

NEVER TOO YOUNG

2018 Young-Onset Colorectal Cancer Survey Report

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Introduction

Colorectal cancer is the third most commonly diagnosed cancer and the second leading cause of cancer death in men and women combined in the United States. The American Cancer Society (ACS) estimates that this year 97,220 people will be diagnosed with colon cancer and 43,030 will be diagnosed with rectal cancer. It is expected that 50,630 people will die from colorectal cancer this year.¹

Colorectal cancer patients are considered young-onset if they are diagnosed before they turn 50 years old. Since 1994, cases of young-onset colorectal cancer have increased by 51 percent, according to the National Cancer Institute.² In the United States, 11 percent of colon cancer diagnoses and 18 percent of rectal cancer diagnoses occur in those under 50.³

The rising incidence of young-onset colorectal cancer has recently led the ACS to update its screening guidelines. The new recommendation from ACS suggests that people at average risk of colorectal cancer start regular screening at age 45 instead of 50.⁴

Young-onset colorectal cancer patients and survivors face unique challenges, and their needs and concerns have traditionally been unmet by their personal and medical networks. The Colorectal Cancer Alliance makes young-onset colorectal cancer a top priority, advocating for research and educational advances in this area, as well as offering support.

At the Colorectal Cancer Alliance's National Conference in 2012, for instance, a symposium dedicated to young-onset colorectal cancer generated overwhelming interest, indicating that

¹ <https://www.cancer.org/cancer/colon-rectal-cancer/about/key-statistics.html>

² <https://seer.cancer.gov/statfacts/html/colorect.html>

³ [https://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00822-7/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(13)00822-7/fulltext)

⁴ <https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/acs-recommendations.html>

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young patients and survivors were eager to learn about topics relevant to them. In 2014, the Colorectal Cancer Alliance collaborated with prominent clinicians and researchers to co-author “The Increasing Incidence of Young-Onset Colorectal Cancer: A Call to Action.”³ And with a promise to fund \$10 million in colorectal cancer research by 2021, including \$3 million dedicated specifically to young-onset research, the Alliance continues to lead research funding efforts in this field.

To better understand and support the population of young-onset colorectal cancer patients and survivors, the Colorectal Cancer Alliance launched a trailblazing pilot survey in June 2016. In its first year, the survey garnered 992 responses from young-onset colorectal cancer patients and survivors. Since its debut, the Alliance has annually updated the survey to collect experiences from patients and survivors, disseminating the results widely.

In June 2018, the Colorectal Cancer Alliance launched its third annual survey of young-onset colorectal cancer patients, survivors, and, for the first time, caregivers. The Alliance uses the survey to learn about and track the self-reported medical, psychosocial, and quality of life experiences of these often overlooked groups. The Alliance solicited participation over social media, email, and web-based communities. Over a 30-day period, the Alliance received 1,622 responses (1195 patients/survivors and 427 caregivers) from 38 countries (Figure 1).

The data collected through this survey is critically important because it provides real-world evidence from patients and survivors supporting findings published in scientific reports by researchers and clinicians studying young-onset colorectal cancer. Moreover, the survey is also unique in providing the patient, survivor, and caregiver perspective on a variety of issues.

The Alliance’s study shows that 71 percent of young people with colorectal cancer are diagnosed at advanced stages of the disease, stages III or IV (metastatic), in which case the tumor has spread beyond the colon wall (Figure 5). This is significantly higher than the 60 percent reported for late-stage diagnoses of the overall colorectal cancer patient population, the majority of whom are over 50.⁵ The majority of survey participants (57 percent) were

⁵ <https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/acs-recommendations.html>

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diagnosed between the ages of 40 and 50 (Figure 2), which may suggest that the new screening recommendation from ACS may still miss many young-onset patients.

The 2018 survey showed that many respondents were initially misdiagnosed. Sixty-seven percent of patients reported they saw at least two physicians, and some more than four physicians, before they were diagnosed correctly with colorectal cancer (Figure 4). Moreover, among patients who reported seeing only one doctor, about 17 percent reported an initial misdiagnosis, corrected over subsequent visit(s). The initial misdiagnosis of patients by their physicians may contribute to a higher percentage of diagnoses at advanced stages among patients under 50 years old.

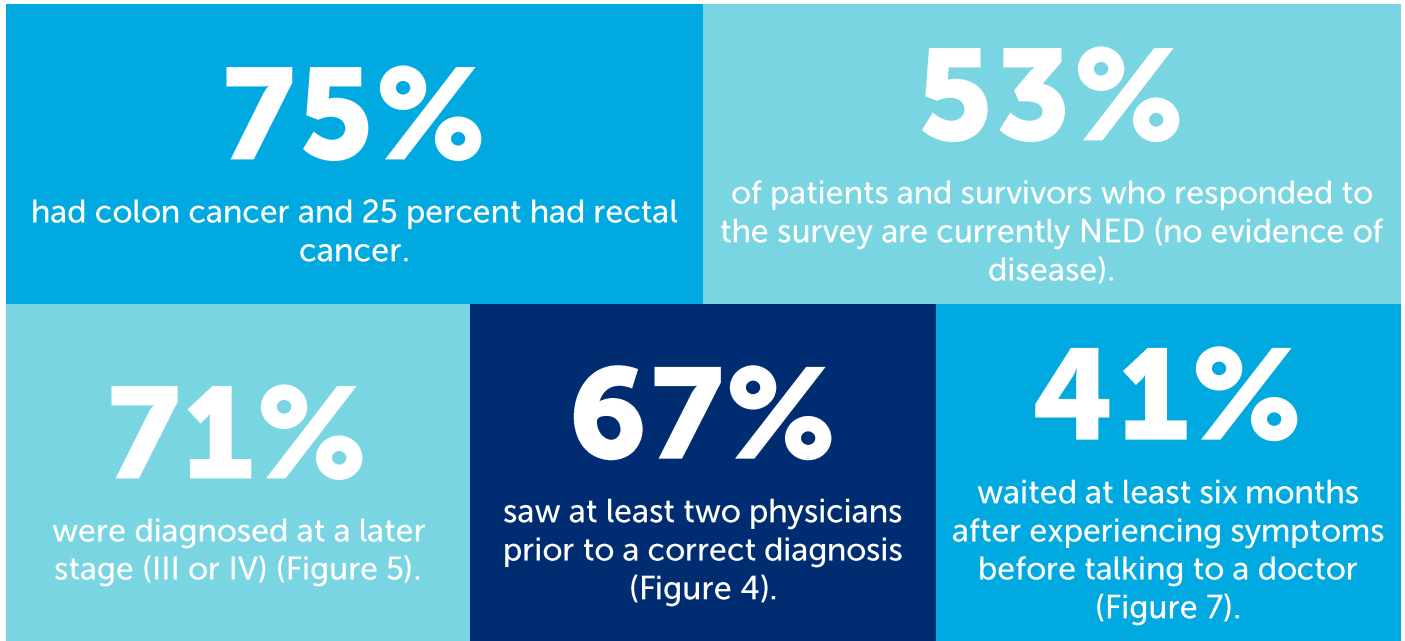
The most common symptoms of young-onset colorectal cancer were constipation, blood in stool, bloating, rectal bleeding, and diarrhea, according to 2018 survey data. Many reported suffering multiple symptoms, and about 9 percent reported no symptoms before diagnosis (Figure 6). The Alliance's study shows 41 percent of patients waited at least six months or more after the initial presentation of symptoms before talking to a doctor (Figure 7), with many receiving an initial misdiagnosis of ulcerative colitis, gastric disorders, or hemorrhoids among other conditions (Figure 8).

A greater percentage of respondents were referred for a colonoscopy by a primary care physician in 2018 (44%) than in 2017 (35%) (Figure 3). Our survey shows that five percent of patients were diagnosed as a result of a preventive care or wellness exam.

