



RESEARCH BRIEF:

New Colorectal Cancer Diagnoses Fall by One-Third as Colonoscopy Screenings and Biopsies Grind to a Halt During Height of COVID-19

Concerns Mount Over Gaps in Care for New and Existing Cases as Nationwide Colonoscopy Screenings and Biopsies Fall Roughly 90%

KEY FINDINGS

- The total number of colonoscopies and biopsies performed declined nearly 90% by mid-April compared to the same period last year.
- New colorectal cancer diagnoses were down more than 32% by mid-April and colorectal cancer surgeries fell by 53% compared to year-ago figures.
- Nearly 40% of colorectal cancer patients and caregivers reported disruptions in their care, especially as it relates to in-person visits and imaging. Of these, 25% said they did not know when their care would be rescheduled, and 34% said their visits changed to telehealth.
- A majority (78%) of colorectal cancer patients feel nervous, anxious, or on edge, and 57% reported they are concerned about contracting COVID-19. Twenty percent report feelings of isolation.

EXECUTIVE SUMMARY

Colorectal cancer is the second-leading cause of cancer death in the U.S., but early screening and detection have been the key to steadily improving survival rates. Between 1970 and 2016, colorectal cancer death rates declined 51%, largely due to increased screening. When colorectal cancer is found at an early stage, the five-year survival rate is roughly 90%.

How will this trend be affected by the two-month pause in preventative screenings caused by the COVID-19 pandemic? Initial data tracking the total number of colonoscopy procedures, biopsies, and colon cancer diagnoses—along with first-hand accounts of colon cancer patients and survivors—suggests that the ripple effects could be significant.

While nationwide efforts to curb the spread of COVID-19 continue to encourage people in many states to stay home, patients fighting existing conditions are faced with an incredibly difficult decision: risk COVID-19 exposure or defer immediate healthcare needs. As such, colorectal cancer patients are navigating significant disruptions to their care while coping with new levels of stress and anxiety, exacerbated by the fact that cancer patients are at high risk for complications from COVID-19. Even patients with a family history of aggressive colorectal cancer are experiencing delays in screenings. Routine colonoscopy screenings have plummeted, and worse, active treatment has been interrupted. Patients report that they are uncertain when their care will resume.

To explore the impact of the COVID-19 on the colorectal cancer community, healthcare technology company, Komodo Health, and Fight Colorectal Cancer (Fight CRC), a patient advocacy group, undertook a study of colorectal cancer care volumes, behaviors, and attitudes. The findings underscore the need for public health and health system policies that can prioritize vulnerable populations and for those whom a delay in care is most likely to result in poor outcomes.

METHODOLOGY

This joint, mixed-methods research leveraged qualitative survey and focus group findings from Fight CRC, as well as a quantitative population health data analysis of colorectal cancer prevention and treatment trends based on longitudinal healthcare data from Komodo Health.

Fight CRC Survey and Focus Groups

The Fight Colorectal Cancer (Fight CRC) COVID-19 patient survey was developed by Fight CRC's patient education and research team to assess the impact of the COVID-19 pandemic on patients, survivors, and caregivers. A convenience sample of 222 patients was found by targeting established online contacts of Fight CRC's patients and advocates, Colontown online communities, and through various social media channels between April 24 and May 5, 2020. Fight CRC staff and advisors developed questions to capture: current health status, impact on care during the pandemic, patient and caregiver support, and patient attitudes. The American Cancer Society Cancer Action Network (ACS-CAN) patient survey was adapted to capture details in healthcare coverage, disruptions in care, standard demographics, and patient characteristics. Additionally, Patient Health Questionnaire (PHQ-2) questions were integrated for standard collection of patient/caregiver reported anxiety. Fight CRC utilized features within the survey tool to assess statistical significance using a confidence level of 95% (p-value < .05)

Fight CRC also conducted virtual focus groups among ten advanced-stage colorectal cancer patients utilizing an online video conference platform.

