

SEPTEMBER 2019 NATIONAL REPORT

RIDING THE ROLLER COASTER OF INFLAMMATORY BOWEL DISEASE:

A NATIONAL STUDY OF CAREGIVERS OF
INDIVIDUALS WITH CROHN'S DISEASE
OR ULCERATIVE COLITIS



IN PARTNERSHIP WITH



FUNDED BY THE DAVID R. CLARE AND MARGARET C. CLARE FOUNDATION



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The Crohn's & Colitis Foundation is the largest non-profit, voluntary health organization dedicated to finding cures for inflammatory bowel diseases (IBD). The Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults who are affected by these diseases. The Foundation works to fulfill its mission by funding research; providing educational resources for patients and their families, medical professionals, and the public; and furnishing supportive services for those afflicted with IBD. For more information visit www.crohnscolitisfoundation.org, call 888-694-8872, or email info@crohnscolitisfoundation.org.



ImproveCareNow (ICN) is a Learning Health Network dedicated to transforming care, health, and costs for all children and youth with Crohn's disease and ulcerative colitis by building a sustainable collaborative chronic care network. ICN enables parents, families, clinicians, and researchers to work together in a learning health care system to accelerate innovation, discovery, and the application of new knowledge.

For more information visit www.improvecarenow.org or email info@improvecarenow.org.



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ABOUT THIS STUDY

Inflammatory bowel disease (IBD) is an umbrella term that describes chronic inflammation of the digestive tract. The two most common forms of IBD include Crohn's disease and ulcerative colitis, which together, affect more than three million Americans.

These conditions are painful, medically incurable diseases that attack the digestive system. Crohn's disease may attack anywhere along the digestive tract, while ulcerative colitis inflames only the large intestine (colon). Symptoms may include abdominal pain, persistent diarrhea, rectal bleeding, fever, and weight loss. Many patients require numerous hospitalizations and surgery. Most people develop the diseases between the ages of 15 and 35, however, the incidence is increasing in children. The diseases tend to run in families and affect males and females equally. Although the conditions can affect anyone, individuals who are white, or Caucasian, are more likely than other racial or ethnic groups to have IBD.

To our knowledge, this effort represents the first public policy study to address the experiences of those who provide unpaid or volunteer care to a friend or relative living with IBD. This study's focus is on people over 18 years old who provide a range of assistance to a person living with inflammatory bowel disease (IBD). The findings from this work provide insight into the experiences and perspectives of this unpaid and under-recognized workforce. In general, and as used in this study, the term caregiver refers to "a family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation," as defined in the RAISE Family Caregivers Act of 2017 (Public Law 115-119).

The caregiving experience can vary greatly. Though there are young adults who may provide care within households, this study's focus is on people over 18 years old who provide a wide range of assistance to a person who is living with IBD. This support may include assisting with daily activities of living, performing medical/nursing tasks, providing transportation to and from medical appointments, helping to secure access to treatments and resources, and providing emotional support to the person who receives care.

The findings and results in this study are based on Fall 2018 survey data from 728 individuals who reported providing unpaid care for someone with IBD. Caregivers shared their experiences using online survey methods. Estimates of the prevalence of IBD vary; between 1 million and 4 million Americans are impacted in any given year.

The survey was commissioned by the National Alliance for Caregiving in partnership with the Crohn's & Colitis Foundation and ImproveCareNow, supported by grant funding from the David R. Clare and Margaret C. Clare Foundation. The survey instrument, initial findings, and final report were reviewed by an independent Advisory committee of subject-matter experts, patient advocates, and family caregivers. The sections that follow describe the survey methods and limitations, key findings, policy recommendations, detailed findings, an analysis of qualitative responses, and next steps.



The findings and results in this study are based on fall 2018 survey data from 728 individuals who reported providing unpaid care for someone with IBD.

Representatives from the National Alliance for Caregiving (NAC)¹, the Crohn's and Colitis Foundation², and ImproveCareNow³ along with researchers from Crimson Research at New Mexico State University (NMSU) worked collaboratively to develop the survey instrument.

METHODOLOGY

Representatives from the National Alliance for Caregiving (NAC)¹, the Crohn's & Colitis Foundation², ImproveCareNow³ and researchers from Crimson Research at New Mexico State University (NMSU) worked collaboratively to develop the survey instrument. Content from earlier NAC surveys, including their 2018 rare disease survey (www.caregiving.org/rare/), provided the foundation for the current survey content.

Questions were asked in multiple content areas including:

- Demographics of caregivers and care recipients
- The caregiving situation
- Caregiving tasks
- Medical assistance
- Other support
- Caregiver involvement and informational support
- Access to treatment and needed services
- Effects on work and school
- Caregiver well-being
- Insurance and financial impacts

Crimson Research fielded the survey using Qualtrics survey software. The survey opened for responses on September 13, 2018 and closed October 8, 2018. It used non-probability sampling methods and recruitment was primarily through distribution of survey links via multiple press announcements and distribution lists maintained by NAC, the Crohn's & Colitis Foundation, and ICN. The NMSU Institutional Review Board reviewed and approved the study.

To participate in the survey, respondents had to consent to participate, report being 18 years of age or older, reside in the United States, and report providing unpaid care to an adult or child with IBD currently or at some point in the past. Although the study was completely anonymous, participants could link to an independent questionnaire to request a copy of the final study when complete.

One-thousand eighty-two individuals (1,082) initiated the survey on Qualtrics. Of that total, survey programming prevented 21 (2%) responders from continuing to the survey because they reported not being 18 years or older or not residing in the U.S. Survey programming prevented an additional 20 (2%) responders from reporting in that they did not provide unpaid care for an adult or child with IBD. Finally, after examining the initial data, 313 responses were excluded (29%) because they opted out of the survey early and did not provide sufficient data. In the end, the final analysis was conducted on the remaining 728 (67%) survey respondents who were eligible for the study and who provided sufficient data on their caregiving experiences. All numbers have been rounded to the nearest hundredth place. In addition, "don't know" or "refused" responses are not always reflected in figures.

¹www.caregiving.org/

²www.crohnsandcolitisfoundation.org

³www.improvecarenow.org/

STUDY LIMITATIONS

Readers of this study should be aware of the limitations that may affect the interpretation of the results. Some reflect choices made in the design and development of the survey while others stem from the nature of the methods employed.

This study utilized convenience sampling to field the questionnaire and a “non-probability sampling” method to recruit study participants, which allowed participants greater freedom to self-select into the study. In contrast to probability sampling, which purposely selects individuals to be in the study in an effort to ensure representativeness and reduce the potential for bias, in non-probability sampling, the individuals who self-selected into the study may not be representative of all IBD caregiving experiences. Participants were recruited via direct solicitation through e-mail distribution lists and distribution of the survey link on select relevant websites. Partnering patient advocacy organizations, including the Crohn’s & Colitis Foundation and ImproveCareNow, distributed the questionnaire to their networks.

As policymakers and others consider support needed for the friends and family of people living with IBD, it is important to note that this method of survey may not fully reflect the views and experiences of all IBD caregivers. The experiences of the high-participating subgroups, such as those who are engaged in patient advocacy groups, may differ significantly from the experiences of under-represented subgroups. Although the use of non-probability sampling methods does not necessarily mean the results of any study are biased, additional studies would be required to determine representativeness. In particular, there is need for further study of groups beyond the respondents captured here who may be impacted by IBD caregiving, including men, ethnic and racial minority groups, individuals with less than a college education, and those families that may be less economically secure.

Another limitation is that this study focused on adult caregivers and excluded child or youth caregivers under age 18. The focus on adult caregivers was made in part because this survey was the first-of-its-kind and it was unclear to what extent minors provide care. One consideration for future study is a survey focusing on child caregivers, which might provide greater insight into their unique experiences.

In addition to the above, standard limitations of survey methods apply. All collected data rely on “self-report,” which assumes that people are willing and able to share their experiences honestly, accurately, and without reservation or personal bias. The length of the survey, although providing great depth of information, may have deterred some individuals from starting or completing it.

Finally, and although not a methodological limitation *per se*, the types of individuals who live with IBD (many of whom are young), the intermittent nature of the disease itself, and the relationship of these individuals to their caregivers (frequently parents) may also affect the results. In particular, a large number of respondents were also the parents of adolescents, making it possibly harder for the young adults to distinguish between *caregiving experiences* and more general parenting experiences. Although it was very common for caregivers to provide meal preparation for their care recipients, it is unclear how much of this type of assistance the parents might have provided even in the absence of IBD. The complete questionnaire is available as an appendix to this study.

Where useful, open-ended responses are provided throughout the text to illustrate trends and patterns that emerged from the data. For an analysis of the qualitative responses, please see section IV.R.



Caregivers relied heavily on healthcare professionals and IBD-specific organizations (e.g., Crohn's & Colitis Foundation and ImproveCareNow) as their main sources of informational support regarding IBD, with nine in 10 reporting accessing these sources. Use of social media and online support were reported by a significant minority, just a little more than three in 10.

KEY FINDINGS

- Most caregivers were assisting a son or daughter (70%) or assisting a spouse or partner (25%) with IBD.
- Most caregivers had been providing care for two years and between 10-20 hours per week.
- Providing or preparing meals and attending appointments with healthcare professionals were the two most widely reported activities, with nine of 10 caregivers reporting these types of assistance.
- Talking/communicating with healthcare professionals, providing transportation, and grocery shopping were also frequently reported, with eight in 10 caregivers reporting these types of assistance.
- Assisting with medication, doing housework, and managing finances were also commonly reported activities, with more than six in 10 caregivers reporting these types of assistance.
- Less than one in 10 caregivers reported use of paid help with caregiving tasks.
- If caregivers received assistance from others, it most likely came from a family member such as a father, spouse or partner, or sibling.
- Large proportions of caregivers, more than eight in 10, reported advocating for their care recipient with healthcare providers, schools, or other services/agencies.
- Caregivers relied heavily on healthcare professionals and IBD-specific organizations (e.g., Crohn's & Colitis Foundation and ImproveCareNow) as their main sources of informational support regarding IBD, with nine in 10 reporting accessing these sources. Use of social media and online support were reported by a significant minority, just a little more than three in 10.
- Nearly a quarter of caregivers reported that treatment was not available to their care recipient (24%) and more than a third (35%) said that they could not handle the condition.
- Medical professionals (95%), well-stocked pharmacies (85%), and nutritionists (75%) were the most sought-after support services.
- Only 5% of caregivers sought information or support from a genetic specialist, however over twice as many reported needing that service (13%). Seeking genetic counseling was also rated as one of the most difficult services to access. Similarly, 28% sought access to clinical trials, but such trials were rated the most difficult to access.
- A large majority of caregivers worked full- or part-time while providing care (81%) and many of these individuals reported that providing care caused them to lose time at work (94%) and their productivity to suffer (55%). More severe consequences such as losing one's job, losing benefits, or giving up work were relatively rare (less than 10%).



