

# Caregiver Survey Report 2020

---

Findings from an online survey  
of young-onset colorectal cancer  
patients and survivors.

# Executive Summary

---

Young-onset colorectal cancer (YO-CRC) refers to people diagnosed under the age of 50, which is the recommended screening age by the United States Preventive Services Task Force. An article from 2014 predicted an increase in colon cancer diagnoses in people under the age of 50, with the largest increase of 90% in the 20-34 year age group specifically by 2030, and an increase of 124% in rectal cancer by 2030.<sup>1</sup>

With this growth in mind, the Colorectal Cancer Alliance launched a pivotal annual research initiative called the Never Too Young Survey in 2016. The survey was expanded in 2019 to address additional topics including demographics and lifestyle; pre-diagnosis symptoms; knowledge of biomarkers and clinical trials; quality of life; and included a separate track for caregiver respondents. Findings and themes from caregiver responses is the focus of this report.

A total of 204 caregivers responded to the survey. The average caregiver age was 40, and the average age of the person they were caring for was reported to be 42. Of the caregiver respondents, 89% resided in the United States and the remainder resided in Australia (3.5%), Canada (2.5%), United Kingdom (2.5%), and five other countries. Eighty-eight percent identify as female, 12% male, 90% White, with 5% identifying as Hispanic or Latino, 2.5% Asian or Pacific Islander, and one respondent is Native American/American Indian. The remainder self-identified as "other." Zero respondents identified as African American.

The majority (65%) of the caregivers reside in the suburbs; 78% have a college degree, with 43% of those having a graduate or professional degree. Of the respondents, 70% are spouses or partners of the patient, and 18% are parents of the patient or survivor. Seventy-seven percent have children, and 60% of the children are under the age of 18. Fifty-one percent have two children and 30% have three or more children.

We realize that our survey respondents are not a cross-section of the overall population and not a representation of those who have or have had colorectal cancer. The channels we used for the survey reached people that are highly informed and engaged in colorectal cancer. Future research will emphasize channels to reach a more diverse population.

---

<sup>1</sup> JAMA Surg. doi:10.1001/jamasurg.2014.1756

Approximately one-in-seven adults in the United States — about 40 million people — provides some type of unpaid care to another adult. On average, adult caregivers spend almost 80 minutes per day providing unpaid assistance that includes bathing, bill paying, dressing, eating, home maintenance, medical care, and transportation to appointments. One-in-five spends less than 20 minutes per day providing necessary care; however more than one-in-ten requires three hours or more daily, the equivalent of a part-time job.<sup>2</sup> This is significant and comes with worrisome implications which we dissect in this report.

When it comes to employment, 70% of caregiver respondents work full-time jobs, and 63% reported missing eight hours or more each month. This resulted in 40% leaving school or a job due to caregiving responsibilities. Working caregivers have many additional job strains, particularly if the person they are caring for was working and becomes unable to work due to treatments.

Multiple differences in patient and caregiver perspective were noted. The majority (59%) of our caregiver respondents said that they encouraged their loved one to seek treatment or medical advice based on symptoms, yet most patient/survivor respondents (81%) reported at least three symptoms of colorectal cancer prior to diagnosis; the majority (62%) waited over three months to go to the doctor. Interestingly, 69% of caregivers encouraged the patient to seek a second opinion, and yet patient cohort findings show that only 39% of patients/survivor respondents received a second opinion.

Most caregiver respondents (88%) took an active role in the patients' medical decisions, and 87% reported they, and the patients (82%), understood all treatment options and risks before treatment began. Seventy-three percent of caregivers stated that neither they nor the patient received YO-CRC support or information from healthcare professionals.

It is important that all patients/survivors and their family members be aware of their family history of colorectal cancer and advanced adenomas. A family history increases the risk of developing colorectal cancer and changes the guidelines for screening. According to the caregiver respondents, 78% of medical professionals spoke to the patient/survivor and their family about the increased risk of CRC to their first-degree relatives, indicating that colonoscopy needed to start ten years prior to their diagnosis or age 40, whichever occurs earlier.

Fertility consequences and sexual dysfunction are a concern for young patients and their caregivers based on treatments and side effects in CRC. Failure to address sexual health can contribute to long-term impacts related to identity, interpersonal relationships, and quality

---

<sup>2</sup> <https://www.pewresearch.org/fact-tank/2018/11/08/adult-caregiving-often-seen-as-very-meaningful-by-those-who-do-it/>

of life. Although there are fertility preservation options available, only 50% of patients/survivor respondents stated that they were informed about potential changes to their sexual function or fertility. Among caregivers, 31% of respondents reported that there was never a discussion with their patient's healthcare provider about fertility or sexual dysfunction.