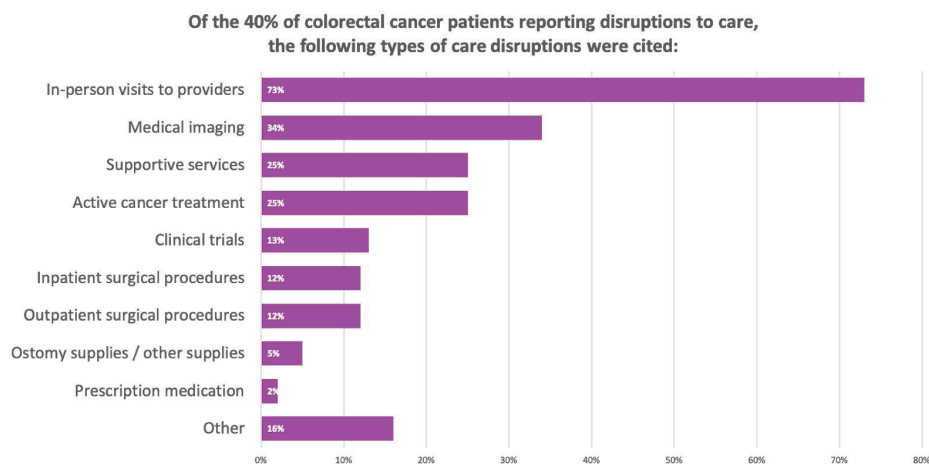
Komodo Health Data Analysis

Komodo's Healthcare Map, which tracks the patient journeys associated with 320 million individuals in the U.S., was used to report volumes of colonoscopy screening, new colon cancer diagnoses, biopsies, and colon surgeries before and after shelter-in-place orders. Weekly clinical volumes were compared between 2019 and 2020. Only visits prior to April 13 were included to ensure volume changes were not attributable to lag. To quantify the daily utilization rate for each test, the unique patients seen each day were divided by the total number of unique patients seen in the data from 2019. This rate was then translated to match a standard actuarial figure of tests per 1,000 patients in the total population. Common non-clinical sources of variation including lags in data processing and ingestion were controlled by a linear function from previous analysis based on Komodo's Healthcare Map.

RESULTS: SURVEY AND FOCUS GROUPS

In total, 68% of survey respondents were colorectal cancer patients or survivors, 13% were caregivers, 8% were immediate family members, 3% were extended family members, 3% were medical professionals, and 2% were friends. For all survey reports reported below, the confidence interval was equal to or greater than 95%. Focus group participants included three Stage III and seven Stage IV colorectal cancer patients.

Care has been disrupted and patients are uncertain when it will resume: Nearly 40% of survey respondents reported disruptions in care, especially as it relates to in-person visits and imaging. Of these, 23% said they did not know when their care would be rescheduled and 34% said their visits changed to telehealth.



Colorectal cancer patients experience fear, frustration amid pandemic: In navigating day-to-day activities as well as healthcare interactions, 63% of colorectal cancer patients reported they are concerned about contracting COVID-19 and for the health of their families. Fifty-one percent reported general concern for the future, 45% said they are concerned about government leadership, while 21% reported concerns about finances, and 19% reported feelings of isolation. Overall, the majority of respondents (78%) feel nervous, anxious, or on edge, and 50% say they “can’t stop worrying.”

One focus group participant compared the anxiety and fear surrounding COVID-19 to their experiences at the time of their diagnoses, fueled by uncertainty and threats to their health.

“In February I had a terrible upper respiratory infection ...now they think it’s possible I did have [COVID-19]...I remember first of all being really scared when it started traveling across the world, and then when it got here, 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.”

As states and counties begin to re-open, participants expressed stress in planning for future events. For example, one participant was unsure if she should attend her son’s high school graduation. Her local community was outraged over the prospect of canceling, but the risk of exposure concerns her if she were to attend. She explained that, due to the many “unknowns,” her son may have to graduate without her.

Colorectal cancer patients want safety measures in healthcare facilities and in their communities: Focus group participants mentioned changes in the experience of their care, such as safety measures implemented at their cancer centers. This included personal protection equipment (PPE) for healthcare workers, removal of brochures and chairs in waiting rooms, and a reduction in companions joining patients for appointments. While these measures negatively impacted the “human side” of cancer care, they also reassured patients that their providers were taking the necessary precautions to keep them safe, especially in infusion rooms. One focus group participant remarked that during her infusion appointment:

“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 uniformly expressed frustration with community members who do not follow recommendations, such as mask-wearing. Several participants expressed concerns about states re-opening sooner than the science recommends, saying they were “scared to death,” “petrified,” or “terrified” that the virus would spread further and create additional risk.

