



talk about it
Cancer and Mental Health



Cancer and Mental Health

New Research to Elevate a Conversation

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Foreword

At BeOne, we believe in the importance of treating cancer holistically – putting patients first and at the center of everything we do. Our core focus is developing innovative medicines designed to improve treatment outcomes and access for patients worldwide. Yet, we also know that access to medicines is not enough. Physical health and emotional wellness are inextricably linked, particularly during the cancer journey. That's why we launched *Talk About It: Cancer and Mental Health* - to elevate the important intersection of mental health and cancer care.

For many cancer patients, due to their immunocompromised status, the impact of the Covid-19 pandemic is not over. Repeatedly, across age, disease type, stage, and organization, we heard mental health concerns emerge as a pressing issue impacting all aspects of cancer patient lives. So we did the work we are here to do; we listened. Our patient-centric focus gave us an opportunity to humbly act on what we heard from, and in collaboration with, the patient, advocacy, psycho-oncology and healthcare communities.

With guidance from an advisory panel of experts in psychosocial oncology, BeOne developed *Talk About It* to help advance enhanced integration of mental health and emotional wellness into quality cancer care through the engagement and mobilization of patients and caregivers, healthcare professionals and policymakers.

Talk About It is informed by research commissioned by BeOne and conducted by the Cancer Support Community (CSC), a nonprofit network of cancer support worldwide, to better understand the mental health concerns of cancer patients and any gaps they face in seeking proper emotional support. The survey findings and recommendations outlined in this report will inform BeOne and partner efforts to reignite the conversation around cancer and mental health. The time to get started is now!

We are honored to be on this important journey to support cancer patients and caregivers. We invite you to join us!

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The isolation, stress and access issues experienced by cancer patients point us to a truth that was already self-evident within the cancer community, which is that mental health care matters. CSC's findings underscore the importance and urgency of this conversation that is amplified in a post-COVID environment.”

– BeOne Leadership



Executive Summary

Cancer is More than the Biology of the Disease

Over the past several decades, research advances have revolutionized cancer care, substantially improving survival and quality of life for patients. As treatment innovation has improved, so has recognition of the significant psychological impact of a cancer diagnosis on patients and their caregivers.

As many as one-quarter of people living with cancer are also living with depression,ⁱ and up to 20 percent live with anxiety.ⁱⁱ Despite the widespread prevalence of mental health concerns, psychological distress in cancer patients can be difficult to identify, as feelings of fear and sadness can be overlooked as “normal” responses to the diagnosis. Further, the physical manifestations of emotional distress – such as fatigue, poor appetite, and irritability – can be misattributed as treatment side effects.ⁱⁱⁱ

COVID-19 Exacerbated Cancer and Mental Health Concerns

COVID-19 continues to impact the mental health of cancer patients. In addition to being at risk of infection due to their immunocompromised status, many studies reported that imposed social distancing, restricted access to physicians, and delays in treatment and follow-up care resulting from the pandemic have significantly increased psychological distress among patients and survivors, including anxiety, depression and fear.^{iv}

Mental Health Care is a Critical Component of Quality Cancer Care

The repercussions of untreated psychological issues in cancer patients can be significant. Studies show growing correlations between mental health concerns and lower survival rates, increased healthcare costs, and poor quality of life.^v We see a clear opportunity to accelerate intervention, which is known to lead to better treatment adherence, fewer calls and emergency-related visits, and prevention of more severe mental health disorders.^{vi}

New Survey:

Mental Health Challenges for Cancer Patients and Survivors

With support from BeOne, CSC conducted an online survey as part of its flagship research study, the [Cancer Experience Registry](#), that evaluated the care experiences of more than 600 U.S. cancer patients and survivors who self-identified as having faced emotional or mental health concerns. Findings illuminated key themes and challenges:^{vii}

Key Insights

- **Emotional Distress is Prevalent Across the Cancer Continuum:** Emotional distress is highest during diagnosis, treatment, and recurrence. But, even those who are in post-treatment or have no current evidence of disease are often impacted.
- **Many Patients and Survivors Are Not Receiving Mental Health Support:** 60 percent of respondents were not referred to a mental health professional by their cancer care team, and two in five who specifically wanted mental health support did not receive it.
- **Significant Barriers to Obtaining Mental Health Care Exist:** Individual viewpoints (i.e., beliefs that emotional distress will resolve on its own, discomfort discussing feelings) and access issues (e.g., financial barriers to treatment and telehealth, long appointment wait times, difficulty getting an appointment) are among the barriers reported.
- **Interventions to Complement Both Medication and Counseling are Desired:** While 58 percent of respondents received care from a mental health professional, and 48 percent were prescribed depression or anxiety medication, many respondents wanted other services and activities to help reduce distress and improve emotional well-being, such as exercise (66%), meditation classes (62%), nutrition programs (61%), and support groups (60%).