In addition to the medical needs and consequences for the patient, caring for a YO-CRC patient can cause physical and emotional stress. Young-onset colorectal cancer not only affects the patient's health and quality of life, it also changes how the family system functions. Nearly 75% of patients/survivors shared that they have been concerned about their mental health, and 64% responded that they have needed help for their depression. Further, 67% of caregivers surveyed responded that they were also concerned about their mental health, and 68% responded that they needed help with their depression. Seventy-one percent of caregivers often feel sadness, and 30% indicated that they had lost hope. This is a clear reminder that psychosocial support needs are not just for the patient stakeholder.

Emotional exhaustion was reported by 77% of caregivers, whether they were providing round-the-clock care or caregiving from a distance. The effect was more pronounced in the patient/survivor cohort, with 95% indicating that emotional exhaustion impacted their lives. As a result, 71% of caregivers and 29% patients/survivors indicated that they had withdrawn from other people.

A YO-CRC diagnosis changes what the patient/survivor can contribute to the family, both physically and emotionally, resulting in the caregiver having a change in their previous responsibilities. Of our respondents, 48% of caregivers indicated that their role in childcare changed; in addition, changes occurred in household responsibilities (77%), sexual/intimacy (51%), work (59%), and financial responsibility (42%).

Financial toxicity and financial distress are terms used to describe how out-of-pocket costs of cancer treatment cause financial problems. Of the respondents, 63% stated insurance offered adequate coverage for the patient's treatment needs, while 38% still worried about financial problems in the future due to the patient's illness and treatments. Forty percent of caregivers reported they always or often feel financially stressed, and 40% reported the need to take a leave of absence (either quitting a job or leaving school) because of the patient's diagnosis and their increased responsibilities. Our patient/survivor survey found that over 50% of the respondents indicated they feel financially stressed and worry about the loss of their family's financial stability, as well as the financial problems they will face in the future. Although 75% of patient/survivor respondents were employed full-time when they were diagnosed, only half were employed at the time of the survey.

Despite the stated limitations in the population surveyed, several important themes were identified. YO-CRC caregivers are usually caring for people with advanced stages of colorectal cancer. This impact includes unique problems with fertility and sexual dysfunction, and changes in parenting, child care, and finances. The physical and emotional stress on caregivers is frequently not addressed which indicates a knowledge gap, not only in the lay population but also within the medical community. The Alliance is dedicated to working with all stakeholders, including policymakers, to address the unmet needs among caregivers, aiming to improve quality of life outcomes for caregivers in conjunction with their patients.

## 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 estimates that 147,950 people will be diagnosed with colorectal cancer in 2020, with 104,610 people diagnosed with colon cancer and 43,340 people diagnosed with rectal cancer. Estimates show that 17,930 (12%) under the age of 50 will be diagnosed with colorectal cancer and approximately 3,640 (8%) will die from the disease. Unfortunately, these numbers are growing due to the COVID-19 global pandemic, with interruptions in routine preventative care and screening.<sup>1</sup>

Young-onset colorectal cancer (YO-CRC) refers to individuals diagnosed under the age of 50. Colorectal cancer incidence has increased in adults aged 20-39 years since the mid-1980s and in adults aged 40-54 years since the mid-1990s, with the steepest increase in the younger age groups. In recent years, the incidence has increased by 2.2% annually in individuals younger than 50 years, and 1% in individuals 50-64, in contrast to a 3.3% decrease in adults 65 years and older. Even more shockingly, mortality rates have decreased in individuals diagnosed over the age of 50, while they are increasing in individuals diagnosed under the age of 50 by 1.3% per year. While 15-25% of cases can be attributed to familial or hereditary conditions, it is not clear why the remaining 75-85% of individuals under the age of 50 develop colorectal cancer.<sup>1</sup> There are multiple lifestyle hypotheses currently under investigation, including diet, physical activity, smoking, and alcohol consumption, as well as the role of the microbiome and environmental exposures before and after birth.<sup>2</sup>

The Colorectal Cancer Alliance launched a trailblazing colorectal cancer survey in 2016 to better understand challenges and unmet needs in the under-50 population. The Never Too Young Survey series introduced a set of questions geared towards caregivers for the first time in 2018—a questionnaire that was greatly expanded in 2019. As previously reported by the Alliance and is evidenced elsewhere, young-onset colorectal cancer patients are increasingly diagnosed with advanced disease requiring aggressive treatment in comparison to those diagnosed after the age of 50, the current recommended screening age. Yet there are limited studies that address the impact of young-onset colorectal cancer outcomes on quality of life (QoL) and unique unmet needs for these patients, survivors, and their caregivers.