“I want to get outside, but I can’t trust others to practice safe social distancing and wear masks.”

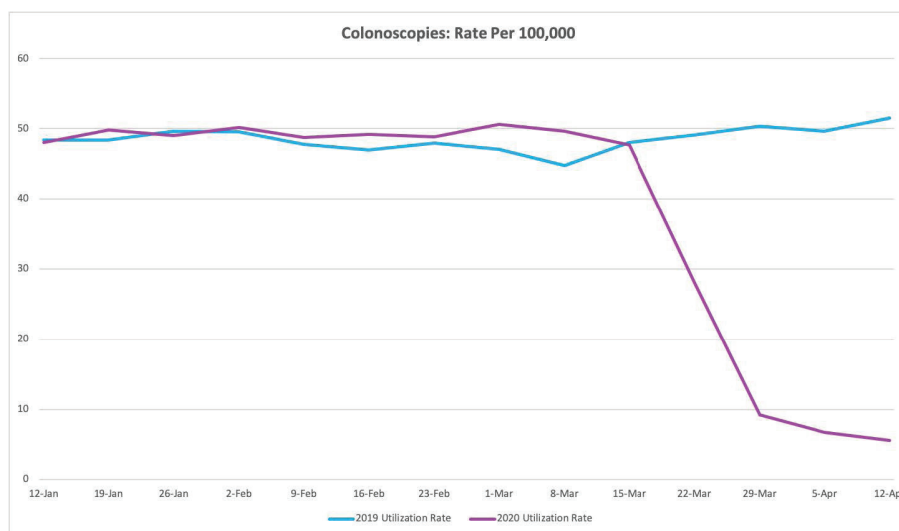
“I worry about going back to the office when the stay-at-home orders are lifted.”

Disparities in care surface amid COVID-19: Low-income, underserved, and rural patient groups reported more challenges in their care experiences, finances, and anxiety. Patients using Medicare were more likely to face challenges communicating with their care team and acquiring essential supplies, including food (18%) than those using private insurance (2.9%). Patients in rural areas were more likely to be Medicaid beneficiaries and face higher rates of disruption to their active treatment for cancer care (14% rural, 3.5% suburban, and 2.7% urban areas). Rural respondents were also more likely to report a significant need for financial support compared to those in suburban and urban areas (36% rural, 18% suburban, and 23% urban).