- Emotional stress was common among caregivers. A majority of respondents found caregiving to be emotionally stressful (59%), with 49% feeling overwhelmed, and 44% reporting that caregiving affected their mental health. A full 16% reported experiencing depression from providing care.
- More than a third of caregivers (35%) felt guilty because they thought they should be doing a better job of providing care.
- Caregiving affected the physical health of many, with 44% reporting feeling fatigued and 39% reporting they were not getting enough sleep.
- A remarkably high number of caregivers, more than six in ten, reported struggling with a sense of loss over what the care recipient's life would have been like without IBD.
- Many caregivers found something positive in providing care, with more than 50% taking pride in learning about the care recipient's condition and feeling a valued part of the healthcare team.
- In general, caregivers did not feel stigmatized because of their role in caring for someone with IBD with the majority (54% – 86%) reporting “not at all” to a series of questions asking about stigma.
- Almost a quarter of caregivers reported having less time for themselves due to caregiving, and a significant number of caregivers indicated that they had less time to socialize with friends (22%) or felt socially isolated (20%).
- Spending time away from the care recipient was the most reported coping behavior reported (57%) followed by exercising (51%). Although less frequent, but of concern, 12% reported substance use as a form of coping with their caregiving role.
- Consistent with the general affluence of the sample, most care recipients were covered by a privately insured employer plan (72%); only 3% were uninsured.
- Although reports of severe financial strains like bankruptcy (2%) or selling large assets like a home or boat (5%), were rare, nearly two-thirds (62%) reported cutting back on spending.

Many caregivers found something positive in providing care with more than 50% taking pride in learning about the care recipient's condition and feeling a valued part of the healthcare team.

The “typical” IBD caregiver has been caring nearly eight years (7.89) and providing approximately 20 hours of care each week, with a little more than half of caregivers (53%) reporting that they were the sole provider of care.

DETAILED FINDINGS

THE PORTRAIT OF AN IBD CAREGIVER

The survey included several questions that assessed characteristics of caregivers, the persons receiving care, and the caregiving circumstances. The summary of these findings is included in Table 1 below.⁴ The table provides ranges for continuous variables, such as age. For variables where extreme values made the mean a poor estimate of what was typical, the table includes the mode, or most common value, as an estimate of what most caregivers reported.

The “typical” IBD caregiver has been caring nearly eight years (7.89) and providing approximately 20 hours of care each week, with a little more than half of respondents (53%) reporting that they were the sole provider of care. A majority of caregivers (81%) reported that they felt they had no choice in providing care. Most caregivers (87%) live with the care recipient. In this study, the age of the caregivers ranged from age 20 to age 83, with care recipients as young as two and as old as 94 years of age. More detail on these demographics follows below.

Table 1. Caregiver and Care Recipient Demographics and Descriptive Statistics (N = 728)

	MEAN OR PERCENTAGE	MIN	MAX	MODE
Caregiver age (years)	48.82	20	83	
Recipient age (years)	26.42	2	94	14
Caregiver gender (% Female)	82%			
Recipient gender (% Female)	48%			
Caregiver Race (% Caucasian)	92%			
Caregiver identifies as Hispanic (%)	6%			
Caregiver education (% with 4-yr degree or higher)	72%			
Caregiver currently provides care (% yes)	83%			
Caregiver cares for their own child (% yes)	70%			
Caregiver cares for spouse/partner (% yes)	25%			
Caregiver lives with care recipient (% yes)	87%			
Percent caregivers providing care < 1 year (% yes)	15%			
Recipient lives in rural area (% yes)	22%			
Caregiver dependents in the home (dependents)	1.08	0	6	1
Average years providing care (years)	7.89	1	48	2
Average hours providing care each week (hours)	20.59	1	168	10
Solo caregiver	53%			
Choice in deciding to provide care (% no choice)	81%			

⁴In line with the earlier section on limitations, 82% of survey respondents were women and were often white, college-educated individuals. This is consistent with similar caregiving studies that have been fielded via patient advocacy groups and may underrepresent the needs of these families as a whole. See, for example, NAC in partnership with Mental Health America, *National Alliance on Mental Illness, On Pins & Needles: A Study of Caregivers of Adults with Mental Illness* (February 2016), at www.caregiving.org/research.

AGE, GENDER, RACE, EDUCATION, AND INCOME

Caregiver mean age was 49 years and 82% of them were women. With regard to their racial identity and ethnic background, the majority of IBD caregivers in this study were Caucasian (92%) or non-Hispanic (94%). Additionally, most were highly-educated (72% stated having a four-year college degree or higher) and had relatively high annual incomes (see Table 1).

Those receiving care (described as “care recipients” in this study) were younger (average age 26 years) and relatively equally distributed across male and female care recipients. Roughly 50% of care recipients captured in this study were 21 years old or younger, with the most commonly reported age (i.e., the mode) being 14 years.

CAREGIVING RELATIONSHIP

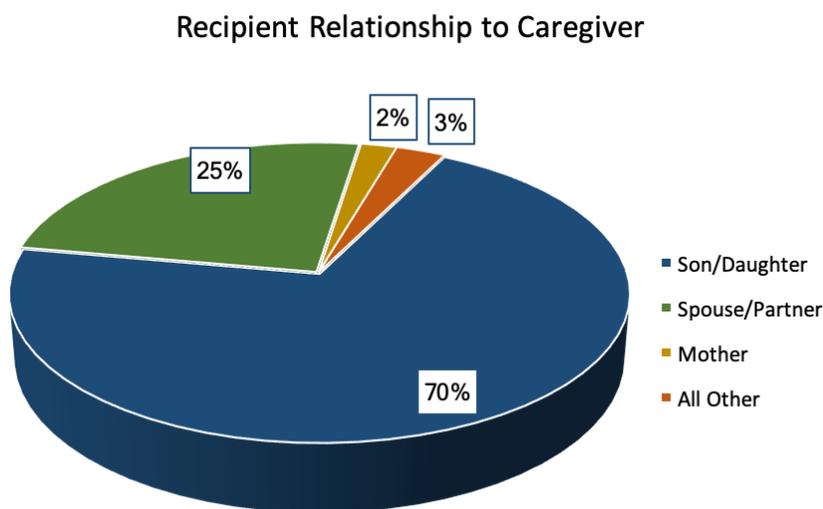
Most caregivers were currently providing care (83%) and most reported caring for their own child (70%) or a spouse or partner (25%). The distribution of the relationship of the care recipient to the caregiver is shown in Figure 1.

Caregivers of people with IBD had several factors that may make the caregiving relationship more stressful, such as length of time providing care, hours of care per week, co-residence, lack of additional help, and choice in taking on care.

On average, caregivers had been providing care for about eight years and for about 21 hours/week. Most caregivers lived with the care recipient (87%). More than half of caregivers (53%) were the sole providers of care for their care recipient, and most (81%) reported that they had no choice in deciding to provide care. As in care recipient age, the mean value for years of care was biased by high values, with the most common (i.e. modal) value for length of care being two years. For care hours per week, the modal value was 10 hours.

Caregivers of people with IBD had several factors that may make the caregiving relationship more stressful, such as length of time providing care, hours of care per week, co-residence, lack of additional help, and choice in taking on care.

Figure 1 Recipient Relationship to Caregiver





IBD CAREGIVING: EBBS & FLOWS

As the IBD care journey progresses, caregivers and individual with IBD may experience a different intensity of care during course of the disease.

“The care took place over a long period of time, [and] the amount of care was different depending on her age, how her health was, and if she was hospitalized or not.”

“Though my husband was diagnosed at 31 and is now 57, there are many times he is fine. Throughout this time, though, he has had three surgeries and a few hospitalizations. There are also days he isn’t well. When those times have happened, I have to take care of him. It’s not every day.”

“As my daughter became older and her Crohn’s more controlled, life became somewhat easier.”

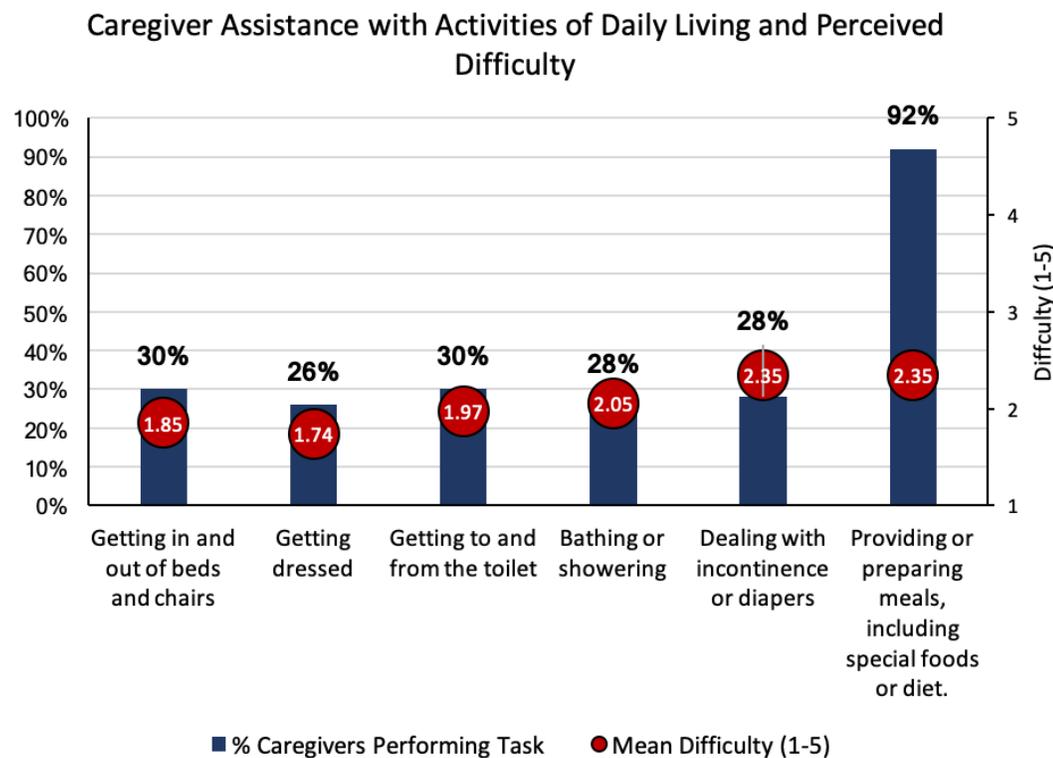
“My daughter was 13 when she was diagnosed. I was ‘on call’ 24/7 until she was about 21...I made frequent emergency trips to college to care for her during flares. We absolutely did not treat her as a victim. She graduated high school... graduated with honors from [college], got her masters in architecture... She is 30, now married with a 7-month-old. I will always be a ‘Crohn’s’ Mom’. Always.”

HELP WITH ACTIVITIES OF DAILY LIVING (ADL)

The survey asked caregivers the degree to which they assisted with a number of activities of daily living and, if they did, how difficult they found that activity on a 1-5-point scale (1= not at all; 5 = extremely difficult). Figure 2 lists these activities along with the percentage of caregivers who provided the service. The figure also shows the average difficulty ratings for each task.

Nearly all IBD caregivers (92%) reported providing or preparing meals including specialty foods, which was also reported as being one of the most difficult tasks. Although a quarter to a third of caregivers reported assisting with other Activities of Daily Living like toileting (30%), bathing (28%) or dealing with incontinence (28%), providing support for nutrition and cooking specialty meals was the most common ADL. None of the tasks were perceived as being particularly difficult. On a scale of 1 - 5 (5 being the most difficult), the task perceived as being the most difficult received an average rating of 2.35.