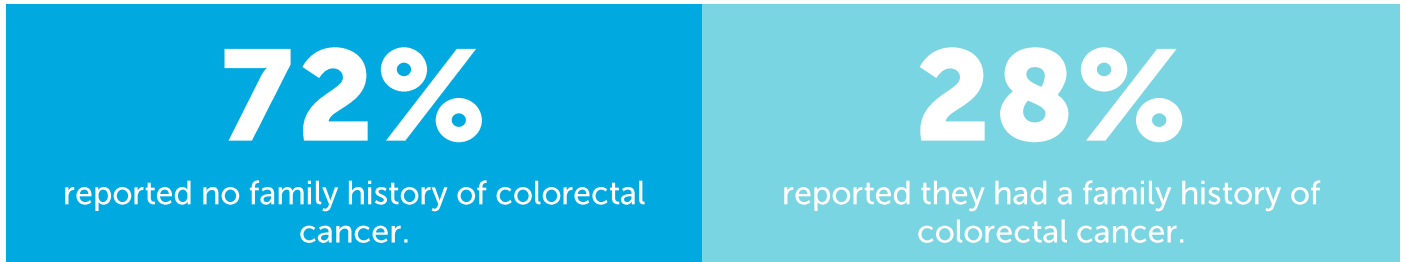
Overall, our study shows an acute need to raise awareness of young-onset colorectal cancer among the general population and among physicians, especially primary care physicians who are often first to see patients with symptoms of colorectal cancer.