A Call to Action: Let's *Talk About It*!

Created for patients and caregivers, healthcare professionals and policymakers, *Talk About It* features innovative empowerment strategies, advances public policy conversations and inspires dynamic health equity initiatives to support people throughout their entire cancer journey. The CSC survey identified key opportunities to engage diverse stakeholders to address the mental health needs of the cancer community.

- **Patients and Caregivers:** Learn to recognize the signs of emotional distress and seek resources to best meet individual needs
- **Healthcare Providers:** Continue to find innovative ways to make mental health a central part of quality cancer care
- **Policymakers:** Remove persistent financial and access barriers to professional mental health services
- **Advocacy Organizations:** Unite, expand and raise awareness of initiatives and programs that promote mental health education and access
- **Healthcare Companies:** Understand and support mental health needs of patients, caregivers, advocates, and healthcare providers

“

The *Talk About It* initiative, along with the findings from the Cancer Support Community survey, comes at a punctual moment in the mental health space – shedding light on an urgent and prevalent crisis in mental health care for cancer patients and survivors. By driving multi-lateral stakeholder discussions and empowering patients and caregivers, we can ensure that the highest quality of care – focused on the whole patient – is being delivered to those along the cancer journey.”

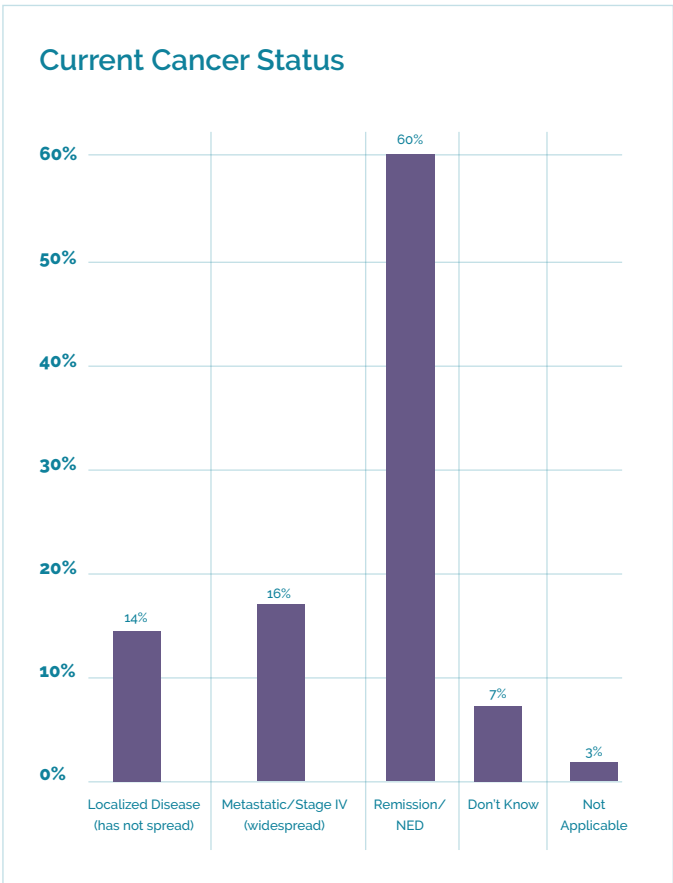
CLICK HERE

To learn more about *Talk About It* or download resources

www.cancerandmentalhealth.com

About the Survey

CSC conducted a cross-sectional observational survey to explore the experiences of care for emotional and mental health concerns among a national-based sample of more than 600 U.S. cancer patients and survivors participating in CSC's Cancer Experience Registry.



“The biggest stressor following my diagnosis was planning for a future I may not have. I felt like I should not plan too far ahead because I didn't know what to expect.”