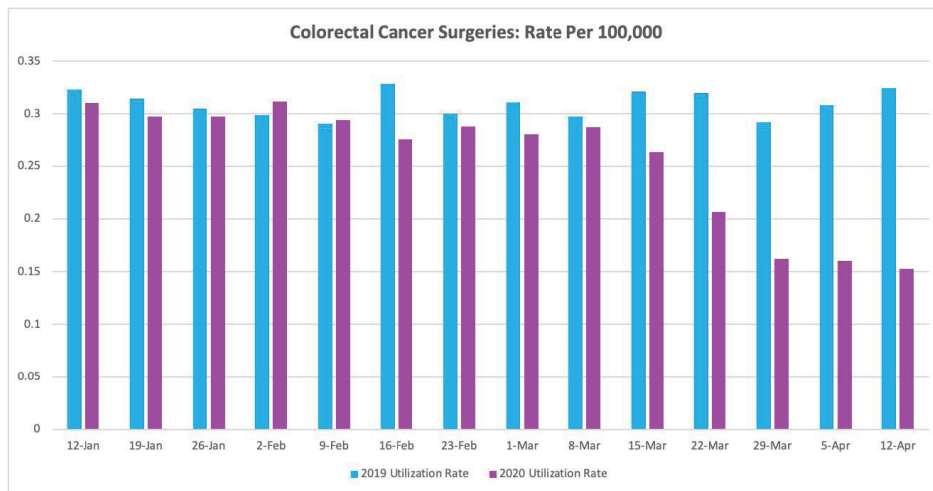
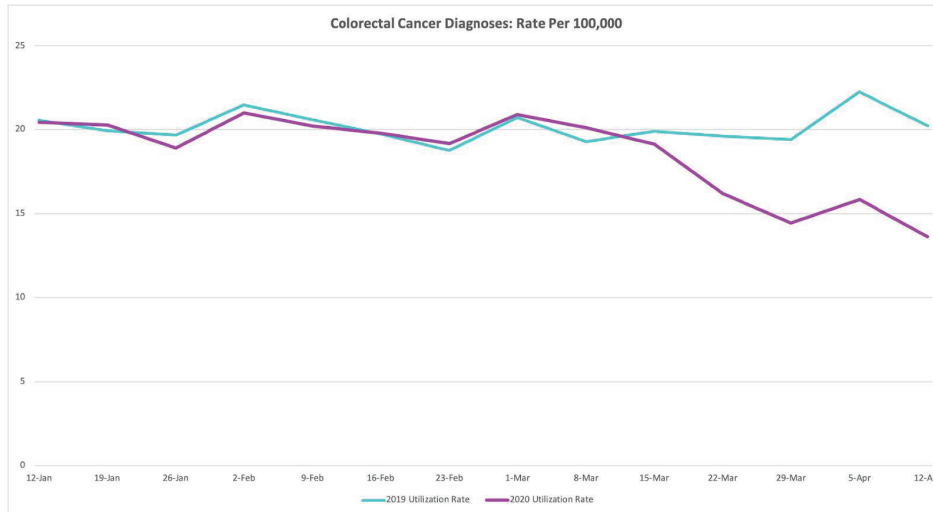
Geographic Location	Difficult to Afford My Treatment	I Need Financial Assistance	I Feel Like I am Struggling
Rural	5%	36%	13%
Suburban	1%	18%	7%
Urban	4%	23%	3%

RESULTS: POPULATION HEALTH DATA ANALYSIS

Colonoscopy screenings and biopsies declined sharply following shelter-in-place orders: Colonoscopy rates were stable over the first 11 weeks of 2020, prior to the first shelter-in-place orders that began in California on March 19. During the week of March 16 to 22, colonoscopies fell 42%, and by April 12, colonoscopies had fallen 89%. In line with screening declines, biopsy rates also declined by 88.8% by mid-April.



Colon cancer diagnoses declined while treatment plummeted: New colon cancer diagnoses were down more than 32% by mid-April. More surprising though, colorectal cancer surgeries fell by nearly 53% in the same time period. Some of this decline in treatment can be explained by the drop in diagnoses, but the steep drop-off in surgeries suggests a more dire situation in which patients newly diagnosed with colon cancer in the preceding months have had their surgeries postponed. This delay in surgery could result in progression of disease in a vulnerable population. In many cases, as shelter-in-place orders continue for much of the country and as fears of infection persist, those delays could continue into the foreseeable future.



DISCUSSION

The decline in colonoscopy screening rates during the height of the COVID-19 pandemic is not surprising. These procedures largely take place in hospitals, surgical centers, and doctors’ offices—all places people have been advised to avoid. However, the extent of the decline is alarming.

Another concern raised by this analysis is how long this deferral of care will last and when—if ever—will the last two months of missed appointments be absorbed by the healthcare system. Additionally, for patients whose active treatment has been disrupted by COVID-19, will that disruption affect the quality of care they receive and impact their healthcare outcomes. As of right now, we know that 32% fewer colorectal cancer cases were diagnosed in early April 2020 versus 2019. That surely does not mean 32% fewer people have the disease.

The steps taken by our healthcare system next—as we move into a period of recovery following the first phase of COVID-19—will determine whether the trends and clinical delays described in this analysis become a lasting public health crisis. High-risk patients with a family history of colorectal cancer represent a particular concern. And, it will be important to ensure that the care needs of vulnerable, underinsured populations are not deprioritized as health systems sift through the patient backlog.

It is critical that we make colorectal cancer screening a priority in the healthcare system’s recovery efforts. It’s also essential that we continually track patterns of patient behavior to identify potential gaps in colorectal-cancer screening and care before they become problems. This analysis captures a pivotal point in time when vital preventative care was severely compromised by exogenous factors. It will be important to continue to track those trends over the coming weeks, months, and years to ensure the pattern does not continue.

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