Key statistics: Patients and survivors

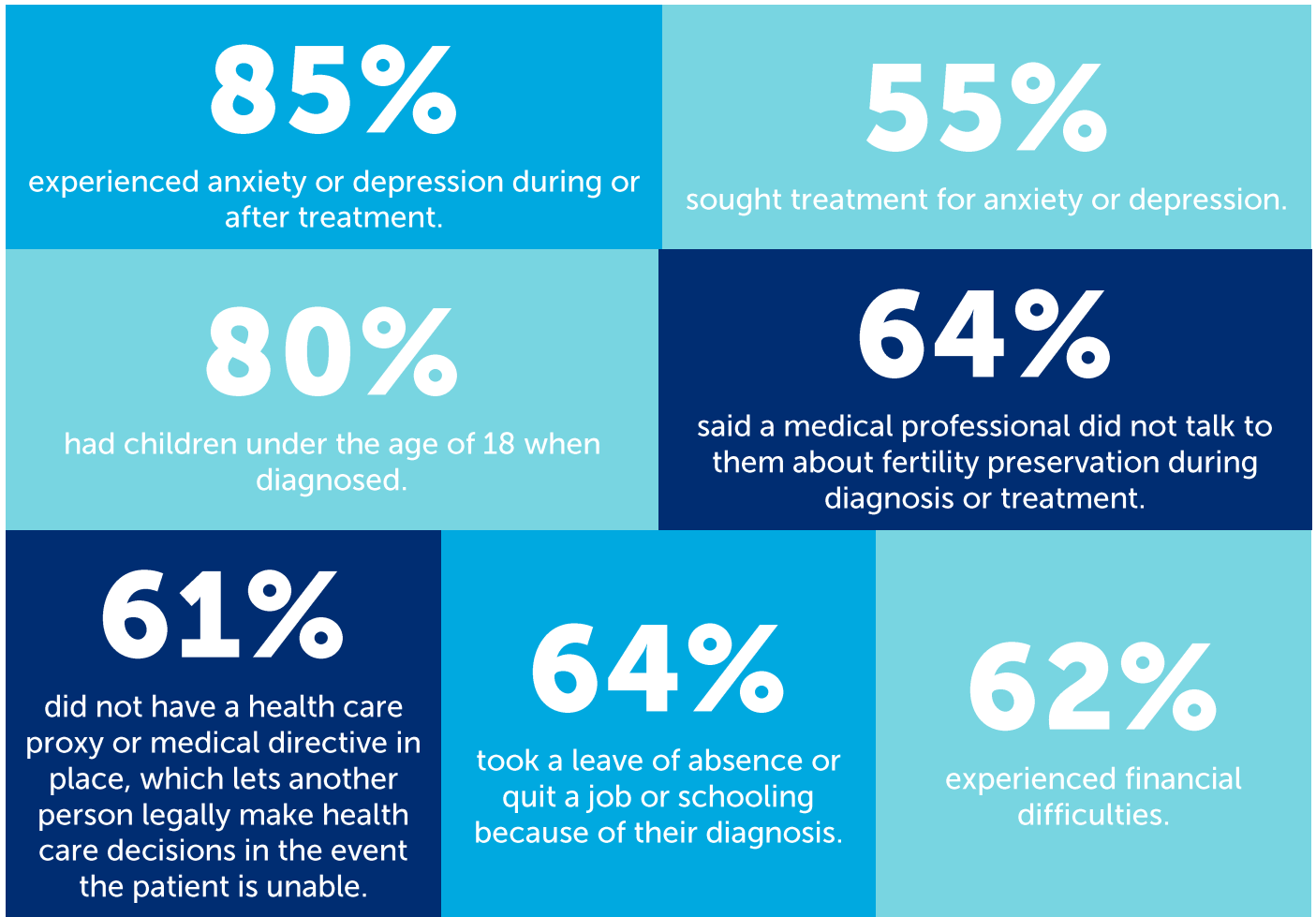
Diagnosis



Family history



Quality of life



Clinical trials



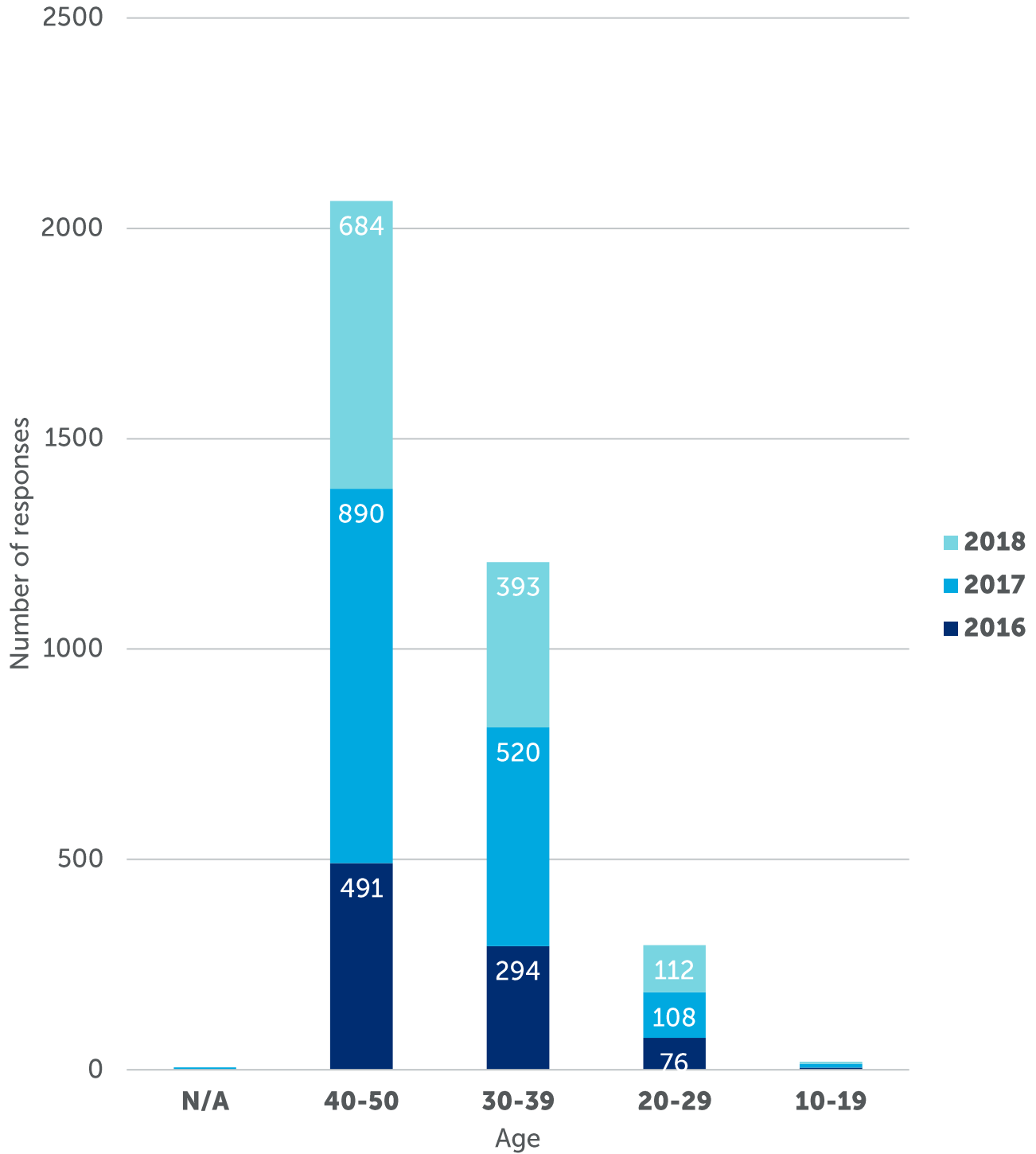
Illustrations: Patients and survivors

Figure 1: Geographic distribution of survey participants



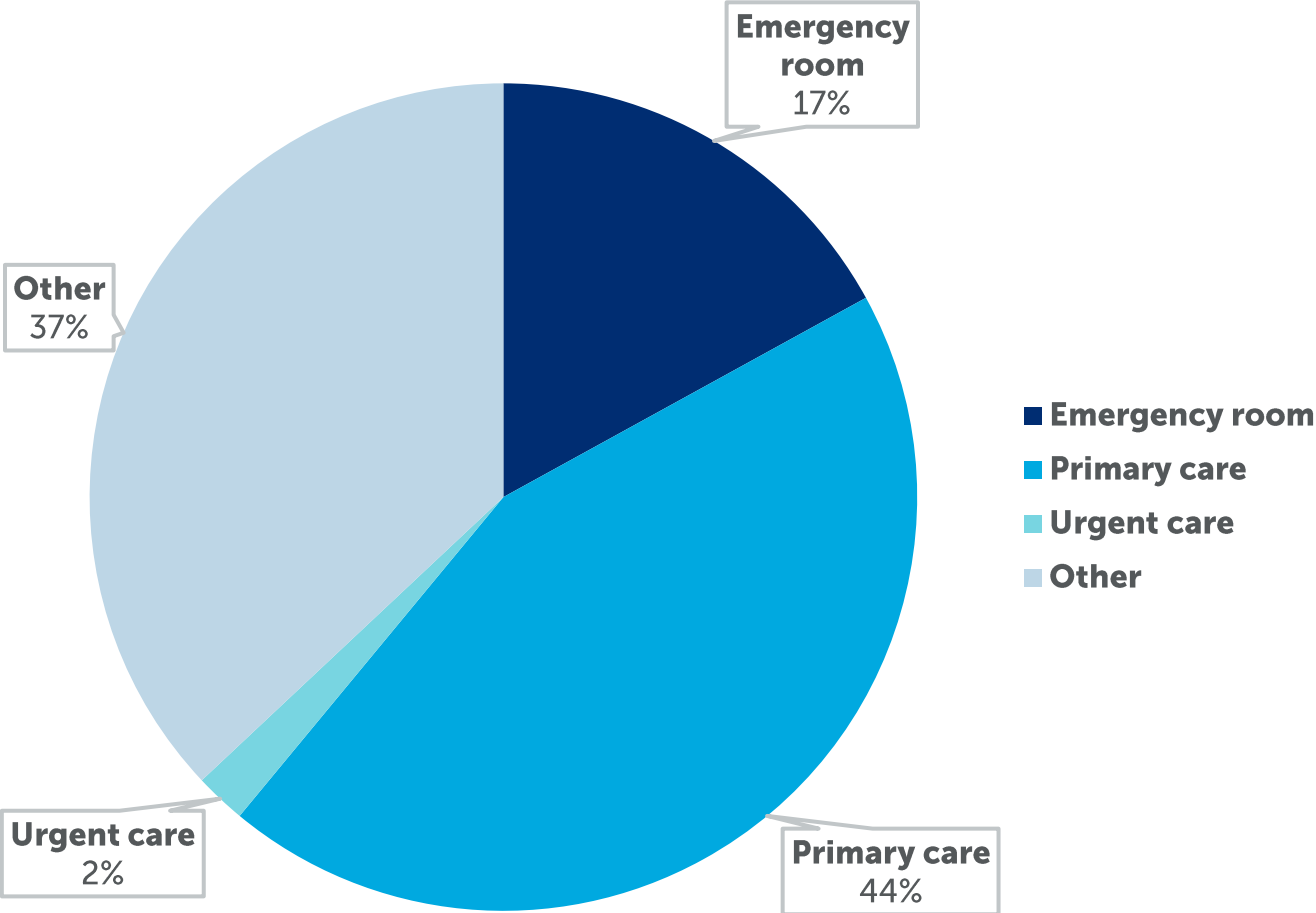
The survey collected responses from 38 countries. Most responses (1,478) came from the United States.

Figure 2: Age at diagnosis



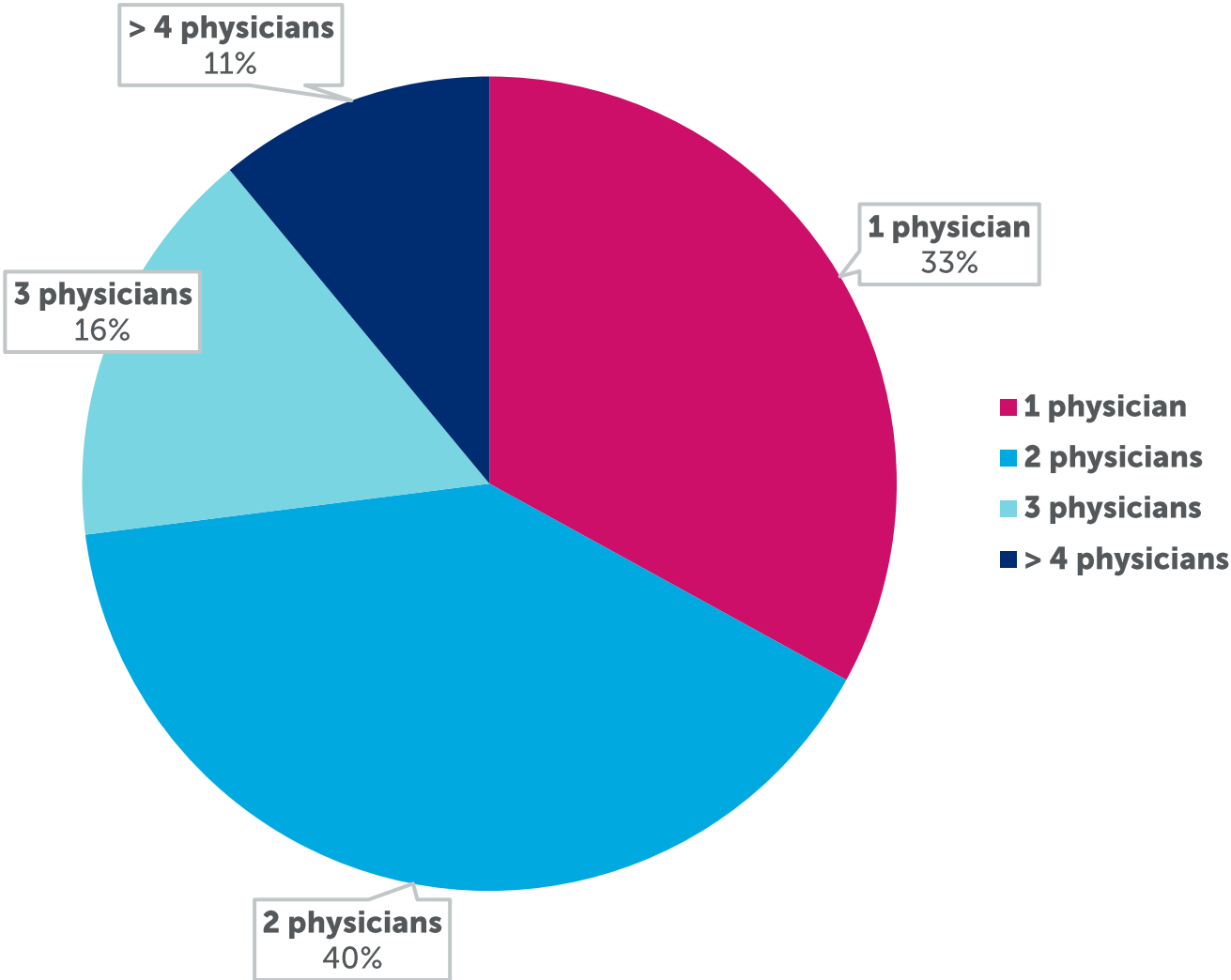
The majority of survey participants (57 percent) said they were diagnosed between the ages of 40 and 50.