For purposes of this report, we define a caregiver in YO-CRC as an unpaid member of a person's family or social network who supports daily living activities and serves as a liaison to the medical community and the patient's social network.<sup>3</sup>

Caregivers report numerous life challenges as a result of their experience with young-onset colorectal cancer, yet little research has been conducted on the coping strategies that either maximize or impede daily life. Even less information is available on interventions medical providers can suggest to ease the caregiving burden.<sup>4</sup>

---

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

<sup>2</sup> <https://doi.org/10.1038/s41575-019-0253-4>

<sup>3</sup> <https://pubmed.ncbi.nlm.nih.gov/25372703/>

<sup>4</sup> <https://doi.org/10.2147/PRBM.S164946>

Even without tactical answers, we know that caregivers need adequate support from medical providers to help manage demands and reduce impact on their own health and well-being. For many in this age group, a cancer diagnosis does not initiate the family's caregiving role, but rather expands upon or adds to an already existing set of care responsibilities. Physiological changes in the patient along with drug-related toxicities may contribute to side effects for months and even years following treatment. This report aims to elucidate these challenges caregivers are facing, how they are functioning, and coping strategies while supporting the patient during their cancer journey.

The Colorectal Cancer Alliance is dedicated to casting a light on the challenges and exploring the experience of caregivers who are caring for YO-CRC patients. Improving understanding of the caregiver-associated stressors is critical to the development of effective resources and support programs.

## Methodology

The 2019 Colorectal Cancer Alliance Never Too Young survey was designed based on several established and validated instruments including AYA-HOPE, EORTC-QOL-30, EORTC-CR-29, EORTC-SHC-22, PROMIS-29, FACT-C, and COH-47. It pertains to several domains of caregiving including working while caregiving, understanding treatments, biomarkers, personal and financial implications of being a caregiver, and coping mechanisms. The Alliance's Never Too Young Advisory Board contributed feedback through the process to improve the literacy and efficiency of the questions. The final survey instrument and research plan were reviewed and approved by the Aspire Inc. Institutional Review Board.

The survey was launched in the summer of 2019 and disseminated through the Alliance's social media platforms, as well as numerous advocacy partner channels. The survey remained open for eight weeks, during which 885 patients and survivors and 204 caregivers completed the questionnaire that contained up to 140 questions (dependent on response logic). The majority of caregiver respondents (87%) participated in the Never Too Young Survey for the first time. Approximately 12% of respondents indicated that they had participated in the previous year's survey.

Descriptive statistics were used in thematic analysis and characterization of the unmet needs in each of the domains. In addition to analysis of the caregiver data alone, comparisons were drawn on the reported unmet needs between respondent types—caregivers, patients, and survivors—and based on variables including type of cancer, gender, education, residential community (rural, suburban, or urban), and stage of patient diagnosis.

## Participant Characteristics

Of the 204 caregiver respondents, 89% reside in the United States. Responses were also received from Australia (3.4%), Canada (2.5%), the United Kingdom (2.5%), as well as several other countries. Within the US, most responses were received from caregivers in California (9.3%), Illinois (7.1%), New York (6.6), Maryland and Texas (4.4% each), Arizona, Colorado, New Jersey and North Carolina (3.8% each).

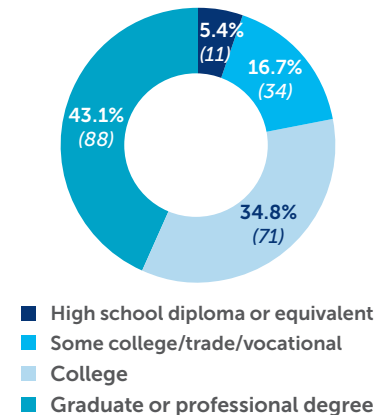
Of the 204 participants, 88% were women and 12% were men. Sixty-nine percent of respondents indicated they were a spouse or partner, 18% parents, 6% siblings, 5% children, and 1% friend or other. The average age of caregivers was 42 years old; the average age of the patient they were caring for was 40, with 28% diagnosed under the age of 40 years. The majority of respondents (60%) reported also caring for children under the age of 18 at the time of patient diagnosis.

Most caregiver respondents (90%) self-identified as White or Caucasian, with 5% Hispanic/Latino, and the remainder a mix of Asian/Pacific Islander, Native American, and other races. The majority (78%) reported having at least a college degree, with 43% having professional or graduate degrees. Approximately 5% did not have any college experience, and 17% had some college or vocational experience.