Figure 2 Activities of Daily Living



Nearly all IBD caregivers (92%) reported providing or preparing meals, including specialty foods, which was also reported as being one of the most difficult tasks.



CAREGIVER PERSPECTIVE

PREPARING MEALS AND SPECIAL FOODS

“There needs to be a better understanding from doctors and surgeons about the need for nutritional counseling for patients with IBD, ileostomies... Food is a HUGE obstacle for patients with these conditions.”

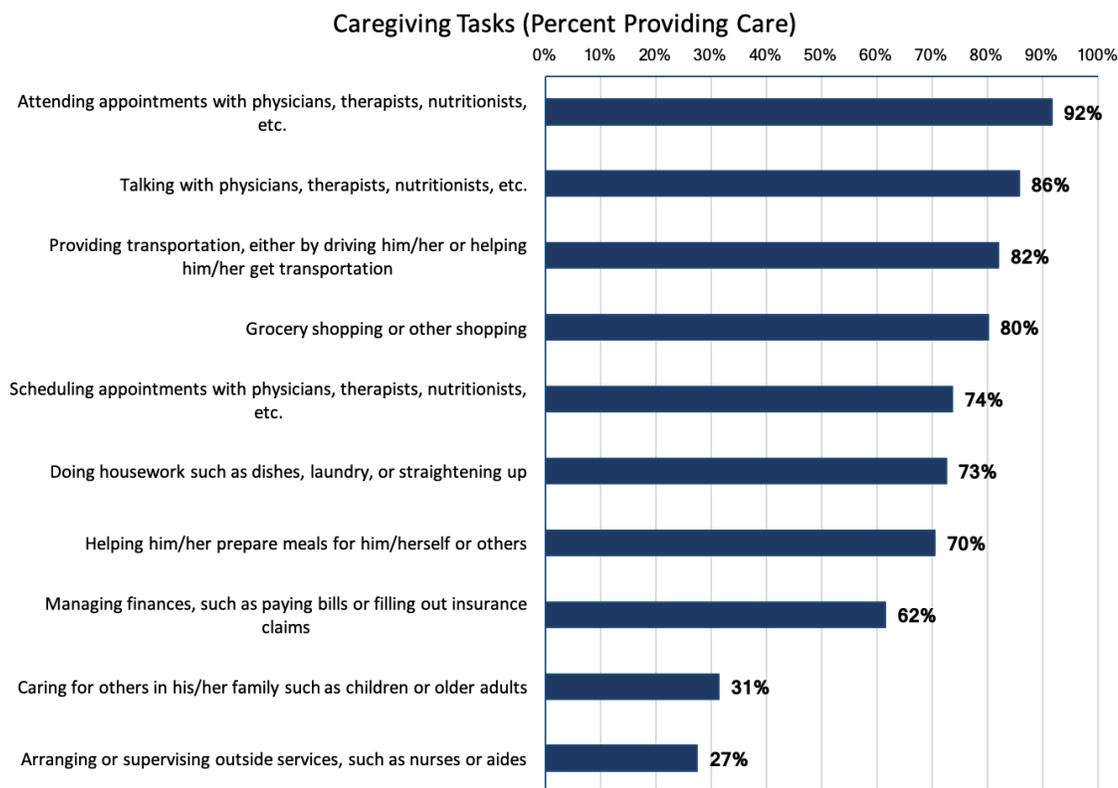
“[Caregivers need more information on] nutrition for the care recipient and for the caregiver: access to nutritious foods; cost of nutritious foods; time spent fixing nutritious foods; receiving support in cooking, grocery shopping...”

HELP WITH INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs)

In addition to helping with the high-touch activities of everyday life, many IBD caregivers provided help with care coordination, household management, and finances. As shown in Figure 3, most IBD caregivers reported scheduling and attending appointments; and talking with physicians, therapists, and nutritionists. Eight out of 10 IBD caregivers reported providing or helping to find transportation (82%) and grocery or other shopping (80%). Roughly three in four IBD caregivers (73%) reported doing household chores, and more than half (62%) assist with managing finances and filing for insurance.

In addition to helping with the high-touch activities of everyday life, many IBD caregivers provided help with care coordination, household management, and finances.

Figure 3 Caregiving Tasks



MEDICAL/NURSING TASKS

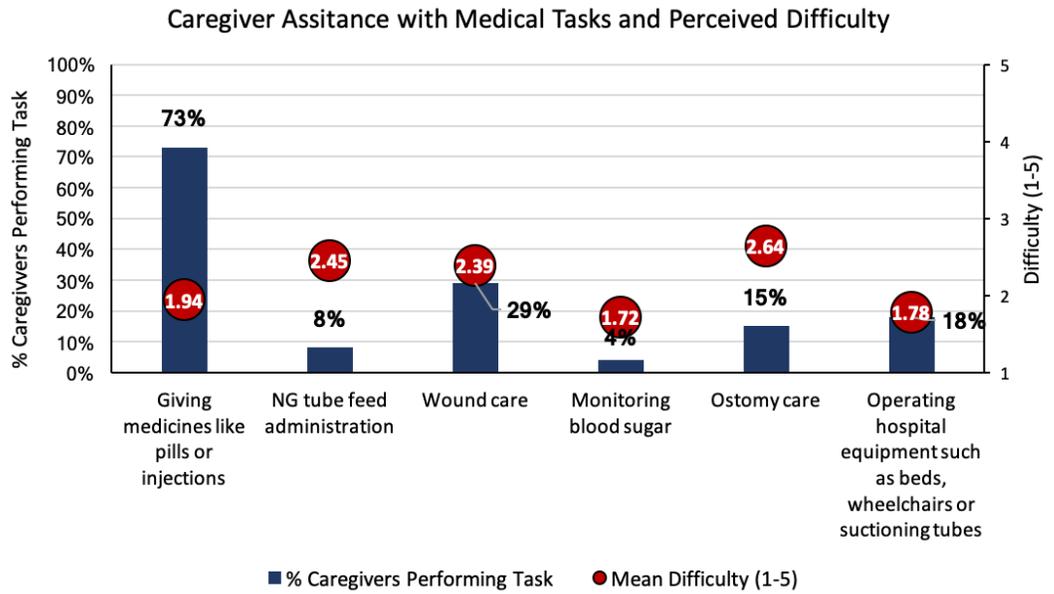
As with other types of caregiving, IBD caregivers may also assist with medical/nursing tasks. The most commonly reported medical/nursing task was assistance with managing medication, with nearly three in four caregivers (73%) helping with pills or injections. Nearly a third of IBD caregivers (29%) assisted with wound care, and roughly one in five (18%) assisted with hospital equipment, such as suctioning tubes. Although other caregivers did support medical tasks beyond these (as described below), these tasks were the most common. Of the medical tasks, ostomy care was rated as the most difficult task.



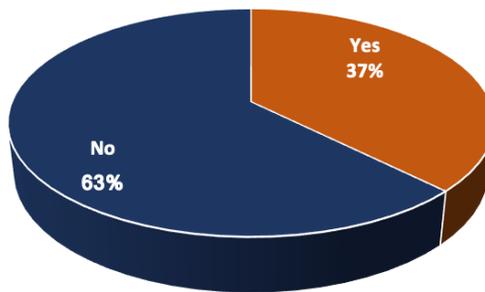
Of the caregivers who reported conducting medical/nursing tasks, only about one-third of caregivers reported having received prior preparation or training to perform medical tasks.

Of the caregivers who reported conducting medical/nursing tasks, only about one-third of caregivers reported having received prior preparation or training. This suggests a gap where medical professionals, such as a treating physician or nurse, should consider how to provide training to IBD caregivers, particularly for medically complex tasks such as operating hospital equipment or ostomy care, as described in Figure 4.

Figure 4 Assistance with Medical Tasks



Did Anyone From Medical/Healthcare Community Train or Prepare You to Assist with Medical/Nursing Tasks?

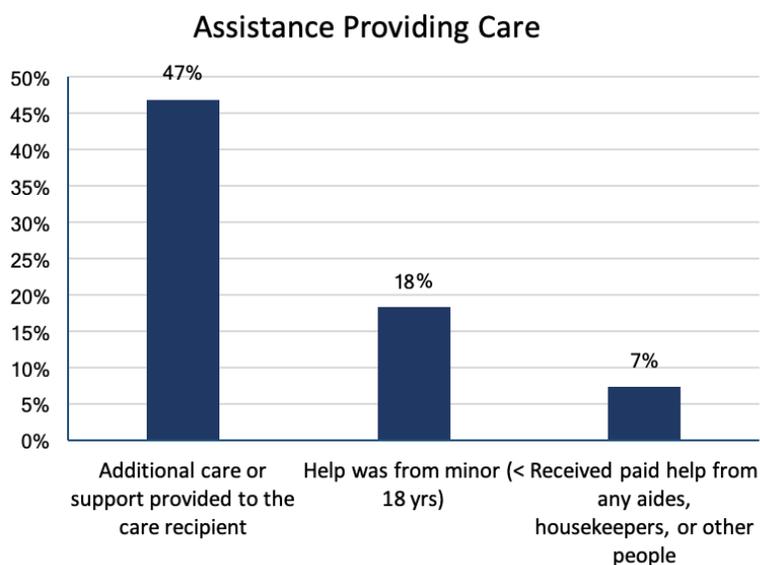


ADDITIONAL CAREGIVING HELP

The survey asked IBD caregivers additional questions related to assistance and support in providing care. More than half of caregivers (53%) were the sole caregivers, lacking unpaid or paid support from others.

The remaining 47% of IBD caregivers did receive some additional help. Of these, 18% reported assistance from a minor aged 18 or less; 7% reported receiving paid help of some kind (see Figure 5).

Figure 5 Assistance and Support



More than half of caregivers (53%) were the sole caregivers, lacking unpaid or paid support from others.

If respondents indicated that they received assistance, a follow-up question was asked about the specific source of support. Nearly half of caregivers who had help in providing care (48%) reported that such support came from the care recipient’s father. More than a third reported help from the care recipient’s spouse or partner (35%) and a quarter reported help from the care recipient’s sibling (24%), among other care providers (See Figure 6).