Figure 3: Colonoscopy referrals by provider type



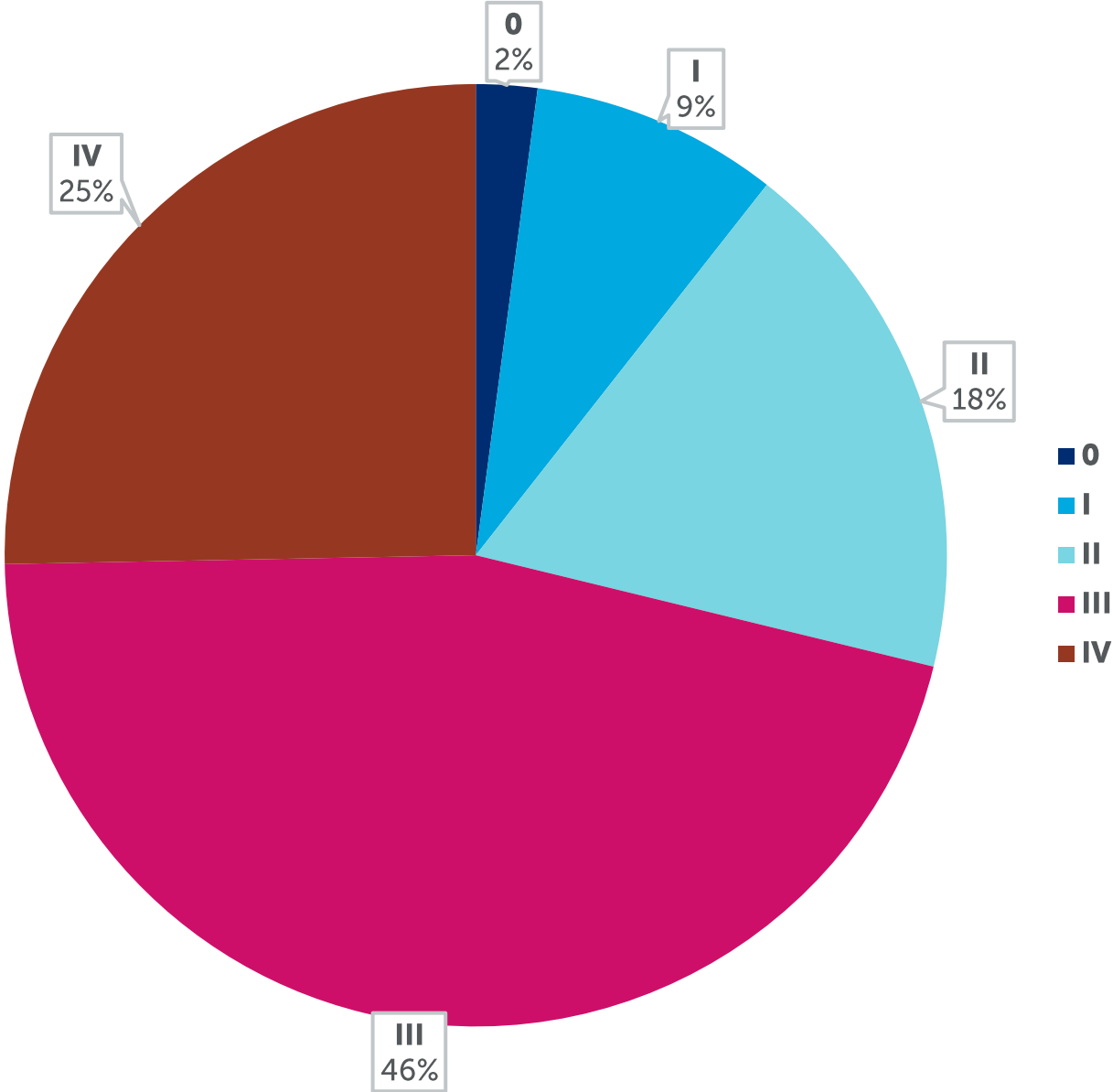
A greater percentage of respondents were referred for a colonoscopy by a primary care physician in 2018 (44%) than in 2017 (35%).