### Participant Demographics

Race	Frequency	Percentage
Asian/Pacific Islander	5	2%
Black or African American	0	0%
Hispanic or Latino	10	5%
Native American	1	1%
Other	4	2%
White	184	90%

### Education Level

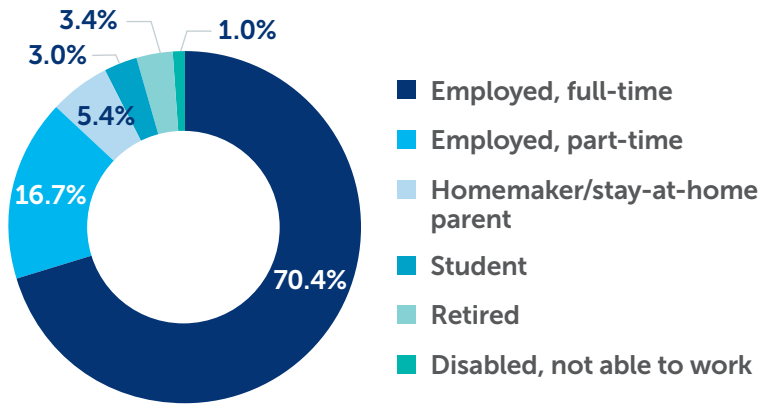


Working caregivers often suffer work-related difficulties due to their “second careers” as caregivers.<sup>5</sup> Seventy-percent of caregivers reported they worked full-time jobs at the time of their survey response; 63% reported missing 8 hours or more each month. This resulted in 40% of caregiver respondents leaving school or a job due to caregiving responsibilities.

Among caregiver respondents, 19% reside in an urban area, 16% live in a rural environment, and the majority (64%) reside in the suburbs.

<sup>5</sup> <https://www.caregiver.org/caregiving>



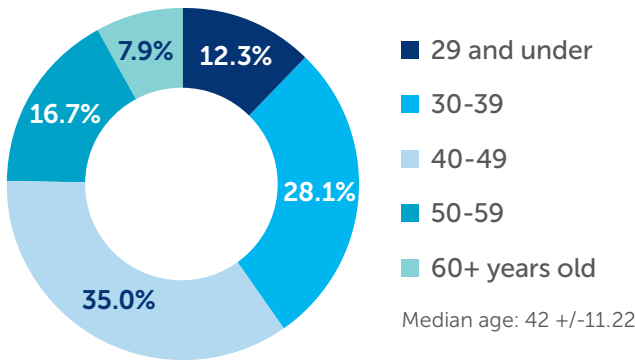


One identified limitation of this survey is that the respondent pool did not represent an accurate cross-section of the population or of those who have or have had colorectal cancer. Future studies will seek out additional channels aimed at reaching a more diverse sample.

