



2017

Young Onset Colorectal Cancer Survey Report

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Colorectal cancer is the third most common cancer in the United States and the second leading cause of cancer death, claiming the lives of more than 50,000 people every year. This disease affects men and women of all racial and ethnic groups, and while the average age of diagnosis is 68-72 years old, incidence in those younger than 50 is on the rise.



According to data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, there has been a 51% increase in young onset colorectal cancer incidence within the 20-49 age group since 1994¹, and without taking action, researchers predict that by 2030, "more than 1 in 10 colon cancers and nearly 1 in 4 rectal cancers will be diagnosed in people younger than the traditional screening age."²

Since 2012, the Colorectal Cancer Alliance has been advocating for research and educational advances related to young onset colorectal cancer. At our 2012 National Conference, we held a symposium dedicated to young onset colorectal cancer, and based on the response from our constituents, it became

¹ <http://onlinelibrary.wiley.com/doi/10.3322/caac.21395/pdf>

² <http://archsurg.jamanetwork.com/article.aspx?articleid=1920838>

abundantly clear that young onset colorectal cancer is on the rise at an alarming rate. Since then, we have continued to lead the charge for young onset colorectal cancer within the community.³ In February 2014 we coauthored a whitepaper, "The Increasing Incidence of Young-Onset Colorectal Cancer: A Call to Action"⁴ and since 2014 we have committed more than \$400,000 to support young onset colorectal cancer research.

There are unique challenges that young survivors face, and in an effort to better understand and support this unique population, the Colorectal Cancer Alliance launched a groundbreaking pilot survey in June 2016 that garnered 992 responses from young onset colorectal cancer survivors. The results found that 82% were initially misdiagnosed before ultimately being diagnosed colorectal cancer, with 39% being misdiagnosed with hemorrhoids. In addition, 20% waited more than 12 months from initial presentation of symptoms to talk to a physician and 44% felt that their diagnosis was delayed because of their age. Due to various factors, 57% of respondents were diagnosed at an advanced stage of colorectal cancer (stage III or IV). Based on our results from the previous year, we updated our initial survey and this year disseminated it through social media platforms for a period of one month. Our 2017 survey resulted in 1,535 responses from young onset colorectal cancer survivors from 28 countries around the world.



³ <http://ccalliance.org/blog/never-too-young-represents-at-cancercon/>

⁴ [http://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00822-7/fulltext](http://www.mayoclinicproceedings.org/article/S0025-6196(13)00822-7/fulltext)

2017 Survey Results

71%

said they were diagnosed with colon cancer, while 28% were diagnosed with rectal cancer

58%

of respondents were diagnosed between the ages of 40-49

73%

were diagnosed at an advanced stage of colorectal cancer (stage III or IV)

46%

currently have no evidence of disease

The top three symptoms

respondents experienced that led them to visit a medical professional were blood in their stool (47%), diarrhea or constipation (44%), and persistent cramps (44%)

15%

reported that an emergency room doctor ordered the colonoscopy that led to their diagnosis.

62%

did not have a family history of colorectal cancer, and 10% had a family history but were unaware of it before their diagnosis.

67%

stated they did not have Lynch Syndrome, while 16% were unaware of what Lynch Syndrome is.

45%

had a child under the age of 10 at the time of their diagnosis.

67%

of respondents saw at least two doctors before being diagnosed with cancer.

88%

had health insurance when they were diagnosed.

65%

had to take a leave of absence or quit a job or schooling because of their diagnosis.

61%

said they experienced financial difficulties due to the cost of their cancer treatment.

79%

experienced anxiety or depression during or after treatment, or both, but only 42% said they sought treatment or are currently seeking treatment.

69%

said a physician or medical professional did not talk to them about potential sexual side effects prior to treatment.

40%

reported that a physician or medical professional did not talk to them about fertility preservation at any point during their diagnosis or treatment.

Only 40%

were aware of clinical trials during their treatment, and only 10% actually participated in clinical trials



“What is the biggest challenge you’ve faced as someone diagnosed (with colorectal cancer) under 50?”

Themes that emerged were:

- **The challenges of being taken seriously because of age at diagnosis**

“My primary doctor, thinking I was there for pain medication instead of trying to find out the cause, wrote me off as a medication seeker.”

“I was completely ignored for years by multiple doctors. It was only when I nearly died that someone even listened to me.”