– Patient

“My emotional problems were after treatment. No one remembered my cancer anniversary or seemed to really celebrate with me when a scan came back good or tried to empathize while I was anxiously waiting for results.”

– Patient

About Cancer Support Community and the Cancer Experience Registry

What? An online study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers

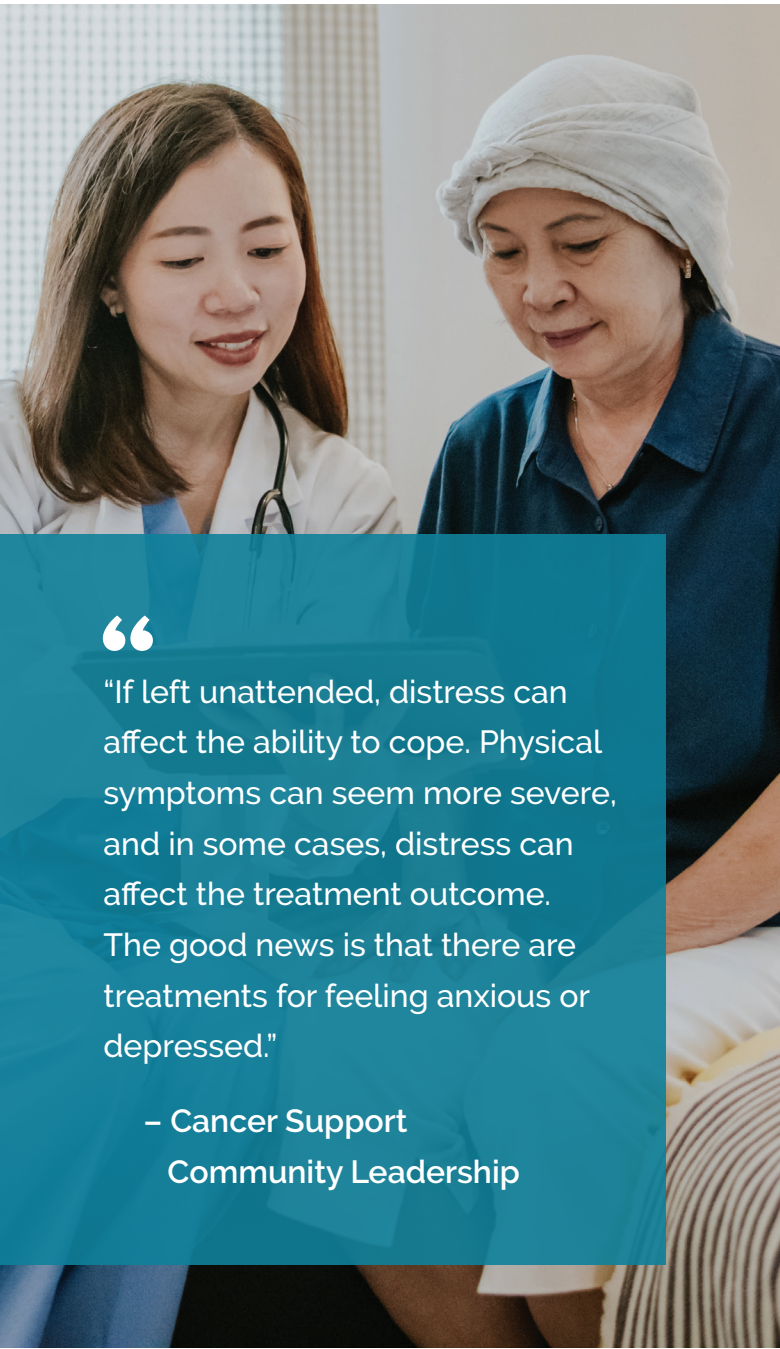
Why? To influence healthcare policies, enhance cancer care, and improve support services for all those impacted by cancer

Who? For patients, survivors, and caregivers aged 18+ impacted by any type of cancer. Learn more at <https://www.cancersupportcommunity.org/registry>.

CSC is a global nonprofit organization that provides free emotional support, navigation, and resources to cancer patients and their loved ones. As part of their mission, they are dedicated to inspiring change that improves the cancer experience by engaging in research that sheds light on the realities of coping with a cancer diagnosis.