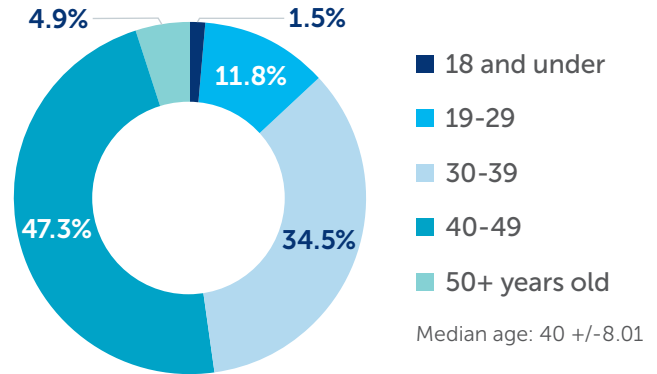
### Gender



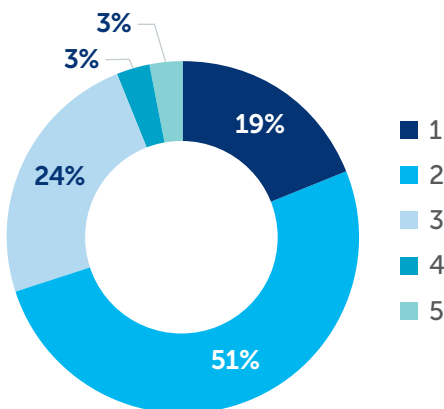
### Caregiver's Age



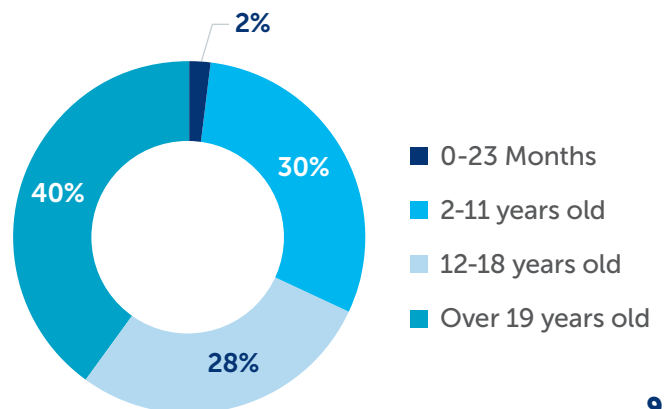
### Patient's Age



### Number of Children



### Ages of Children



## Findings

### SCREENING AND DIAGNOSIS

Colorectal cancer screening was previously recommended to begin at the age of 50 for people at average risk—those without a family history. In 2018, the American Cancer Society suggested reducing the screening age from 50 to 45 years old for those at average risk, which has yet to gain widespread adoption.<sup>6</sup> Individuals under 50 typically do not get screened unless they have a personal or family history. Therefore, it is critical that people are able to recognize symptoms of colorectal cancer and subsequently seek medical advice as soon as possible.

Interestingly, the majority of caregiver respondents (59%) reported having urged their patient to seek treatment or medical advice based on patient symptoms. At the same time, 88% took an active role in the medical decisions that began at the time of initial diagnosis. While sixty-nine percent of caregivers encouraged the patient to seek a second opinion, only 39% of patients reported they sought a second opinion at diagnosis. Sixty-percent of caregivers reported the patient had access to a patient or nurse navigator, and 40% of patients reported more resources around the patient navigation were needed during their treatment.

Treatment options and risks are important issues to be addressed at the beginning of treatment, as discrepancies in understanding between patients and their caregivers can complicate their decision-making processes. While caregivers (87%) reported they understood all options and risks before treatment began, most still need additional information on patient navigation, treatment options, and managing patients' side effects.

Caregivers also reported needing informal care involving family, friends, and community who can help share the caregiving responsibility to help manage patient side effects (56%), childcare (43%), patient transportation (37%), and financial planning (58%). Seventy-three percent of caregivers shared that they did not receive any information on young-onset support groups, organizational referrals, or information from healthcare professionals. Caregivers have a very important job in supporting the patient's medical condition while giving care at home and helping carry out treatment plans. Importantly, more caregiver resources and support must be integrated into the patient's care plan to assist caregivers and their patients.

*“ [It was important to have] a respite option for a nurse or caregiver who my sister also trusted to come give us both needed time away from one another but still maintain a level of care. ”*

*“ We had to get a second opinion almost two hours away to get additional resources and treatment options. ”*

<sup>6</sup> <https://www.cancer.org/latest-news/american-cancer-society-updates-colorectal-cancer-screening-guideline.html>

“ Did not receive information on these topics. Needed more information on treatment options and good patient/nurse navigation. Had to find most of the information ourselves. ”

“ Given the progression of disease upon diagnosis, I feel as though the doctors knew she would not live long, so weren't all that helpful in planning, etc. ”

## FAMILY HISTORY

A family history of colorectal cancer increases one's lifetime risk of being diagnosed with the disease. Nearly 28% of patient and survivor respondents indicated they had a family history of colorectal cancer. Even more, 78% of caregiver respondents shared that medical professionals communicated with familial caregivers about their elevated risk of colorectal cancer and the need for early screening (age 40 or ten years before the patient's age at diagnosis, whichever comes first). Thirty-five percent of respondents from the patient and survivor cohort reported they were offered genetic testing at the time of diagnosis, which differs from 72% of reported caregivers. A majority of caregivers (73%) stated that they will encourage their family members to have genetic testing, and 19% will let their family members make the decision about testing.

“ I tried for 10 years to get the doctors to do a colonoscopy; he had one four months before he died. ”

## GENETIC AND BIOMARKER TESTING

Genetic testing, including biomarkers, is an important step in developing a customized cancer treatment plan. Test results can predict the tumor's response to various treatments, and experts currently recommend genetic testing for Lynch Syndrome in all newly-diagnosed patients under the age of 50.<sup>7</sup> With the increase of targeted therapies and precision treatment options, it is important to know unique tumor characteristics in order to make informed decisions and articulate patient and caregiver preferences to the medical team.