- **Raising a family and being a parent, while also undergoing treatment**

“The thought of not being there for my young children (my youngest daughter was 7 months old when I was diagnosed).”

“Telling my children that I have an incurable disease. The treatments have been very hard but to be honest nothing has been harder than seeing the look in my husband & children’s eyes everyday as they watch me die a little at a time each day.”

- **Finding age-appropriate support**

“I was too old for pediatrics but young enough that I didn’t relate or connect with many people I met that also had cancer. There was no support from someone my age going through what I was or who recently had.”

“Isolation. There are no local colon cancer support groups, I do not have any family members or friends who’ve been treated for colon cancer (or any advanced cancer). While there is no good age for cancer, being younger makes it less likely someone close to you has experienced something that provides support to you.”

- **How to balance a job with treatment or explain their health status during a job search**

“Being the sole family income when diagnosed with a stay at home wife and three kids under 7.”

“Re-engaging back to my career. I was out for nearly a year and almost lost coverage for myself and my kids. I was still having weekly infusions on Fridays. While they were accommodating at first, it was too much stress for me mentally and physically and I found myself no longer able to do a job I did for 10 years prior.”

- **Dating and sexual function during and after treatment**

"DATING.. tough to date and start relationship when you have to cancel plans because of side effects and also when to share when not serious."

"The doctors took no precautions to preserve my vagina...No 43 year old wants to go the rest of their life without sex."

Despite these challenges, respondents still expressed how appreciative they were for the Colorectal Cancer Alliance and all the work we have done for young cancer survivors.

"Thank you for the work you are all doing to eradicate this horrible, mostly preventable disease."

"There's not a huge supportive presence for young adults with this diagnosis...I greatly appreciate the effort of the CC Alliance on this front...Thank you!"

"Thank you to the CCA for all that you do for colon cancer patients."

Conclusion

The data collected through this survey is significant in that it confirms data collected from researchers and clinicians working in this field, while also providing the survivor's perspective. Based on the quantitative and qualitative findings, there is still much to be done to educate the medical community and the public at large about the increasing incidence rates of young onset colorectal cancer.

- **We need better tools to assist the medical community to more readily recognize when a patient is presenting with symptoms of colorectal cancer and recommend the appropriate diagnostic test, regardless of age.**
- **A national education campaign could help more patients understand if they have a family history of colorectal cancer, more quickly identify symptoms, to expedite meeting with a doctor in a timely manner, and to advocate for a diagnostic test.**
- **Young onset colorectal cancer patients and survivors would benefit from more support services that are designed specifically for their age group.**

As the nation's largest colorectal cancer advocacy organization, the Colorectal Cancer Alliance aims to provide a voice and a call to action for those who were told they were "too young" to have colorectal cancer. We will continue to address the unique issues facing this population, as well as to better educate the medical community that colorectal cancer affects all genders, all ethnicities, all ages.

National Statistics

In Americans younger than 50 years, colon cancer incidence ranges from 0.4 per 100,000 individuals (age 15-19) to 18.7 per 100,000 individuals (age 45-49) and rectal cancer incidence ranges from 0.1 per 100,000 individuals (age 15-19) to 12.7 per 100,000 individuals (age 45-49).

Source: Cancer of the Colon, Age-Specific SEER Incidence Rates, 2010-2014; Cancer of the Rectum, Age-Specific SEER Incidence Rates, 2010-2014 (https://seer.cancer.gov/csr/1975_2014/browse_csr.php?sectionSEL=6&p_ageSEL=sect_06_table.11.html)