CAREGIVER PERSPECTIVE

NO “ONE-SIZE-FITS-ALL” – SUPPORTING PEOPLE WITH IBD

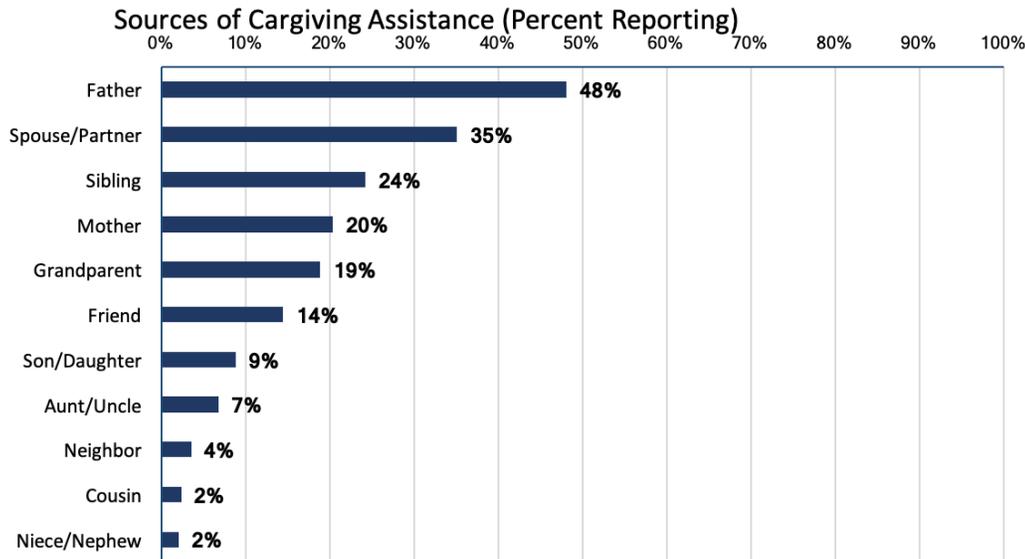
“The boys with IBD that I know do not go to support groups or want people to know about their disease. They become more isolated. That is what my son did. He dropped all friends and tells no one about his disease. He would NEVER go to a support group. The isolation compounds the depression of living with this disease.”

“It is an especially sticky age when they are over 18 but still on [their] parents’ insurance, in college and dealing with such a serious illness. The insurance hoops and privacy hoops to jump through have been so difficult for all of us and very overwhelming for our son. He is an adult but yet very much still a kid trying to deal with all of this and as parents we are trying to do all we can to support him the best way we know how for someone his age, without treating him like a child where we do it all (which as a mom, is what you want to do).”

“I have been my husband’s caregiver and confidant since he was diagnosed in 1993. Our oldest daughter was also diagnosed at the age of 18. My experience with her was far different from the one with my husband. She was allergic to every medication that was tried and spent most of that summer in the hospital.”

“[Sometimes] the caregiver is dealing with more than one diagnosis for the recipient... This caregiver was also dealing with the recipient’s spouse, who had Colitis and Alzheimer’s, for part of this same time period. This caregiver was also dealing with her own Crohn’s disease while being the caregiver.”

Figure 6 Sources of Caregiving Assistance (sources are relational to the care recipient)



More than eight out of 10 IBD caregivers are communicating with healthcare professionals, advocating for the care recipient, and monitoring the severity of his or her condition.

CAREGIVER ADVOCACY AND INFORMATIONAL SUPPORT

The survey asked several questions about participation in other various caregiving tasks and activities. Such activities included (a) advocating for the recipient with healthcare providers, services, schools, or agencies; (b) monitoring the severity of the recipient’s condition; (c) communicating with healthcare professionals, such as doctors, nurses, or social workers; (d) educating healthcare professionals about inflammatory bowel disease; and, (e) living away from home for more than three weeks to help get the care the care recipient needed.

As with other types of caregiving, IBD caregivers often advocate within health and social care systems for support. More than eight out of ten IBD caregivers are communicating with health care professionals, advocating for the care recipient, and monitoring the severity of his or her condition. Roughly a third (35%) of the caregivers are providing additional education to the formal care provider about IBD and the needs of the care recipient, and more than one in 10 (13%) are living away from home to find care (see Figure 7). This shows the caregivers’ active involvement in decision-making, as well as an increased need for a conversation with the care recipient and members of the healthcare team, to understand their role in the clinical care and future well-being.



CAREGIVER PERSPECTIVE

THE CAREGIVER AS ADVOCATE

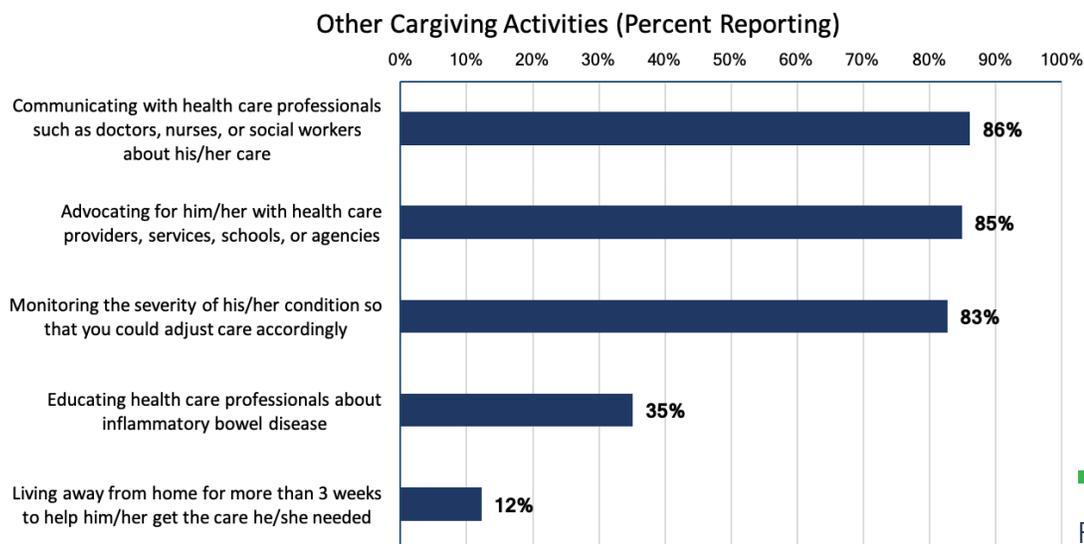
“My biggest hurdle was getting people to understand the seriousness of my daughter’s illness. Many people, including extended family, don’t even know what IBD is or how severe it can be. Those who are familiar with it will cite people who have a mild form or have been able to control it successfully with medication... My daughter had severe Crohn’s. Thirteen medications failed her, including the biologics that worked before her body developed antibodies. Visits to holistic doctors, acupuncturists, nutritionists to help get her disease in remission did not help and were extremely costly...I don’t want my daughter to have a terminal disease, but if she had something that people were familiar with, there’d be fundraisers, assistance, resources. As it stands now, we’re pretty much on our own.”

“Dealing with insurance is the most stressful part of being a caregiver. We should be able to focus on the care and not to have to fight with insurance on a weekly/daily basis.”

“I was very involved for the first six or so years with learning as much as I could about IBD and how I could help my son. It consumed me. And also caused a great deal of stress and some depression. Finally, when he was 17 or 18 years old, I had an epiphany and realized I needed to back off, and that he was an adult and needed to take more responsibility. When I told him this, he said it was what he had been waiting to hear. The weight off my shoulders was immense.”

“Communicating with doctors is the hardest thing about this disease. They are too busy. When we finally connect, it’s less than five minutes. Our pediatrician has also communicated that she is not able to coordinate care for my son like she’d like to. The disease is stressful, but feeling like a bother when talking to a doctor is even more stressful. Open lines of communication are a struggle.”

Figure 7 Other Caregiver Involvement by Prevalence of Endorsement

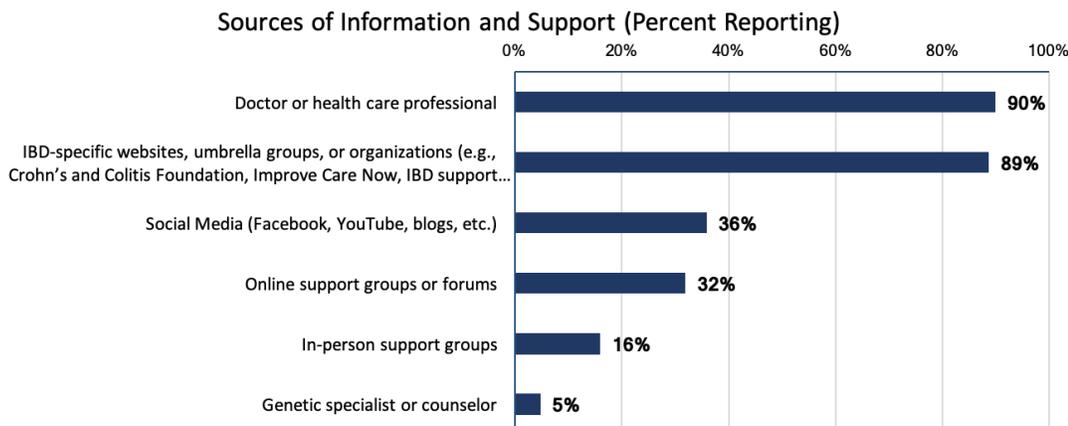


The survey also asked about sources of information and informational support including: (a) IBD-specific websites, umbrella groups, or organizations (such as the Crohn’s & Colitis Foundation, ImproveCareNow or IBD support foundation); (b) doctor or healthcare professionals; (c) genetic specialist or counselor; (d) in-person support groups, online support groups or forums; and, (e) social media such as Facebook, YouTube, or online blogs.

For nine in ten IBD caregivers, doctor or healthcare providers and IBD-specific websites, umbrella groups, or organizations were the first go-to sources of information about how to treat IBD (see Figure 8). In contrast, only about a third of respondents reported using social media and online support groups or forums (32%). Even fewer reported attending in-person support groups or seeking a genetic counselor (5%). These findings indicate that the relationship between formal care providers, such as the primary care physician, and the family are key to improving the IBD caregiver’s understanding of how to support the person with IBD.

For nine in 10 IBD caregivers, doctor or healthcare providers and IBD-specific websites, umbrella groups, or organizations were the first go-to sources of information about how to treat IBD.

Figure 8 Sources of Information by Prevalence of Endorsement



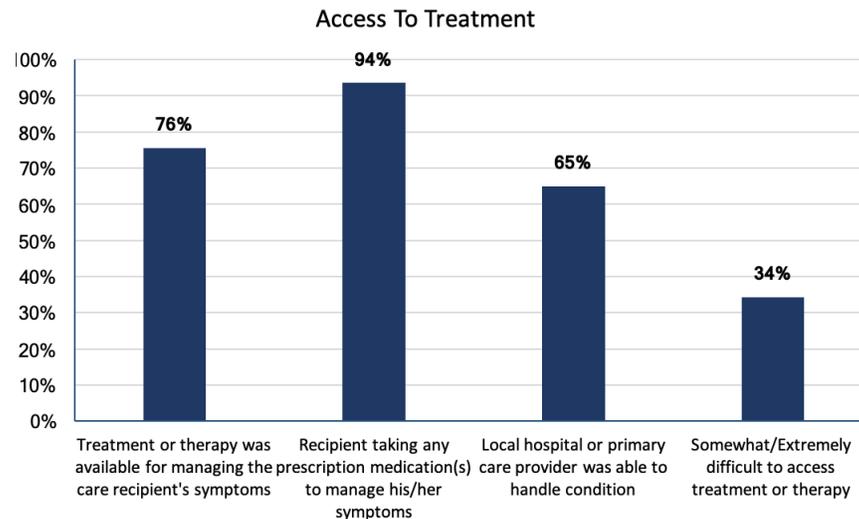
ACCESS TO IBD TREATMENT AND NEEDED SERVICES

The study asked caregivers to report on the availability of treatment, utilization of medications, and success of treatments received. About three-fourths of respondents reported that treatment was available for managing the care recipient's symptoms, with more than 90% reporting their care recipients were taking prescription medications to alleviate symptoms (see Figure 9). Only two-thirds, however, reported that local facilities could handle the recipient's condition.