Figure 4: Many patients saw multiple physicians prior to diagnosis



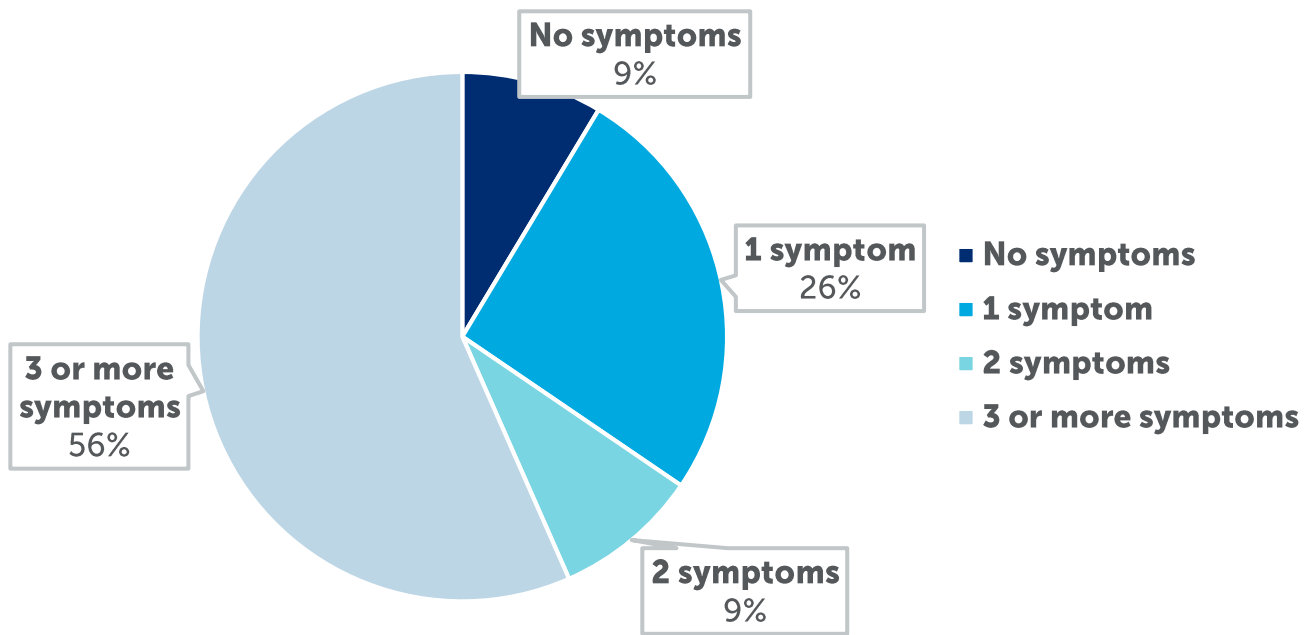
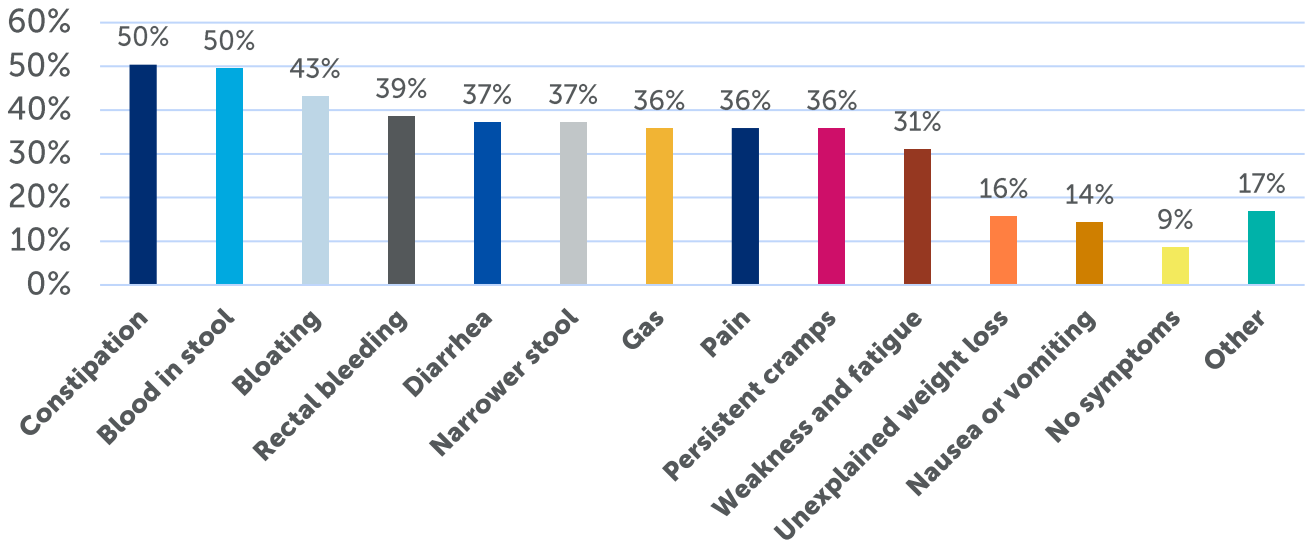
Most patients indicated they had to visit at least two physicians, and in some cases more than four different physicians, prior to their diagnoses with colorectal cancer.

Figure 5: Stage at diagnosis



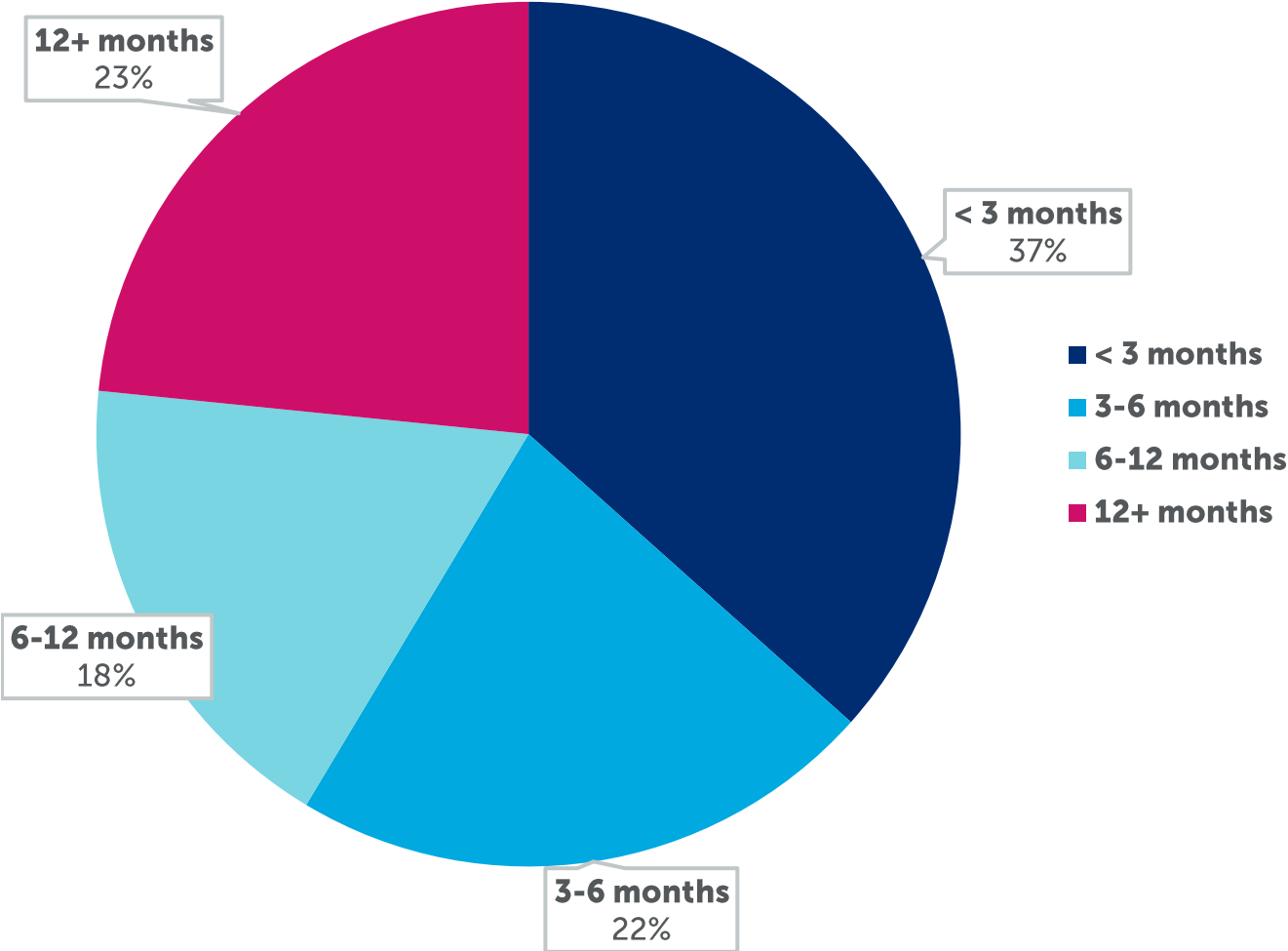
Most survey participants (71 percent) were diagnosed at stage III or stage IV (metastatic). About 46 percent said they were diagnosed with stage III colorectal cancer. A quarter were diagnosed at stage IV.

