL BURDEN

• Those who lost their jobs or who had a household member lose their job were more likely to report that they were not receiving quality care or having good communication from their health care team compared to those who were not financially impacted
• Those who have had their work hours reduced, lost investments, and lost jobs were significantly more likely to report feeling nervous, anxious, and on edge compared to those not financially affected
• Those who faced treatment disruptions indicated needing financial support more than those who didn’t

“ I was also anxious about losing benefits. Losing my health insurance. It created anxiety. There was one night where I was having a panic attack because of COVID and not being able to go outside. And every time I would go to my treatment, there are multiple patients there too. I was scared of getting sick.”

MENTAL HEALTH

• Overall, the majority of respondents reported feeling nervous, anxious or on edge, and unable to stop worrying several days a week. Caregivers are more likely to report feeling this way compared to patients.
• Those who had treatment disruptions experienced anxiety more than normal compared to those who didn’t face disruptions.

“I remembered, because I’m high risk, how I felt when I had the stage IV diagnosis and was going through treatment and knowing that it was quite possible I was going to die. It brought it all back...this whole situation.”

Major Concerns:

- Concerns about contracting COVID-19
- Concerns about the health of my family
- Generally concerned about the future
- Concerns about state/national leadership
- Disruption in cancer care and impact on health
- Finances

Regardless of age, stage IV patients who have been living with disease for an extended period of time felt as though they are being robbed of the time that they do have left.

• “I don’t know how much time I have left...was hoping to travel and complete the bucket list. Makes it tough to stay at home.”
• “As a cancer patient I felt like it was robbing me of more time...I’m already restricted as it is and now I just have to stay home. In that aspect, It’s been hard.”

TOP SUPPORTS:

- Family/partner/roommates: 72%
- Family/friends/virtual support: 65%
- Pets: 50%
- Exercise: 38%
- Medical Providers: 28%
- Watching Netflix: 28%

OTHER NOTEWORTHY ITEMS:
Younger people reporting having more disruptions in clinical trials (35-44) than older counterparts (45-54).
RELENTLESS CHAMPIONS OF HOPE IN THE FIGHT AGAINST COLORECTAL CANCER