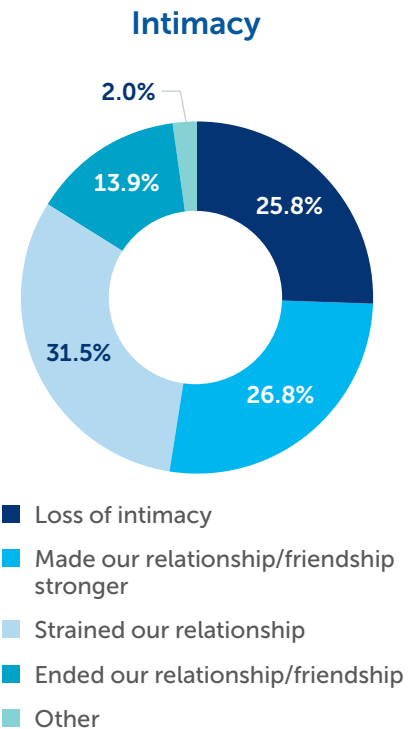
Despite this need, only 36% of caregivers and 56% of stage IV patients reported that healthcare providers discussed biomarker testing with them at diagnosis. More than 50% of eligible patients did not receive biomarker testing, despite 60% of caregivers and 54% of stage IV patients understanding the importance of knowing their biomarker testing results before beginning treatment. Patients stated they were not made aware of biomarkers from their medical team, and the patient biomarker education came from an internet search (56%), a family friend (22%), or a patient navigator (22%). This points to an educational gap that needs to be addressed. The data indicates there is a critical need for enhanced patient and caregiver education regarding biomarker testing.<sup>8</sup>

<sup>7</sup> [https://www.nccn.org/professionals/physician\\_gls/pdf/genetics\\_colon.pdf](https://www.nccn.org/professionals/physician_gls/pdf/genetics_colon.pdf)

<sup>8</sup> <https://www.ccalliance.org/about/never-too-young/survey>

## SEXUAL AND REPRODUCTIVE HEALTH SIDE EFFECTS

Fertility is a critical issue for YO-CRC patients and their caregivers, as the long-term emotional impact of potential fertility side effects from cancer treatment can be extremely distressing. Advances in knowledge about how cancer treatments may impact reproductive health, as well as newer techniques to preserve fertility, offer hope to patients and caregivers who may not have completed their childbearing at cancer diagnosis.<sup>9</sup> Even without childbearing consequences, sexual dysfunction side effects can have implications for the well-being of young-onset colorectal cancer patients and their caregivers. Failure to address sexual health can contribute to long-term consequences related to identity, interpersonal relationships, and quality of life.<sup>10</sup> While 27% of caregivers said the diagnosis made their relationship stronger, many caregivers (26%) reported a loss of intimacy, 32% stated the diagnosis strained their relationship, and 14% stated it ended their relationship. Unfortunately, only 31% of caregivers respondents reported that healthcare providers discussed fertility preservation with them and the patient, which confirms data from the patients/survivor cohort which found that 50% of YO-CRC patients are not informed about potential changes to their sexual function or fertility. Therefore, the opportunity for fertility preservation remains underutilized.



*“At the time my son, Jason, was diagnosed (2011) there were no resources or support for young folks with young-onset CRC. He felt terribly isolated and alone with what we were told was a very rare case of a young person with an old person’s cancer. Since then there are some wonderful online groups for social support and information. I suspect more needs to be shared about these resources with newly-diagnosed young people with this cancer. There definitely needs to be info about preserving fertility. I was the one who initiated that discussion after reading that his scheduled chemo could even cause harm to a future fetus. Not the most comfortable issue to come from your mom, but too important for me to ignore.”*

<sup>9</sup> <https://pubmed.ncbi.nlm.nih.gov/16304430/>

<sup>10</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4173048/>

“After my husband had his ostomy, I hated that he wouldn’t hug or hold me and even though we still slept in the same bed, he would no longer touch me or let me touch him (spoon together) like we used to before surgery. The physical/emotional scars from surgery are hard to get past most times.”

## MENTAL HEALTH

Caring for a YO-CRC patient can lead to numerous emotional and mental health challenges. The cancer journey not only affects the patient’s health and quality of life but also changes the family system. Nearly 67% of caregiver respondents shared that they have been concerned about their mental health, and 68% responded that they needed help for depression. Sixty-six percent withdrew from other people and 53% indicated that mental health concerns significantly impacted their daily lives. Seventy-three percent of caregivers strongly agreed they needed help for panic and anxiety in their lives, more than 71% said they often felt sadness, and 30% percent of caregivers stated they lost hope.

Additionally, many (32%) reported fatigue, which is an overwhelming sense of tiredness. Spouses or partners, adult children, and family members alike are susceptible to caregiver fatigue, whether they are providing round-the-clock care or caregiving from a distance.



“[It is an] emotional struggle to cope with the loss of our “big dreams,” lack of local resources, and taking on all of the daily responsibilities that used to be shared with my spouse.”

“Things are so busy during treatment I was focused on helping my wife. Now that she is gone it’s difficult to focus and find motivation to do anything.”