A final question asked how difficult it was to access treatment services, and about one-third of individuals stating that it was somewhat or extremely difficult to access such services.

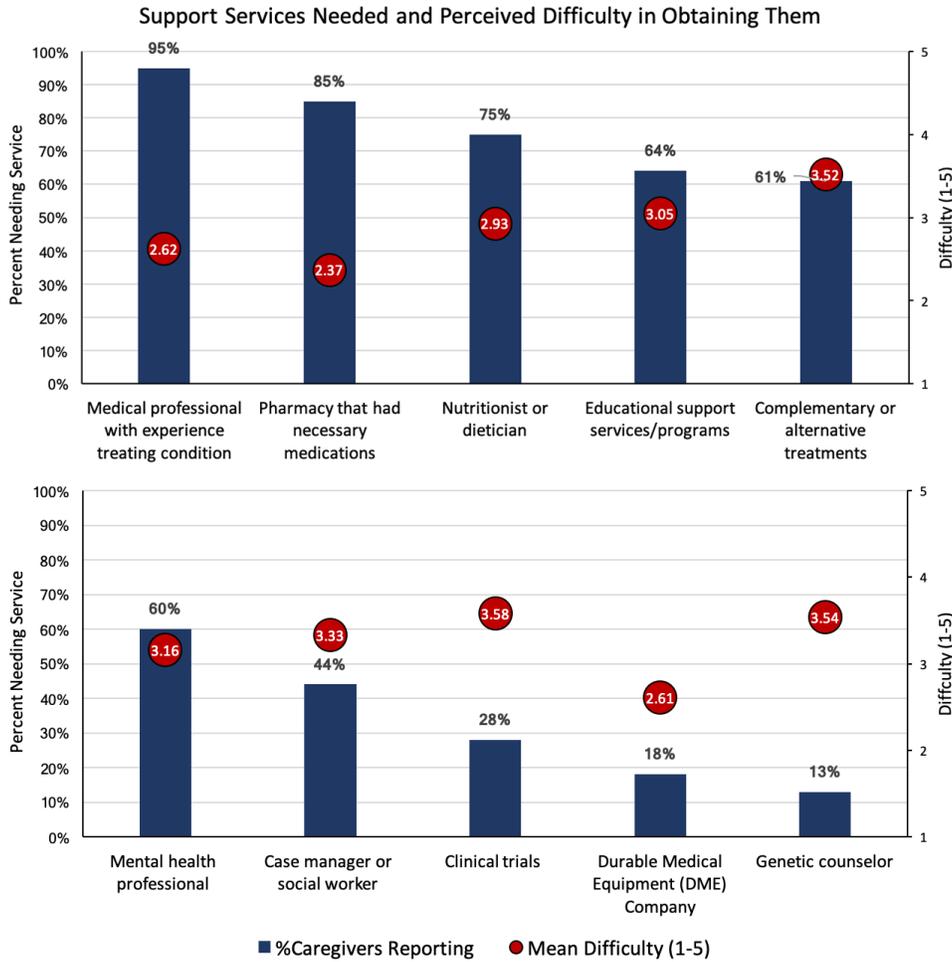
More than three out of four caregivers reported needing experienced medical providers, pharmacies with the necessary medications, and access to a nutritionist or dietitian.

Figure 9 Access to Treatment



A parallel set of questions asked caregivers about the type of services their care recipient needed, even if they were unable to locate this kind of help. Such services ranged from medical providers with experience to nutritionists, case workers, and clinical trials, among others. More than three out of four caregivers reported needing experienced medical providers, pharmacies with the necessary medications, and access to a nutritionist or dietitian. Around two-thirds of participants reported needing access to educational support services, complimentary or alternative treatments, and mental health professionals. Although reported less frequently, access to clinical trials and genetic counselors was rated as most difficult to obtain (see Figure 10).

Figure 10 Needed Support Services by Prevalence of Endorsement

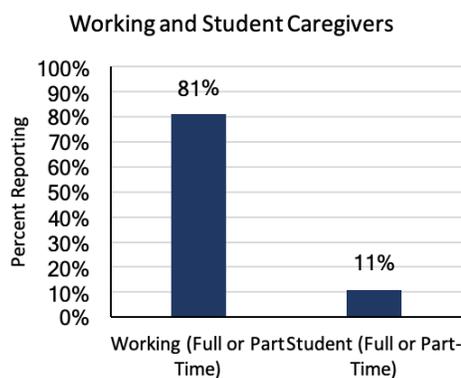


The majority of IBD caregivers reported being employed (more than 8 in 10), and roughly one out of every 10 caregivers in this study were attending school.

BALANCING CARE WITH WORK OR SCHOOL

The majority of IBD caregivers reported being employed (more than eight in 10), and roughly one out of every 10 caregivers in this study were attending school (see Figure 11).⁵

Figure 11 Work and School



⁵This likely reflects that the survey excluded non-adult age caregivers, which probably contributed to the low percentage of student caregivers.



CAREGIVER PERSPECTIVE

WHO CARES FOR THE CAREGIVER?

“One of the hardest things is a spouse who is in pain, frustrated and vents, often on the caregiver... [This] is the source of relationship strain, loss of sympathy perhaps, [when you are] feeling sorry for oneself when a partner is the sick one.”

“As a caregiver, I’ve often felt like I’m not supposed to talk about my own struggles... I think the impact of IBD on a family reaches far past the patient.”

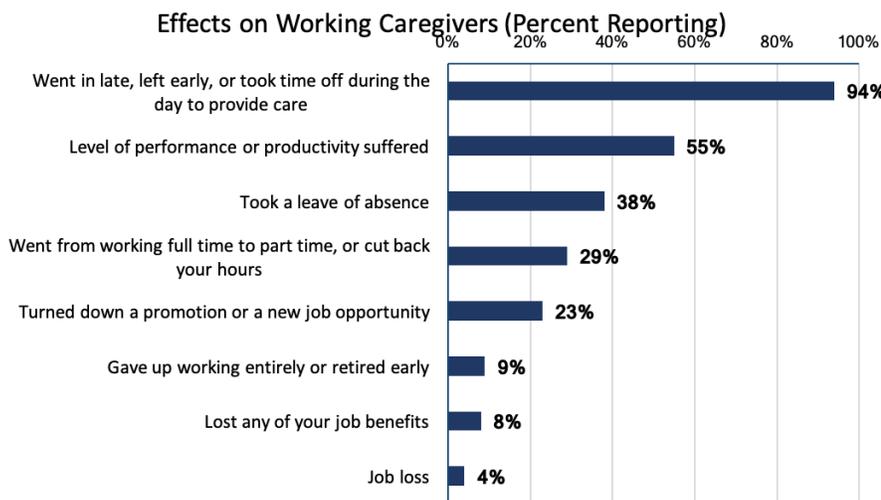
“I wish more people realized the effects of IBD on the whole family unit, and that caregiver burnout is very real. I know IBD is not a terminal illness, but long-term management of a child’s health is exhausting.”

“When I was a caregiver, there really wasn’t much support available. Looking back, I wish I had asked for more help and sought out resources. This was a very difficult time for our family emotionally and financially. We are better suited now to advocate for him now that we’ve gone through the difficult times. And to provide support for others going through the same diagnosis.”

“The sadness of seeing your child suffer, the limitations on their future, the ongoing tests, the endless dealings with insurance and healthcare providers and the disappointment of treatments not working when you have done everything possible in terms of treatment, medication and diet is beyond the ability of any survey to capture.”

Unpaid caregivers who reported being employed (n=559) were asked a series of questions about their experiences in managing work life and caregiving responsibilities. Nearly all unpaid caregivers who worked outside the caregiving relationship (94%) reported missing time at work because of caregiving, and more than half of working caregivers reported declines in their level of performance or productivity (55%). A substantial number of IBD caregivers also reported taking a leave of absence (38%), dropping from full-to part-time or cutting back on work hours (29%), and turning down a promotion (23%). Nearly 10% reported that they either gave up working entirely or lost job benefits (see Figure 12).

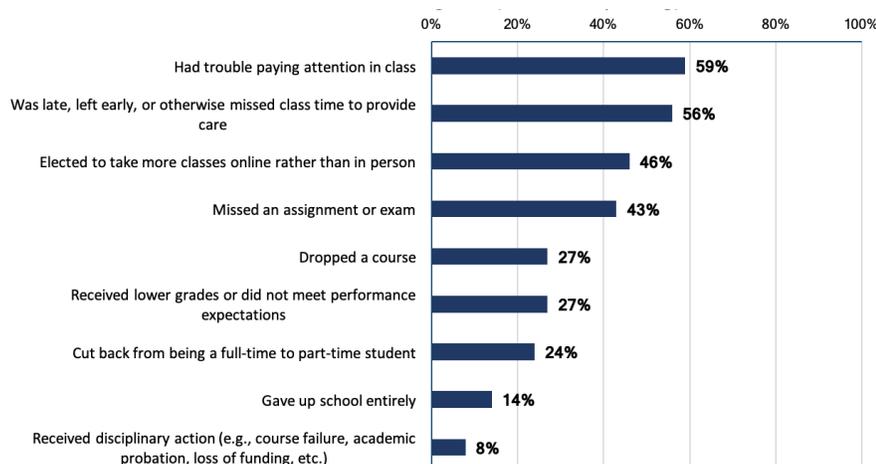
Figure 12 Effects on Work in Order of Prevalence by Reporting



Nearly all unpaid caregivers who worked outside the caregiving relationship (94%) reported missing time at work because of caregiving, and more than half of working caregivers reported declines in their level of performance or productivity (55%).

For those caregivers who were in school (n=75), they also reported difficulty with the balance between school obligations and caregiving responsibilities (Figure 13). More than half missed class time (56%) and nearly six out of 10 (59%) had trouble paying attention in class. Nearly half elected to take classes online or missed an assignment or exam because of caregiving responsibilities. Almost a third of student caregivers reported dropping a course (27%) or not meeting performance expectations (27%), and nearly one in four cut back from full-to part-time student status (24%). Finally, more than one in 10 (14%) student caregivers reported giving up school entirely.

Figure 13 Effects on School in Order of Prevalence of Reporting



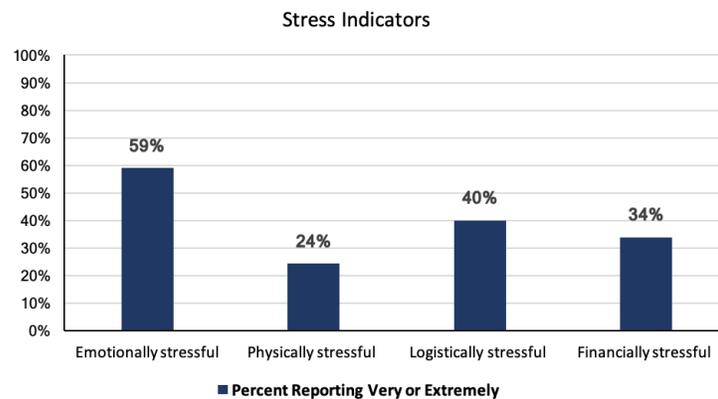
CAREGIVER HEALTH AND WELL-BEING

Given the known effects of caregiving in other disease states, such as caring for a person living with cancer, Alzheimer’s disease, or other chronic conditions, the survey asked a set of questions in several domains relating to caregiver well-being.