Specifically, the study focused on those who self-identify as having experienced an emotional or mental health concern since being diagnosed with cancer. Questions focused on three areas:

- 1. **Emotional and mental health care experiences** among cancer patients and survivors
- 2. **Met and unmet needs** related to mental health concerns
- 3. **Barriers** that stopped, delayed, or discouraged individuals from getting, or continuing with, professional care for a mental health problem

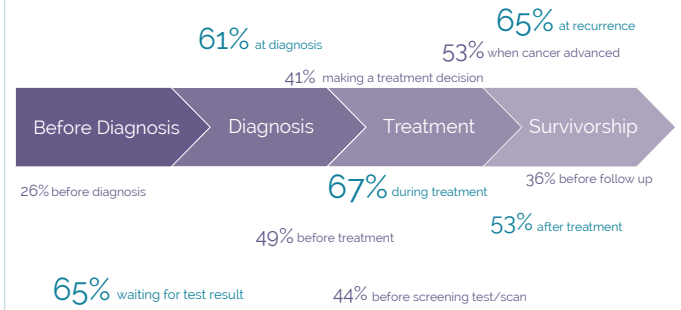


Survey Insights

A Prevalent Challenge for Patients

Whether it is waiting for test results or experiencing a recurrence, there is no denying that emotional distress plays a large role across the cancer continuum.

Concerns Across the Continuum



Among those surveyed, mental health concerns were especially high during treatment (67%), at recurrence (65%), waiting for test results (65%), and at diagnosis (61%). Even those who are post-treatment or have no current evidence of disease often experience some form of emotional distress.

An especially important insight is that pre-existing vulnerability to anxiety or depression is not the only risk factor. In addition to symptom burden and impact, communications with healthcare teams, relationship and intimacy issues, and maintaining a healthy lifestyle are important considerations.

Seeking Care

The good news is that effective treatments exist. However, the CSC survey highlighted that patients who identified as experiencing emotional distress faced challenges in obtaining care.

Two in five patients sought or wanted care but did not receive it, and three in five patients in distress were not referred to a mental health professional by their cancer care team. The survey further explored barriers to accessing care, concluding that mental health and emotional wellness discussions are integral facets of comprehensive cancer care. Previous studies have shown that early intervention and access to mental health tools and resources positively impact the course of and adherence to treatment and improve overall quality of life.^{viii}

“

“If left unattended, distress can affect the ability to cope. Physical symptoms can seem more severe, and in some cases, distress can affect the treatment outcome. The good news is that there are treatments for feeling anxious or depressed.”

– Cancer Support
Community Leadership

60%

of those in distress were **not** referred to a mental health professional by their cancer care team.

40%

who who sought or wanted mental health support did **not** receive it.

Where Do Patients Get Help?

Care engagement is balanced between mental health care specialists, primary care providers, and social workers. Medication rates were reported at 41% for anxiety and 34% for depression. However, one-third of patients taking medication for anxiety or depression indicated they did not receive other professional counseling for emotional or mental health concerns.

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My oncologist is quite caring and looks for ways to encourage and empower me in looking at options when there are physical, emotional, or financial roadblocks. This is most welcome!"