Figure 6: Most common symptoms



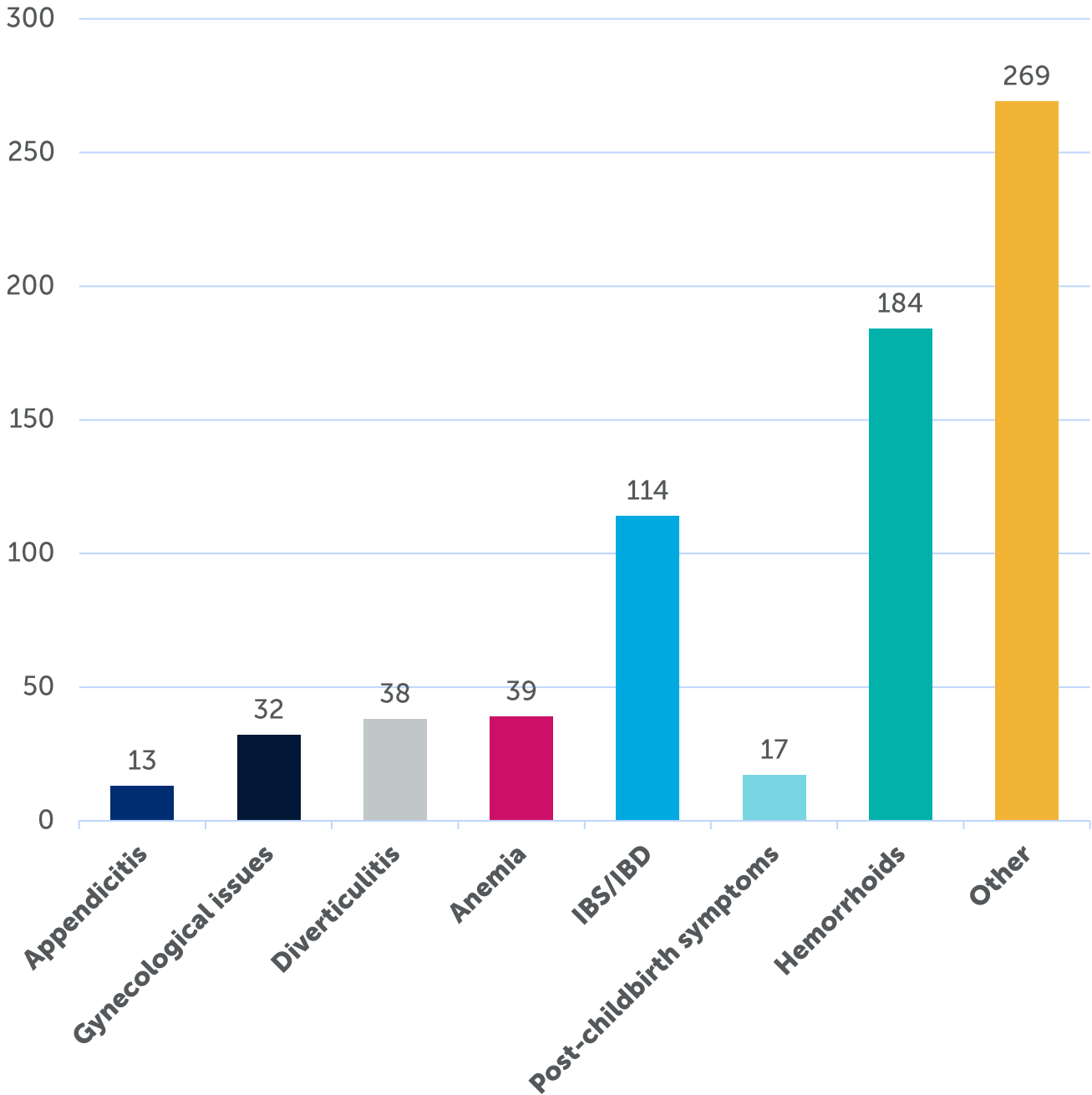
The most common symptoms of young-onset colorectal cancer were constipation, blood in stool, bloating, rectal bleeding, and diarrhea, according to 2018 survey data. Twenty-six percent of patients reported one symptom, while 56 percent reported having at least three symptoms. Other symptoms shared by survey participants: anemia, back pain, Crohn's disease, blockage, fever and/or chills, and shortness of breath.

Figure 7: Duration of symptoms before seeing a physician



Only 37 percent of survey participants reported they reached out to their doctors in less than three months to talk about their symptoms. Nearly one out of five, however, waited more than a year.

Figure 8: Initial misdiagnosis



The most common misdiagnosis among participants was hemorrhoids, followed by irritable bowel syndrome or irritable bowel disease. A plurality of participants said they were diagnosed with “other” ailments, including ulcerative colitis, gastric disorder, gallbladder, gluten allergy, celiac disease, urinary tract infection, gas, or heartburn.

In their own words

Patients and survivors had the opportunity to share their experiences on several topics in their own words. A selection of those responses appears below.

The Alliance asked patients and survivors who were misdiagnosed, "What were you diagnosed with before your colorectal cancer diagnosis?" (Figure 8)

"I was told that I was depressed (by a male doctor) because I had no children. I wasn't. My husband and I chose not to have children. I never went back to that doctor, and the next doctor got me a diagnosis."

"I was told I had colitis due to stress."

"Meniere's disease, anemia, iron deficiency, anxiety."

"I had just delivered my son by caesarean section, and symptoms were attributed to hemorrhoids and scar tissue."

"Hernia for shooting abdominal pain (they did an unnecessary hernia repair on me), and I returned with constipation/bloating. The hernia surgeon told me to drink a fiber supplement for the rest of my life! I was a 40-year-old mom with one-too-many surgeries!"

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The Alliance asked participants, "What is the biggest challenge you've faced as someone diagnosed under 50?"

"I was diagnosed when I was 28-weeks pregnant with my fourth child. The hardest thing was undergoing treatment while pregnant ... and then the day-to-day taking care of a family, including a newborn, while undergoing treatments."

"The hardest part is getting the quality of life back. The side effects of cancer treatment have changed my life completely. I ... now have chronic conditions ... because of treatment. It is very overwhelming, and I might have selected different treatments if I had full knowledge of these life-changing side effects."

"I can say I feel as if my state of mind took a brutal beating. Colorectal cancer is a humiliating disease, and, as a very young adult, I was too embarrassed to talk about my symptoms until they became unbearable. I suffered from severe depression and anxiety. I was diagnosed with post traumatic stress [disorder] and had horrific nightmares that woke me up crying."

"There is very limited funding to help with chemotherapy expenses and things. I ended up canceling my last couple of rounds of chemo because of the financial burden."

"Having no one to talk to who has experienced or gone through the same rare cancer diagnosis as me. Not being listened to by medical professionals after diagnosis when I knew something wasn't right with my chemo treatment."

"Biggest challenge was fear of what the future held for my wife and three kids."

"Socially isolating."

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"Not getting diagnosed for a year after having symptoms. Five different doctors told me I was too young for colon cancer. I was not diagnosed until my colon perforated and I almost died from sepsis. My cancer came back twice, and I have been on maintenance therapy for four years. Had I been diagnosed early, I probably wouldn't have had to do chemotherapy three times and, now, maintenance."

"Not being able to work for several long periods ... over the years and eventually being terminated from my job after 15 years with the company. Financial hardships. Not being able to afford counseling to help my children cope during my illness, anxiety, and residual side effects from treatment."

"My doctors weren't looking for colon cancer. My symptoms were pretty obvious in hindsight, but I don't think they are used to seeing this diagnosis in young people."

"Getting a diagnosis. After a year of arguing, a simple X-ray showed a mass, and even then my primary care doctor just said to monitor it. I insisted on a colonoscopy. Stage III colorectal cancer. Then I had to fight for a colorectal surgeon and a second opinion. I even had a surgeon who kept calling me and telling me I was an idiot to do a pouch and not a permanent ileostomy. Also had problems getting sufficient pain meds after four surgeries."