The first domain was stress. Caregivers were asked how stressful the experience of providing care was across several types of stress including emotional stress, physical stress, logical stress, and financial stress.⁶ Responses ranged from 1= “not at all stressful” to 5= “extremely stressful.” Figure 14 shows the percentage of caregivers reporting that caregiving was very or extremely stressful (i.e., 4 or 5 points on a 5-point scale) within each stress domain. The results show that a high number of caregivers reported feeling very or extremely stressed within each category, with more than half (59%) of the caregivers reporting significant emotional stress.

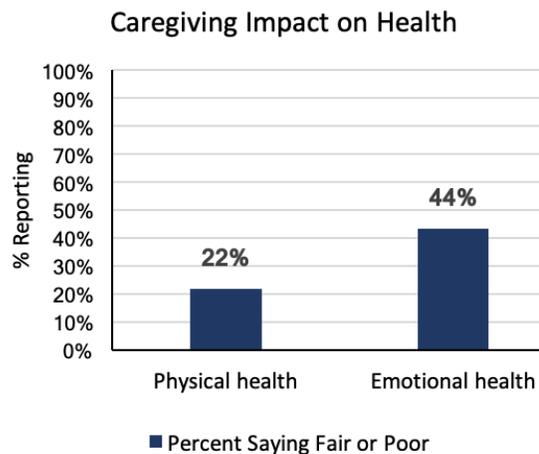
A high number of caregivers reported feeling very or extremely stressed, with nearly two-thirds (59%) of the caregivers reporting significant emotional stress.

Figure 14 Stress Domains



Two questions assessed self-reporting of physical health and emotional health during the time “when caregivers were last providing care.” Responses could range from excellent to poor on a 5-point scale. More than 1 in 5 reported poor (5) or fair (4) physical health (see Figure 15). Twice as many said their emotional health was fair or poor when last providing care.

Figure 15 Self-Report of Health

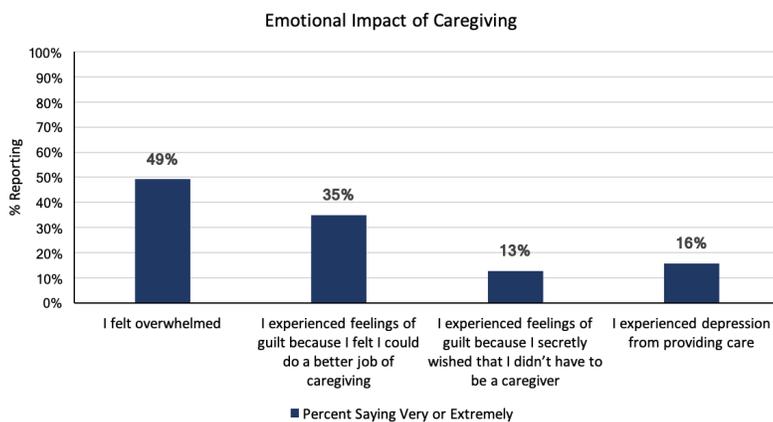


⁶The question read “How [emotionally, physically, logistically, financially] stressful would you say that providing care has been for you?”

In addition to physical health, several questions addressed the emotional impact of caregiving, including feeling overwhelmed, guilt,⁷ and depression. Responses to these items could range from 1 = “not at all” to 5 = “extremely,” and Figure 16 below shows the number of individuals saying very or extremely.

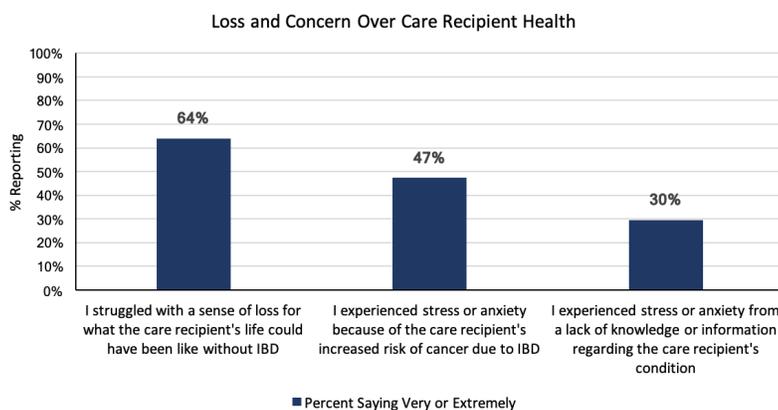
Consistent with reports of feeling fatigued, nearly half (49%) of IBD caregivers reported feeling very or extremely overwhelmed. Regarding feelings of guilt, nearly three times as many caregivers reported experiencing guilt over not doing a better job at caregiving (35%) in contrast to those who felt challenged to provide care because they wished they did not have to be a caregiver (13%). About one-sixth of participants reported feeling depression from providing care.

Figure 16 Emotional Impacts



One aspect of emotional health that is often addressed is the impact of grief or loss on the caregivers. Several questions addressed the extent to which caregivers struggled with a sense of loss for what the care recipient’s life could have been like without IBD; with stress or anxiety because of the care recipient’s increased risk of cancer due to IBD; and, with stress or anxiety from a lack of knowledge or information regarding the care recipient’s condition. Using similar 5-point scales as above, Figure 17 shows that nearly two-thirds of caregivers reported a very or extreme sense of loss over what the recipient’s life could have been like without IBD. Fewer, but still a substantial number, reported very or extreme levels of anxiety over cancer risk and lack of knowledge about the care recipient’s condition.

Figure 17 Feelings of Loss and Concern



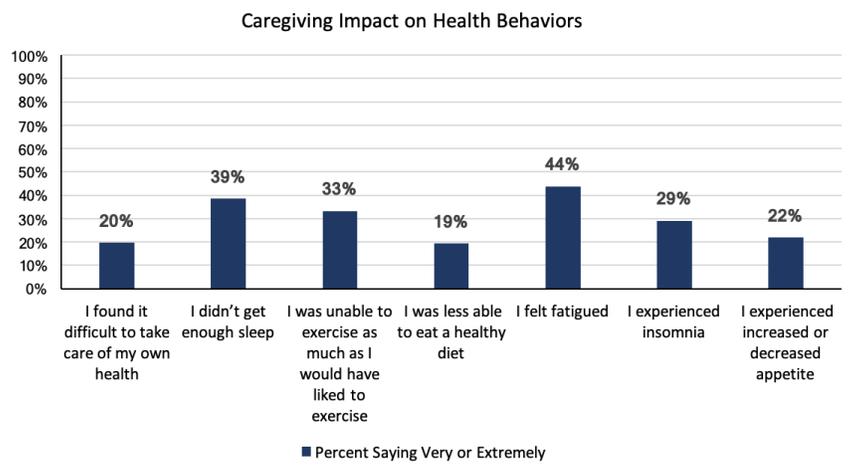
More than a third of IBD caregivers experienced feelings of guilt.

⁷Guilt over wishing I could do a better job and wishing I didn't have to be a caregiver

Only one in five caregivers reported that they were able to get time for themselves when needed.

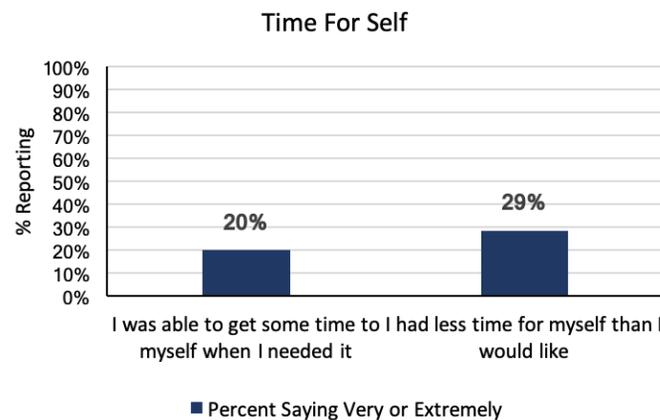
Many IBD caregivers provided additional information on the types of health behaviors and conditions that might contribute to poor health. Specific items asked about taking care of one’s health; getting enough sleep, exercise, or healthy diet and, experiencing fatigue, insomnia, and changes in appetite. Similar to other questions in this section, caregivers provided responses on 5-point scales ranging from 1= “not at all” to 5 = “extremely.” Figure 18 shows almost half (44%) of caregivers experienced fatigue, followed by lack of sleep (39%), and not being able to exercise despite wanting to (33%). Although other health behaviors, such as self-care, insomnia, and changes in appetite, were less severe, nearly one in five caregivers faced these health challenges.

Figure 18 Health Behaviors



Two questions addressed the time for self-care: a) getting time for oneself when needed; and, b) the lack of time for oneself. Only one in five caregivers reported that they were able to get time for themselves when needed. By contrast, 29% reported having less time for themselves than they would like.

Figure 19 Time for Self



POSITIVE IMPACT OF CAREGIVING

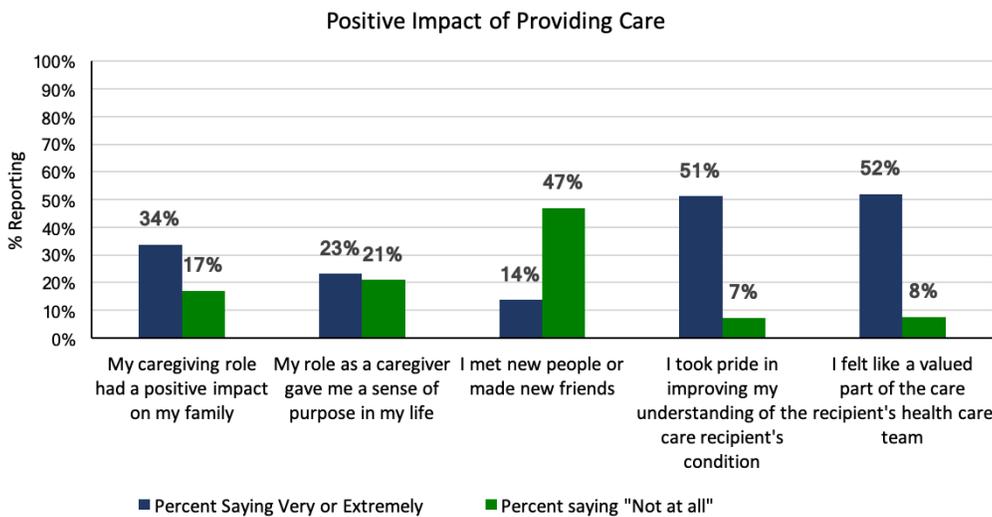
Five questions assessed the extent to which aspects of caregiving had a positive impact on the caregiver's life. These reflected on the impact on family, sense of purpose, meeting new people, taking pride in understanding the care recipient's condition, and feeling of being a valued member of the care recipient's healthcare team.