*“ I have found it nearly impossible to find a therapist. The only therapists who have availability are not accepted by my insurance. ”*

## FINANCIAL TOXICITY OF CAREGIVING

Financial toxicity and financial distress are terms used to describe how out-of-pocket costs of cancer treatment can cause financial problems. Cancer is one of the most expensive medical conditions to treat in the United States.<sup>11</sup> Cancer patients may receive multiple types of costly treatments, including surgery, radiation therapy, and systemic treatments; and colorectal cancer is second for lost earnings among all cancers (\$9.4 billion; 10.0%).<sup>12</sup>

Sixty-three percent of caregivers stated that insurance offered adequate coverage for their patients' treatment needs, but 38% still worried about future financial problems due to treatment costs. Forty-percent reported that they always or often feel financially stressed. This could be connected to the previously reported 40% taking an employment leave of absence, quitting a job, or leaving school due to increased caregiving responsibilities. Given the reality that 75% of our respondents had children, we hypothesize that employment and financial stress are potentially correlated to compounding parental responsibilities.

More than half of the patients and survivor respondents who were working at least part-time at the time of diagnosis were not working at the time of the survey. A significant number of survivors were unable to work after diagnosis. Interestingly, one-quarter of them have been without evidence of disease for 2-10 years, demonstrating that the inability to work continues years after diagnosis.<sup>13</sup>

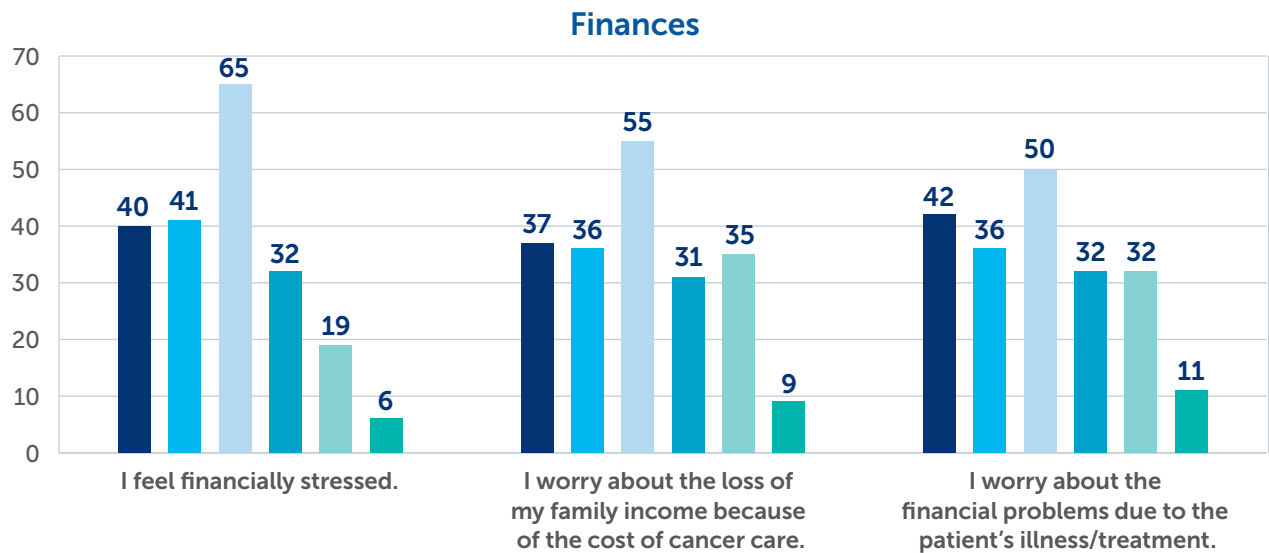
*“ The focus on my husband' health came at the expense of caring for my daughters, my professional life, and my own health. Fighting for him was so worth it, and I would do it all over again, but I wish I hadn't been stretched so thin. He passed away in April [2019] after 16 months of bravely fighting. I find I need help and support now more than ever, ironically. Nothing really prepares you to be the head of the household, and the sole financial and emotional provider for the whole family, while also trying to process your own grief. ”*

---

<sup>11</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3107566/>

<sup>12</sup> <https://jamanetwork.com/journals/jamaoncology/fullarticle/2737074>

<sup>13</sup> <https://www.ccalliance.org/about/never-too-young/survey>



## CAREGIVING TASKS

The growing population of YO-CRC patients has led to a growing population of caregivers who are navigating role changes right along with the patient. Caregivers juggle multiple responsibilities and often find themselves doing more tasks and confronting new needs as their loved ones' health and family dynamics change. Many caregivers needed to restructure their lives to accommodate new role changes with parenting (57%), child care (48%), household chores (77%), and work (59%). These are all time-consuming roles and responsibilities caregivers may need to adapt while taking on a variety of tasks.