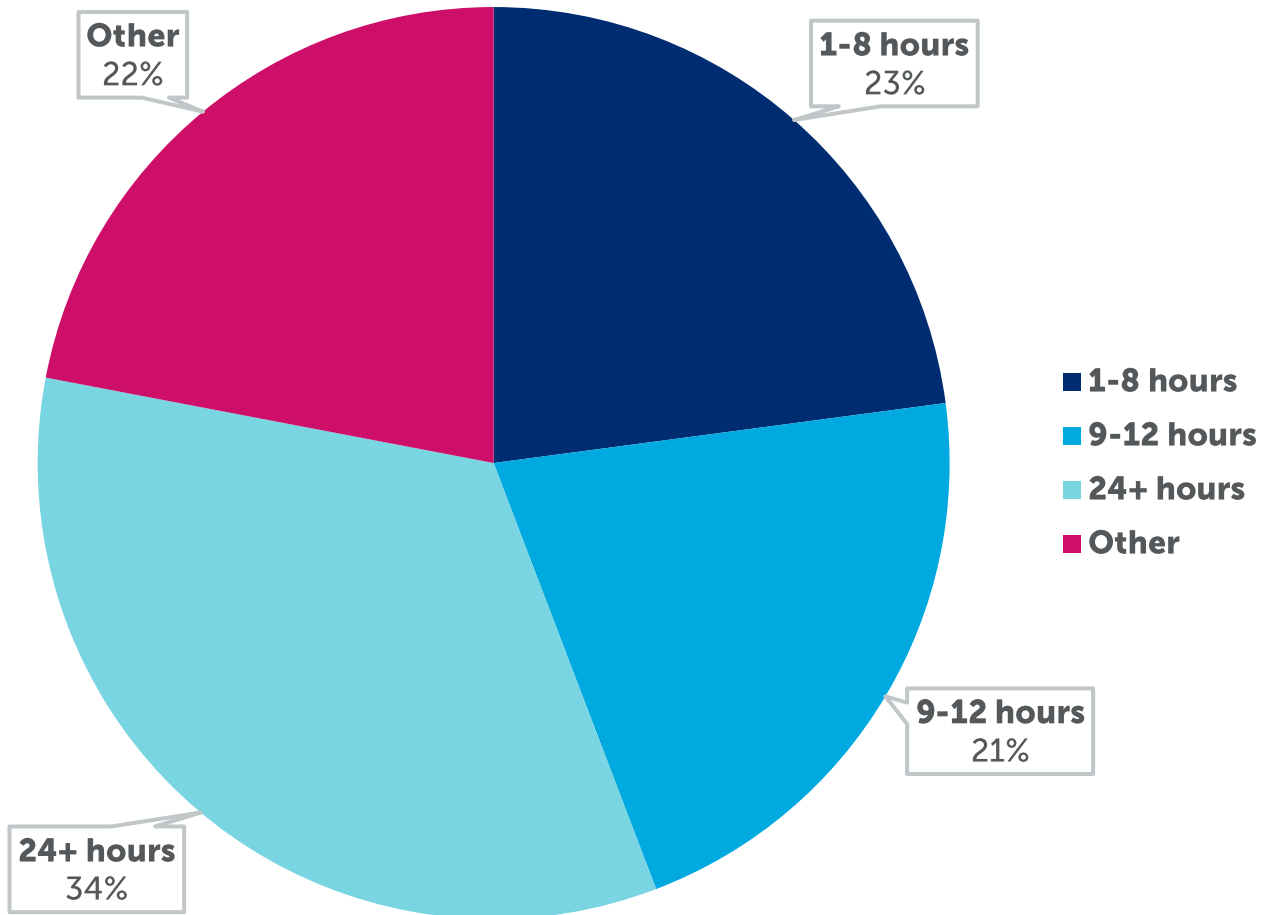
Key statistics: Caregivers

Caregivers play an essential role for patients and survivors. Data shows that upon a patient's diagnosis, caregivers have many questions and struggle to understand treatment options and risks. Caregivers are also in need of more resources regarding financial, psychosocial, and self-care issues (Figure 10).



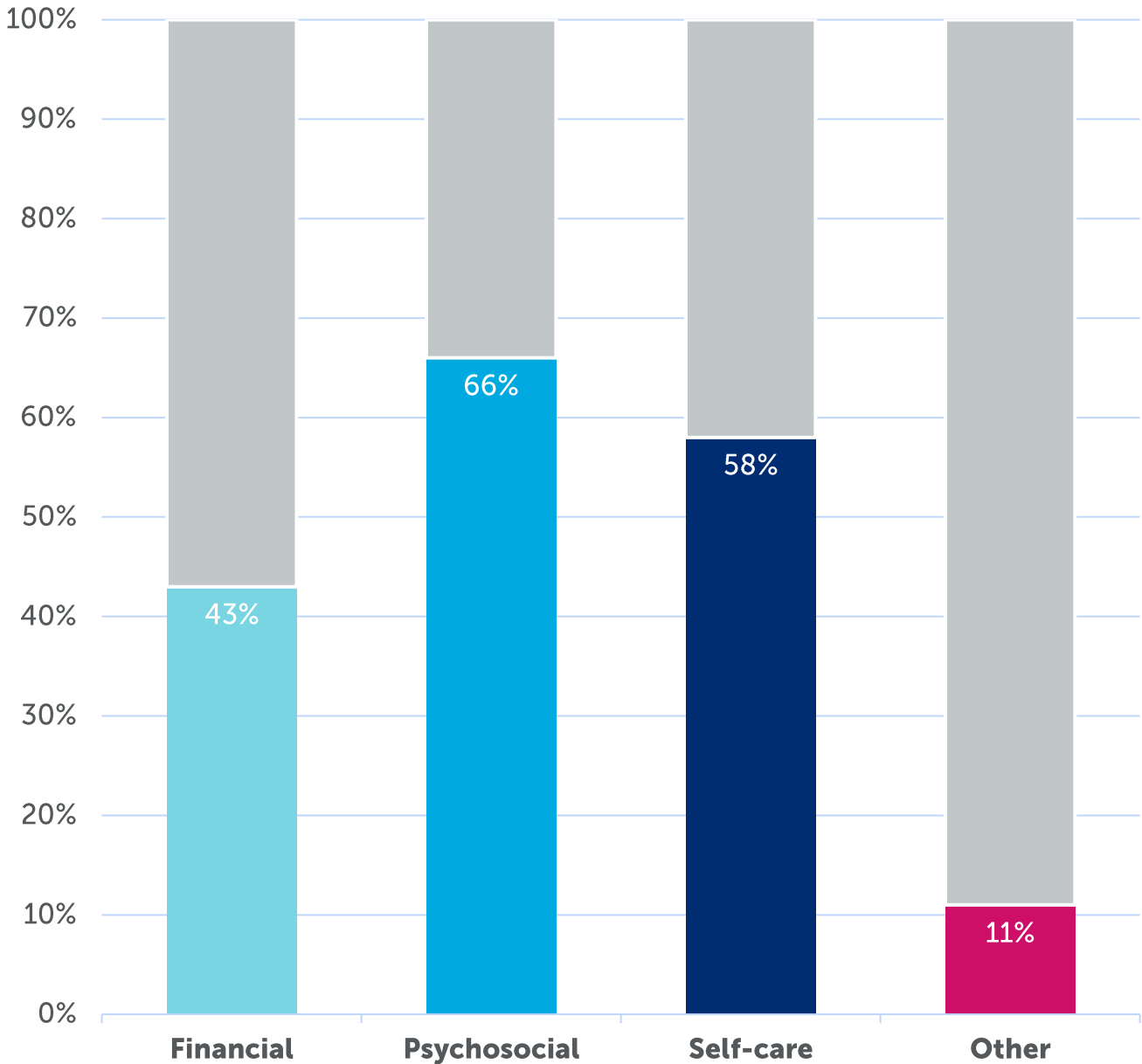
Illustrations: Caregivers

Figure 9: Work missed each month



About one in three caregivers reported missing 3 days (≥ 24 hours) of work or more each month to care for a loved one. Caregivers that selected "other" reported taking leaves from work, quitting work, losing their jobs, acting as a full-time caregiver, or were not working.