As Figure 20 shows, more than half of IBD caregivers took pride in understanding the care recipient's condition and feeling part of the healthcare team. To assess the extent to which caregivers received no benefit to providing care, Figure 21 shows the percentage of caregivers reporting the lack of any positive impact in their caregiving role. Most striking almost as many caregivers said their roles as a caregiver gave them no sense of purpose as those that said it very much or extremely did.



Most IBD caregivers took pride in understanding the care recipient's condition and feeling part of the healthcare team.

Figure 20 Positive Impacts



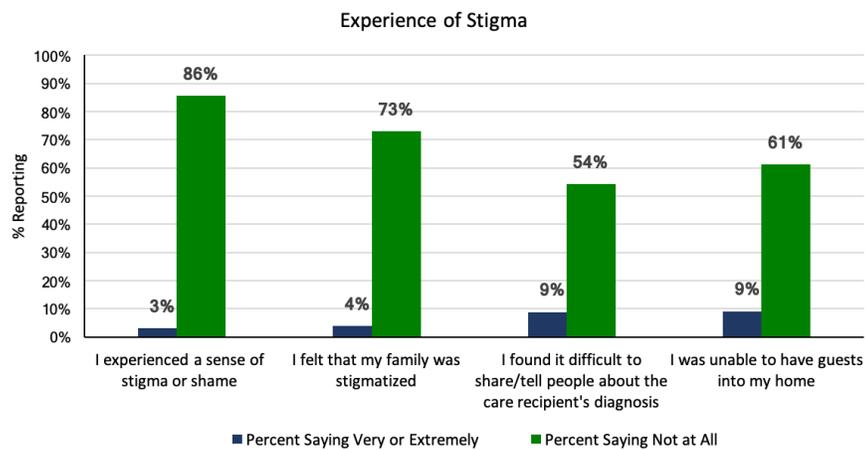


One out of five caregivers were socially isolated, and nearly a quarter felt alone.

STIGMA AND SOCIAL COSTS

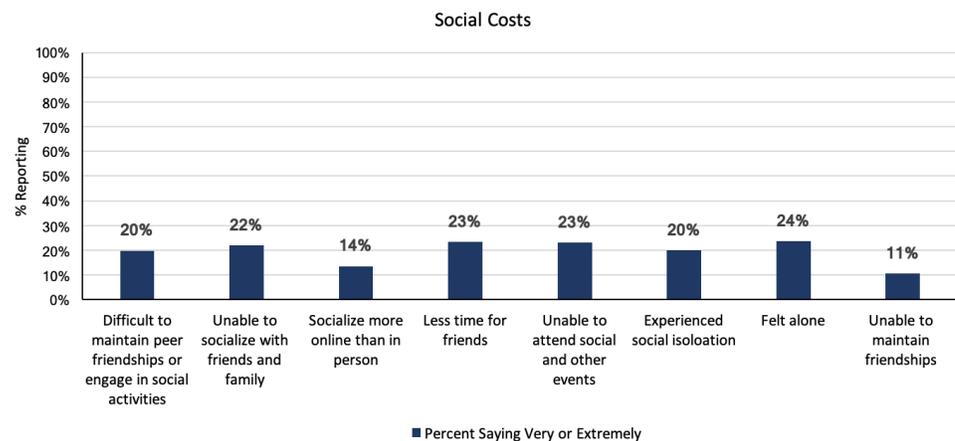
Four questions asked about the stigma resulting from the caregiving role. Specific items assessed stigma resulting from the role, family stigmatization, difficulty talking about the care recipient's condition, and being unable to invite guests into the home. Reports of very or extreme levels of stigmatization were very low. In fact, most IBD caregivers responded not at all to these forms of stigma. Overall, the data point to the minimal to modest experience of stigma in IBD caregiving. (Figure 21)

Figure 21 Experience of Stigma



A series of questions assessed the potential social costs to caregivers of providing care to an individual with IBD. Such costs included difficulty maintaining friendships and engaging in social activities, having less time for friends, experience of social isolation, and feeling alone. Caregivers reported that they were unable to attend social or other events in their daily lives (23%) and that they were unable to spend time with their friends and family (22%).

Figure 22 Social Costs



Two questions assessed the impact of caregiving on the intimate relationships of caregivers. One question asked about the difficulty of maintaining their own intimate relationship with a romantic partner and the second asking about relationship stress and strain. Figure 23 demonstrates that very few caregivers reported very or extreme difficulty in maintaining their own intimate relationships with a romantic partner or experiencing relationship stress.

A final set of questions in this section asked caregivers about their practice of various behaviors associated with reducing stress. Such behaviors included attending local support groups; spending time with friends/family away from the care recipient; participating in religious/spiritual activities; spending time in recreation or doing hobbies, exercising, journaling, meditating; visiting social media sources of support (forums, blogs, Facebook, etc.); breathing exercises or biofeedback to control stress; substance use (alcohol or other drugs); denial or disengagement behaviors; venting or blaming; and, risky behaviors, like gambling or promiscuity. Unlike other questions in this section that used 5-point scales, caregivers responded whether they had engaged in any of these activities.

Figure 24 shows these activities in order of prevalence of reporting. As shown, more than half of caregivers reported spending time away, “respite,” from the care recipient (57%) and exercising (51%) as ways of coping. Other strategies included participating in social media, spending time with hobbies, or participating in religious activities. Venting, substance use, and denial—typically considered maladaptive forms of coping—were relatively rare.

Figure 24 Coping Behaviors

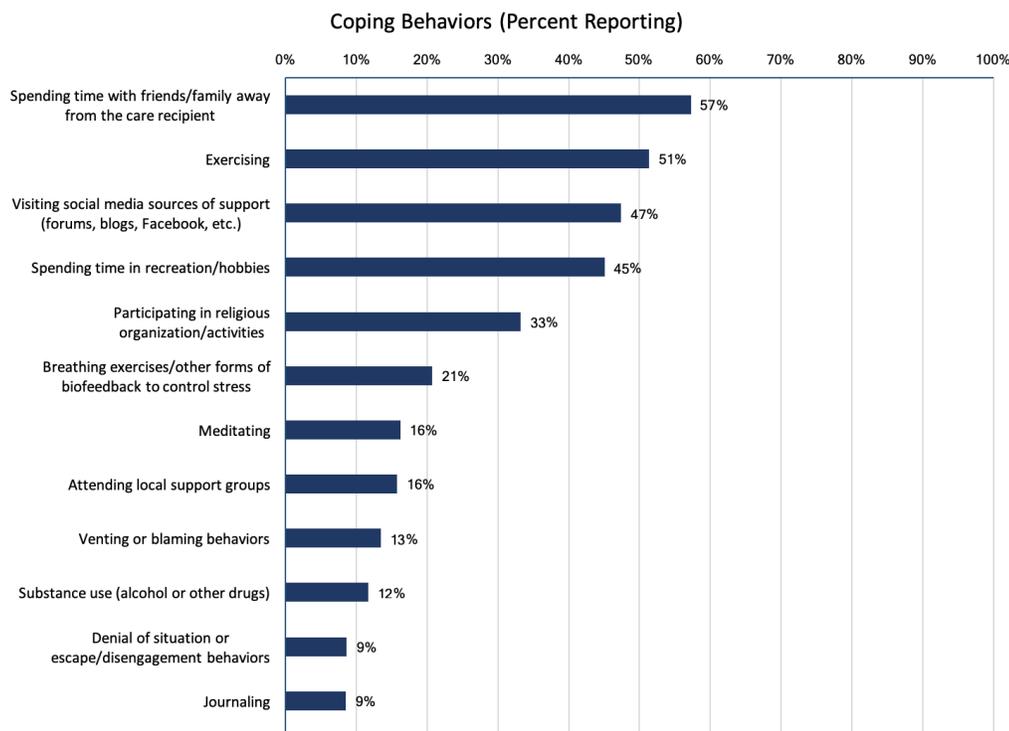
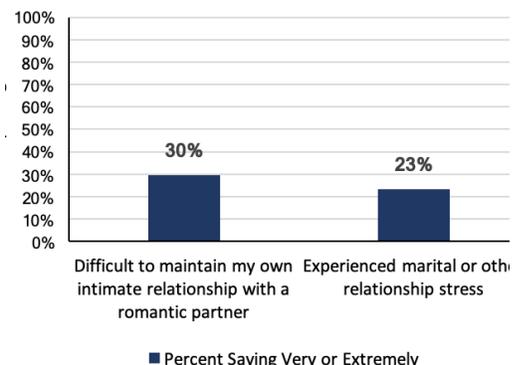


Figure 23 Effects on Relationships
Effect on Caregiver Intimate Relationships



Over half of caregivers reported spending time away, “respite,” from the care recipient (57%) and exercising (51%) as ways of coping.



CAREGIVER PERSPECTIVE

MAKING SENSE OF CAREGIVING

“My house is always a disaster because all my time goes to cooking and transportation to and from appointments. My younger child has not had the benefit of participating in sports or extracurricular activities because I no longer have time to take her to those activities, and instead of having a typical childhood, her young years are being spent visiting her brother in the hospital. I don’t mean to sound bitter about these because I am not, but I have given a lot of thought to how her life is changed as well and it makes me sad for her as well.”

“Resilience and trauma are what make us stronger and give life purpose.”

“It has been a roller coaster ride. Some great wins and also some big disappointments. Parents are less resilient than their child who suffers both physically and emotionally. The disease doesn’t have to define you but it definitely shapes you.”

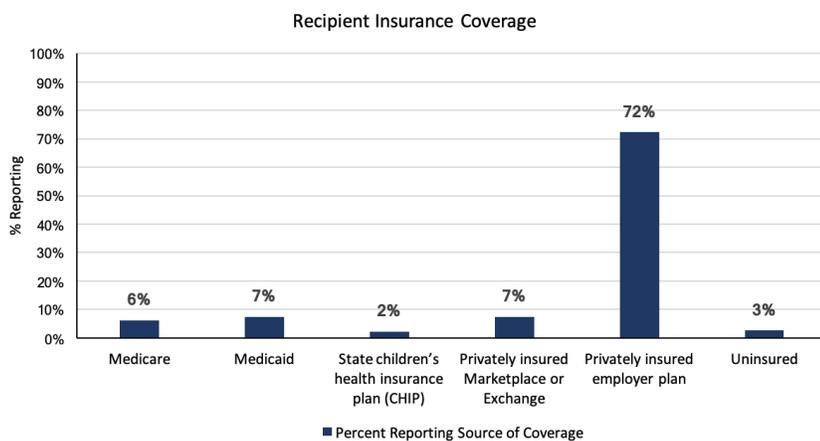
“When a father watches his son suffer for more than 20 years from a disease that has no known cause and no known cure, it takes a toll on the caregiver because he loves him... You feel so helpless and wish that it was you instead of him in pain constantly, everyday, no holiday off, no vacation from it, every frickin’ day of his life.”

INSURANCE COVERAGE

The final section of the survey addressed sources of health insurance for the care recipient and financial impacts of the caregiving situation on the caregiver.