Figure 1: Age at Diagnosis

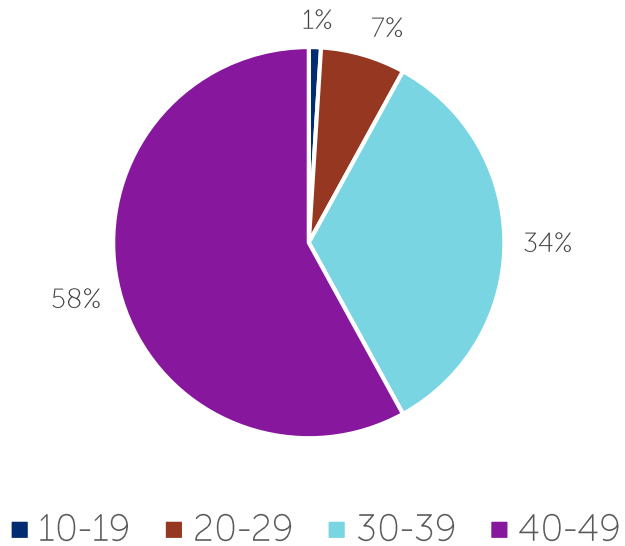
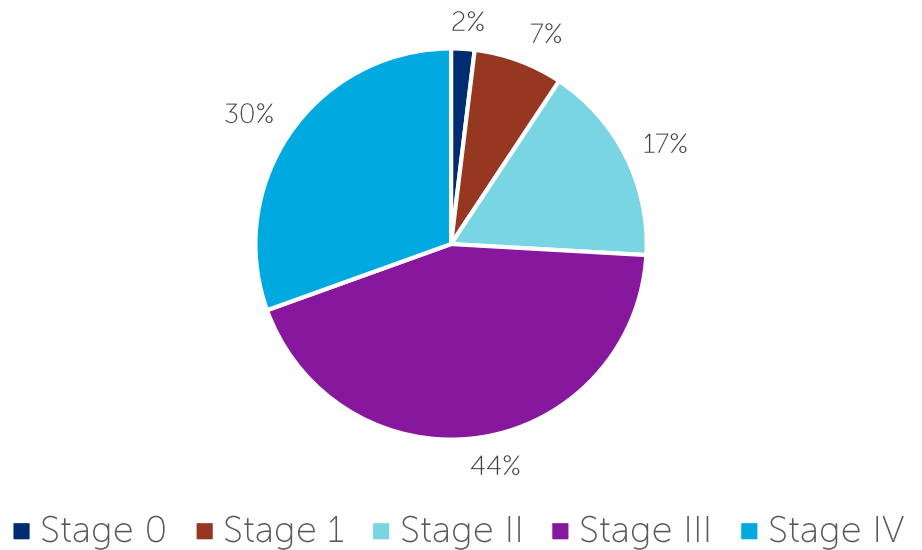


Figure 2: Stage at Diagnosis



Respondents also listed ovarian cancer, IBD/IBS, and diverticulosis as other misdiagnoses.

This may be due to:

- Similar symptoms – abdominal pain, bloating, constipation
- More common in ages 18-35
- Diagnosed without screening test

Figure 3: Types of Ailments Survivors Initially Diagnosed With

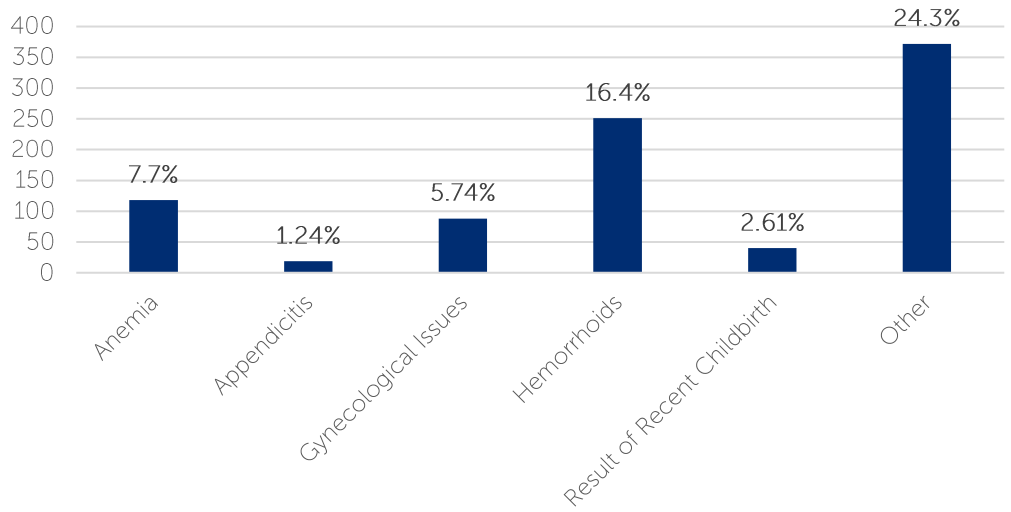


Figure 4: Anxiety/Depression During or After Treatment