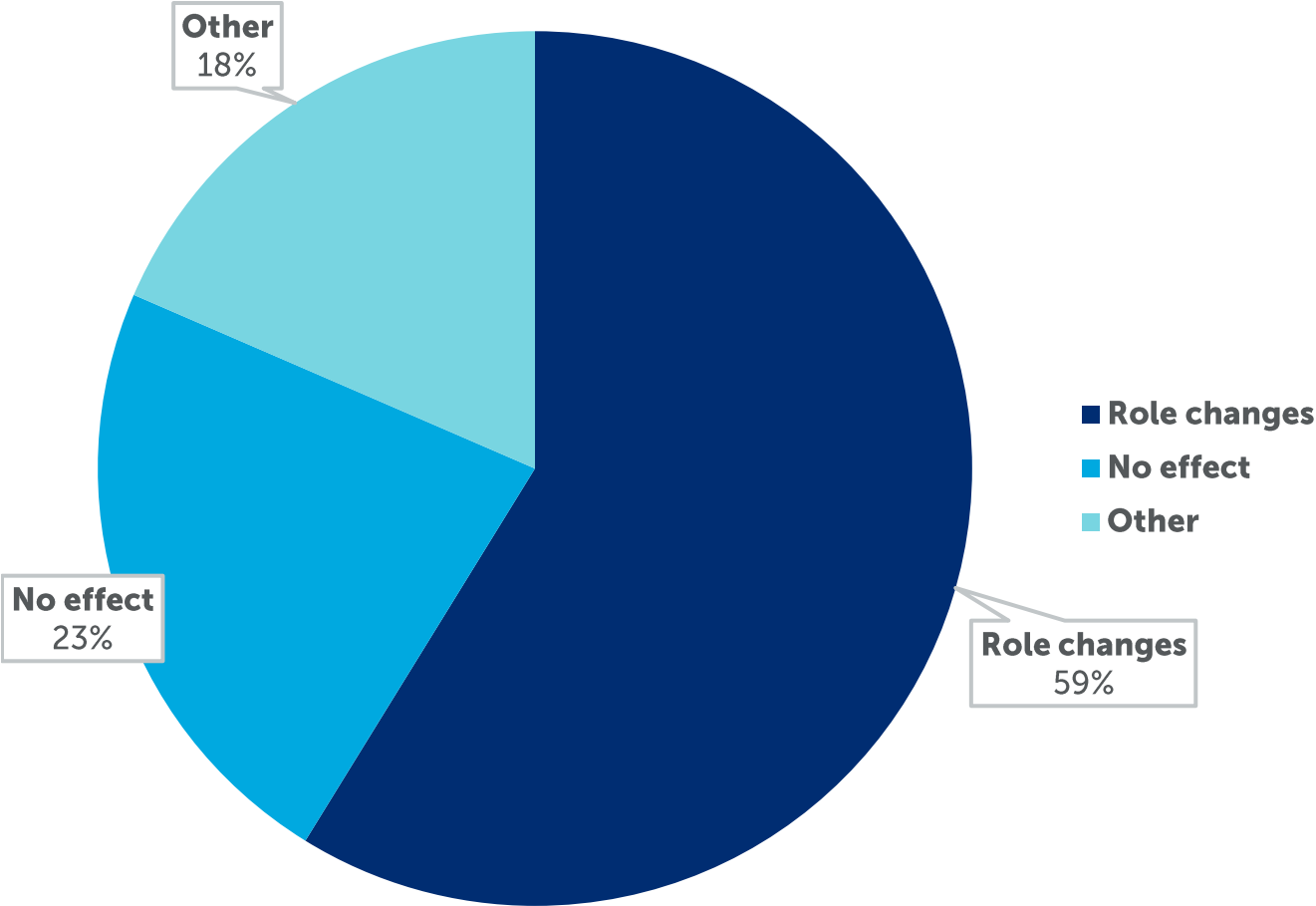
Figure 10: Caregiver needs for supporting resources



Most caregivers indicated an unmet need for psychosocial support. Fifty-eight percent of caregivers said they needed self-care resources. Caregivers were able to select more than one category of unmet need.

Participants also indicated that resources such as transportation, childcare, household maintenance, prevention, and recurrence surveillance information for family members were limited.

Figure 11: Changes in caregiver-patient relationship



The majority of caregivers reported that a loved one experienced changes in their ability to perform expected social tasks, including those of a spouse, child rearer, friend, or worker. Some caregivers also mentioned loss of sexuality, depression, pain, despair, lack of sleep, sadness, and stress, along with loss of faith and hope.

In their own words

Caregivers had the opportunity to share their experiences on several topics. A selection of those responses appears below.

The Alliance asked caregivers, “What do/did you need from your loved one who is/was going through cancer?”

“Honesty. I needed him to be honest ... about how he was feeling physically and mentally so I could best understand what he was going through.”

“Communication about how he was feeling physically and emotionally.”

“More physical contact.”

“Understanding that their illness is not just about them. The caregiver feels their pain and is helpless at times to ease discomfort. The worry never ends.”

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We asked caregivers, "What resources are you in need of as a caregiver?"

"Groups like [the Alliance] to help us through our cancer journey. I didn't know [the Alliance] existed until two years into my husband's illness."

"Advice for after the death of a spouse, such as how to proceed legally with the final tax return, arranging a funeral, and switching bills and accounts."

"Household help and childcare."

"More information about genetics."

"Support for my two children, ages 12 and 15, at my husband's diagnosis."

"Future screening information."

"Navigating all treatment options should first-line therapy not work and how to incorporate supplements and repurposed drugs."

"Medical resources to assist in planning for care and caring for the patient."

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The Alliance asked caregivers, "How did your loved one's diagnosis affect his or her relationships?"

"We are stronger together than on our own."

"Immediately, he had a lot of support from friends and family. Later, as he got sicker, his friends pulled away ... maybe not knowing what to say or do, maybe because of his physical changes."

"My daughter was unable to work because of her cancer, and that put her family in a financial bind. They lost everything. She and her family had to move in with me, and that caused a separation with her husband."

"Withdrawn, completely lost all intimacy."

"I was taking care of my 22-year-old son when he should have been out partying with his friends, meeting girls, figuring out his life. Instead, he had his mom hooking up his total parenteral nutrition (TPN), taking him to the emergency room, crying over him."

"He never got a wife, children, or a home. Women were not interested in a young man with an ostomy bag. It was hard to not be honest, but it was the problem. It is a rare young lady that would have been interested. He passed at 29 and was sick from his teens."

"We lost a lot of friends because they didn't know how to deal with it."

"It changes my role as a daughter to daughter and caregiver. Friends got distant, relationships have been lost."

Conclusions and a call for action

According to the American Cancer Society, 40 percent of colorectal cancer patients across all ages receive a diagnosis at stage I or II.¹ Only 29 percent of young-onset patients who responded to the Alliance’s survey were diagnosed at stage I or II, most likely due to a delay in diagnosis.

These survey results offer two contributing factors for this delay. Our results show most patients are waiting three to 12 months or more to see a primary care physician after symptoms begin. Additionally, once patients seek medical attention, 67 percent had to see at least two doctors—and some more than four—before receiving the correct diagnosis. Based on 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 rate of young-onset colorectal cancer.

Three years of survey data confirm acute need in two areas:

- Medical professionals and young people need to be aware of the increasing incidence rate of young-onset colorectal cancer, the signs and symptoms, and the importance of timely screening when those symptoms are present, regardless of age.
- Young-onset colorectal cancer patients, survivors, and caregivers are in need of more resources and psychosocial support services before, during, and after a diagnosis.

As the nation’s largest colorectal cancer advocacy organization, the Colorectal Cancer Alliance aims to address these needs, providing a voice to all those who were told they were “too young” to have colorectal cancer. Armed with the data from this survey, the Colorectal Cancer Alliance’s Never Too Young Advisory Board and program is committed to raising awareness and offering innovative ways for survivors, caregivers, and the medical community to end colorectal cancer.

Tomorrow can't wait[®]