Figure 25 shows that nearly three-quarters of care recipients (72%) were insured through an employer insurance plan. This is consistent with the number of respondents in Figure 11 who reported being employed outside of their caregiving responsibilities. It also suggests that many of the younger care recipients received coverage through parental health insurance plans.

Figure 25 Insurance Coverage



COST OF CARE

A second series of questions assessed the financial consequences of the caregiving situation. Almost two-thirds of caregivers reported cutting down their spending on various items or activities. In addition, more than a third of caregivers reported they stopped saving (36%), took on personal debt (34%), and used up personal savings (34%); more than one in five reported they'd paid bills late (22%).



Almost two-thirds of caregivers reported cutting down their spending on various items or activities. More than a third of caregivers reported they stopped saving.



CAREGIVER PERSPECTIVE

NAVIGATING ACCESS TO CARE

“If we lose Affordable Care Act protections, which is very possible, my husband will not qualify for any private insurance with pre-existing conditions. As is, our financial situation is manageable but the threat of losing that safety net every time Congress addresses healthcare is a huge source of anxiety for me as a caregiver and him as a patient.”

“The frustrations caused by trying to get medication is a huge problem, the delay caused by medical professionals and insurance is maddening. There simply aren’t enough medications available. We need a cure and more clinical trials.”

“As a single mom, taking care of an IBD sick child is extremely stressful. There was no other income for the bills/medications/hospital stays. I was fortunate to have very good health insurance and still had to take on a loan to pay bills.”

“Even having health insurance, it was a hardship as some meds are not covered at all and if they are covered, the copay is higher than usual.”

ANALYSIS OF QUALITATIVE RESPONSES

At the end of the survey a single open-ended question was asked: “Do you have any final comments about this research?” A total of 184 survey participants (25.27% of the total sample that completed the survey) chose to respond to this item. Each participant generated between zero and 12 substantive⁸ comments (averaging 1.92 such comments per participant) for a total of 353 substantive comments. The 184 responses were entered into a database and parsed into individual comments with substantive meaning.

Themes were observed which informed the assignment of categories in an iterative process; the establishment of each new category began the process again from the beginning so that all data could be considered considering all categories. After this process, six categories emerged:

- (1) Recommendations for future inquiry:** Participants offered many suggestions for topics they wished to see included in future iterations of the survey and suggestions of ways for issues to be phrased to best capture their caregiving experience.
- (2) Recommendations for the field—practice, policy, and resources:** Participants described changes in the field they wished to see to address issues they encounter as part of caregiving.
- (3) Emotions experienced:** Participants described emotions they experienced in different phases of caregiving.
- (4) Approaches taken toward the disease:** Participants offered their strategy for caregiving or for dealing with the disease itself.
- (5) Disclosures:** Many participants used this section as a venue to self-disclose their personal experiences with caregiving. Some of these comments were substantive and some were not.
- (6) Miscellaneous comments:** This category was comprised of comments such as expressions of gratitude for conducting the research, wishing the researchers luck, stating that the research is interesting, beseeching the researchers to find a cure, and the like.

Items (1) – (4) were always considered substantive, item (6) was never considered substantive, and item (5) was sometimes considered substantive (for example, if a participant described emotions experienced as part of detailing the account). As such, a comment could be part of two categories—a participant may have relayed a personal account (disclosure) but in doing so, expressed an emotion or described an approach taken to the disease. For this reason, the percent of total comments was not calculated for each category type; the percent of participants that included that comment type was calculated instead.

Recommendations for future inquiry were made by 58 participants (31.52% of respondents). By far, the most common request (21 participants; 11.41%) was to include survey items that specify the specific disease phase that is being studied, as care differs greatly from one disease phase to the next. The sporadic nature of IBD means that caregiving may increase greatly during flares and decrease or even cease altogether during remission. In ranked order, the following list indicates the top issues caregivers would like future surveys to address. Each item was suggested by at least two participants.

Almost two-thirds of caregivers reported cutting down their spending on various items or activities.

⁸Substantive versus Non-Substantive Comments. A substantive comment was defined as a comment that would contribute meaningfully to the reader's understanding of the issues and challenges that caregivers of individuals living with IBD face. For example, the following comments were considered substantive:

“Thank you for addressing this very important issue. I would like to see IBD centers have teams that are much more hands on and accessible and supportive, especially in the first year of diagnosis and for those with severe or complex disease.”

“Dealing with insurance is the most stressful part of being a caregiver. We should be able to focus on the care and not to have to fight with insurance on a weekly/daily basis.”

The following comments were not considered substantive:

“I was a caregiver to a child that became an adult and moved out. Started at 13. Is now almost 26.

My caregiving ways have changed slightly.”

“Kudos, this is an important (and understudied) field of research.”

The first comment proposes a specific recommendation for practice; the second indicates an obstacle to caregiving. In contrast, non-substantive comments do not offer information that contribute to the understanding of caregivers in a meaningful way; one is a factual description of a personal situation—without emotion or counsel—and one is an expression of appreciation for studying this topic.



By far, the most common request (21 participants; 11.41%) was to include survey items that specify the specific disease phase that is being studied, as care differs greatly from one disease phase to the next.

1. Disease phase (e.g., flare, remission, post-surgery)
2. Competing issues (e.g., patient co-morbid disease, caregiver illness, taking care of others such as well children or aging parents)
3. Factors contributing to relationship strain
4. Insurance issues/stress caused by insurance issues
5. Working with schools/teachers and 504 plans
6. Stigma (specifically the feeling that caregivers are not supposed to talk about their struggle)
7. Effects on family such as consequences for well children in household
8. Stage of life of patient (e.g., childhood, adolescence, adulthood)
9. Diet and food preparation
10. Clinical aspects of the disease that affect caregiver stress (e.g., severity, duration, progression)

Recommendations for the field were made by 33 participants (17.93% of respondents).

These included items that caregivers would like to see enacted in practice, changes to policy, and/or resources they would like provided. In ranked order, the following list indicates the top recommendations made by participants; each item was suggested by at least two participants.

1. More resources and assistance for caregivers overall, but specifically including:
 - Resources on how to support and motivate IBD care recipients
 - Resources for intimate couples in which one partner has IBD
 - Caregiver-accessible care teams in IBD centers
2. More support groups, including:
 - Support groups for parent caregivers
 - Support groups for parents of adult children with IBD
 - Support groups for children and teenagers with IBD
3. More information and more research on alternative/non-traditional treatments:
 - Treatments besides medication
 - Holistic medicine to complement Western medicine
4. More information about nutrition and diet:
 - Better nutritional counseling from medical providers
 - Further research on IBD diets
5. More publicity about IBD, including:
 - Publicizing symptoms so that faster diagnoses can be made
 - Publicizing how debilitating the disease can be because current public perception is inaccurate
 - Publicizing effects of the disease on the family unit, such as burnout
6. Financial assistance for middle-class caregivers:
 - State funding
 - Financial aid programs

7. Improved quality of care; specifically:
 - Doctors more attentive/really listen to caregivers
 - Doctors address emotional aspects of the disease
8. Better provision of mental health resources for patients
9. Job placement and coaching for IBD patients who cannot work in a workplace but can work from home



Emotions experienced were indicated by 64 participants (34.78% of respondents). By far, participants described their caregiving experience as “stressful,” “extremely stressful,” or involving “stress” more often than any other emotion (24 participants; 13.04%), followed by “difficult” (16 participants; 8.70%). In ranked order, the following list indicates the top emotions expressed. Each emotion was expressed by at least three participants.

1. stress/ stressful/ extremely stressful
2. difficult/ very difficult
3. strain
4. guilt
5. sad/ very sad
6. worry
7. anxiety
8. frustration
9. depression
10. struggle

Approaches taken toward the disease were described by nine participants (4.89%). Although five participants each offered a separate approach/strategy, four agreed on the approach of teaching children with IBD (particularly children in their late teens) to be self-sufficient and self-manage their disease.

Lastly, 96 caregivers (52.17% of respondents) shared a personal experience (disclosure) and 99 caregivers (53.80% of respondents) offered a *miscellaneous comment* as described earlier.

By far, participants described their caregiving experience as “stressful,” “extremely stressful,” or involving “stress” more often than any other emotion.

Expand research on caregivers of people with IBD and other common autoimmune disorders to better identify the need for support.

POLICY RECOMMENDATIONS AND NEXT STEPS

As in other studies of caregivers, findings in this study demonstrated that IBD caregivers are a partner in supporting health and wellness for the person living with IBD. They provide more than just physical assistance – offering support for care coordination, activities of daily living, medical/nursing tasks, and emotional support. Although the care provided is unpaid, it is not without cost to the caregiver, as many of these volunteer helpers face challenges managing their own health, careers, and well-being.

Given the above findings and the research described within this study, the following recommendations may offer a path for policymakers to better support these families:

- Expand research on caregivers of people with IBD and other common autoimmune disorders to better identify the need for support.
 - Support continued or expanded funding at the Centers for Disease Control and Prevention (CDC) to better understand IBD and its impact on underserved audiences and caregivers.
- Ensure the financial security of caregivers so that families and friends may care for people with IBD without risk of personal impoverishment.
 - Provide support for family caregivers in the workplace, including flexible schedules, opportunities to telework, support or affinity groups, and other resources that can enable caregivers to continue working while meeting their family responsibilities.
 - Expand the reach of programs such as the National Family Caregivers Support Program and others that may offset the cost of caregiving through community-based services for nutrition and transportation.
- Improve the delivery of health care services by providing the IBD caregiver with resources needed to support care and by including the caregiver in shared-decision making.
 - Expand telemedicine and coverage for in-home care – including blood draws, infusions, and similar procedures – to ease travel and other burdens for both the caregiver and person with IBD.
 - Ensure the inclusion of the family caregiver as a vital member of the health care team, and provide training on activities of care to improve outcomes for individuals with IBD.
 - Increase insurance coverage and access to nutritionists for people living with IBD.
 - Ensure coverage in the Medical Nutrition Equity Act for enteral and other medical foods that may be needed for IBD.
 - Ensure family caregivers receive comprehensive training and information to perform their duties of care, including medical tasks, to support individuals living with IBD.
- Support the health and well-being of the caregiver.
 - Increase insurance coverage for the caregiver and expand the use of respite programs to allow caregivers time for self-care, such as sleep or medical appointments.
 - Provide support for mental and behavioral health supports that will strengthen the caregiver's relationship with the person with IBD and reduce the impact of emotional distress.
 - Recognize the role that IBD caregivers provide within care settings and expand research on how to amplify the positive experiences of IBD caregiving through the use of evidence-based interventions for caregivers.

WHY RESEARCH MATTERS: LISTENING, ACKNOWLEDGING, AND RESPECTING THE ROLE OF CAREGIVERS



“Thank you for acknowledging the important role of caregivers. I also do volunteer caregiving for elderly people in my community. I find it very rewarding to help others but it’s also quite stressful to have a child with IBD as well as parents who have increasing health issues.”

“Thank you for asking about us.”

“I thank you for asking these questions because frankly, it is a very stressful situation. I am an RN and our family is financially stable. I grieve for the people who have little emotional support and resources to deal with the needs of a person with autoimmune disease. Thank you for listening.”



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