*“ We needed someone to help document memories, financial help, babysitting and pet sitting. So much of what is challenging is day to day stuff. We’ve got a strong network of support, and it still gets overwhelming, especially with little kids. ”*

Caregivers identified gaps around understanding treatment options (48%), and healthcare decisions (38%), while navigating the patient’s diagnosis. Additional assistance and information was needed around financial planning (33%), household responsibility (48%), intimacy (51%), and patient transportation (20%) to help manage their loved one’s needs and life changes.

*“ I feel that it was up to us to find out a lot about the treatment and managing side effects etc by ourselves, which we did mainly online. There seems to be a lack of funding for CRC, particularly compared to some other cancers, and this meant that things like patient/nurse navigation, transportation and childcare resources were either non-existent or not discussed with us. I think older people who have been part of the wider healthcare system already and ‘linked in’ probably have better access to resources and know what is available, compared to us who this was our first time really even in a hospital. ”*

“Hospice care was available, but not entirely what I expected. We could get a volunteer to come and sit with my husband when we were gone briefly, and nurses came in twice a week to check on him, but there was not round the clock or even partial day care. That was all on the family to arrange. Very difficult to arrange that while working full time and I didn’t qualify for FMLA because I had started a new job. I needed people to drive him to/from doctor appointments and he was constantly in the hospital for days at a time after chemo treatments.”

“We needed an advocate to help with insurance that denied so many things. A doctor who didn’t sugar coat things. A hospice team that didn’t expect me to do a job that I was unqualified for.”

“It became isolating, family and friends that I thought would be supportive weren’t. I’ve made some new friends and also use online support groups.”

## COPING STRATEGIES

There is also evidence that coping styles can act as a buffer for depression in cancer caregivers. One study found that caregivers’ perceptions of the efficacy of their coping strategies allowed for an improved relationship between strain and depression. However, when compared with other mental health dimensions of cancer caregiving such as stress or depression, coping has remained relatively unexplored.<sup>14</sup>

Caregivers use various coping methods to minimize the effects of caregiving-related emotional issues. We asked caregivers to rank their coping mechanisms in order of use. Caregivers who stated they suffered from mental health and depression issues maintained healthy ways to cope, compared to caregivers who reported they did not suffer from mental health issues.

---

<sup>14</sup> <https://www.dovepress.com/the-impact-of-coping-strategies-of-cancer-caregivers-on-psycho-physiology-peer-reviewed-article-PRBM>



## Self-reported Coping Mechanisms

Reported Coping Method	Self-reported no mental health issues	Self-reported mental health issues
<b>Mindfulness</b>	5%	5%
<b>Exercise</b>	4%	12%
<b>Volunteering</b>	7%	7%
<b>Therapy</b>	7%	9%
<b>Online support</b>	21%	23%
<b>In-person support</b>	8%	12%
<b>Medication</b>	6%	7%
<b>Smoking</b>	8%	5%
<b>Drinking</b>	14%	6%
<b>Eating</b>	4%	6%
<b>Work</b>	7%	12%

### CAREGIVER STATEMENTS

“It is exhausting. Providing emotional support, physical care for a sick spouse, caring for kids struggling emotionally, advocating for care and assisting with decision making, while maintaining a household and family.”

“I had no support. I was taking care of my husband, working full time, sitting/waiting in hospitals and raising two kids by myself. I felt stressed and drained, emotionally and financially.”

“I felt that it was up to us to find out about the treatments and managing side effects by ourselves, which we did mainly online.”

# Conclusion

---

The responses to or in this survey highlight numerous gaps for cancer caregivers supporting young-onset patients, including needs related to medical decision making, financial support, parenting, mental health, and household and patient transportation issues. This further supports the assertion that caregivers should be acknowledged as important healthcare partners and engaged in the entire care plan.

Caregivers often do not know how to help and may feel unprepared to meet the patient's needs. Role changes may occur as patients and caregivers cope with the disease and treatment journey. The majority of caregivers will adapt to these challenges; however, we do not know whether adaptation would occur sooner with psychosocial intervention. For some individuals, caregiving had positive effects and brought the caregiver closer to the patient. In several cases there was a loss of the relationship and/or a loss of intimacy.

The Colorectal Cancer Alliance is committed to meeting these needs and providing resources that support caregivers. Information and services may also assist the caregiver in helping the patient make decisions, including treatment options, managing side effects, or and shifting roles and routines in response to changing demands of YO-CRC. Further studies should investigate financial and psychological well-being and support strategies specific to the impact of child rearing and employment. Programs tailored to the YO-CRC community should consider the unique challenges for caregivers due to these employment changes, parenting roles, and the likelihood for financial toxicity.