– Patient

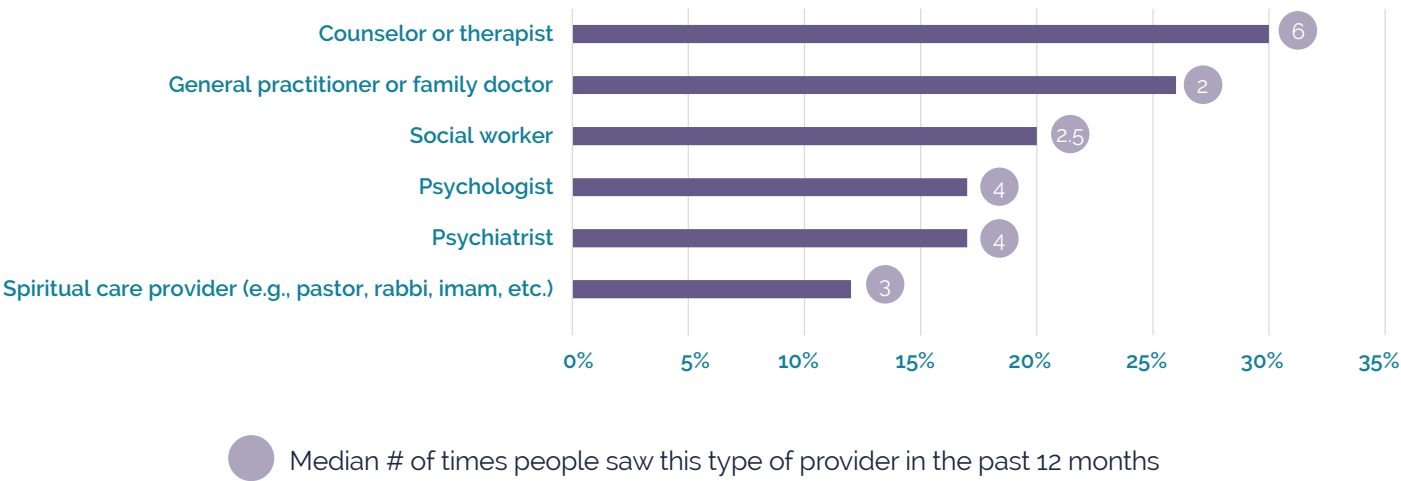
“

My PA [Physician Assistant] is part of my medical oncology team and is just the most caring and empathetic person. She cares about me as a whole person, not just as a cancer patient."

– Patient

Utilization of Care Services

Since being diagnosed with cancer, did you receive care for an emotional or mental health concern from any of the following types of care providers?



n = 652 *Note: This question was "Select all that apply"



“

There is a lack of availability of mental health professionals who deal with cancer or chronic illness because so many people are seeking help since the pandemic. Cost is an issue because some specialists don't take insurance."

– Caregiver

Barriers to Mental Health Care Still Exist

Persistent barriers to mental health care were key survey findings. Unfortunately, and understandably, these obstacles can appear seemingly insurmountable as seen through the eyes of a person experiencing anxiety, depression, fear, and grief. The survey found that individual viewpoints of mental health (i.e., beliefs that emotional distress will resolve on its own, discomfort discussing feelings, fear of appearing “weak”) are common barriers that hold people back from getting support. The top access barriers reported were difficulty getting an appointment, long appointment wait times, and inability to afford mental health services.

A Crisis in Mental Health Care Access

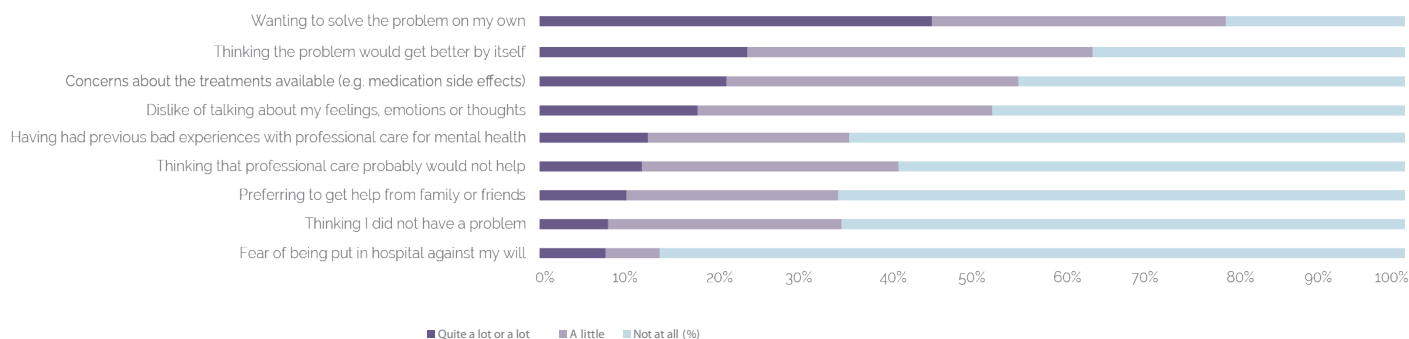
The crisis in mental health care in the United States during and following the devastation caused by the COVID-19 pandemic is well documented. People in the U.S. and around the world experienced heightened levels of stress, disconnection, isolation and depression. It is believed that the impact will be felt for years to come.^{ix}

For cancer patients, this impact is magnified. The CSC survey findings highlighted current health system constraints that prevent individuals with emotional distress from receiving important mental health care services. For example, nearly 30% of survey respondents reported having to pay more for their emotional and mental health care than they could afford, highlighting the additional financial burden placed on patients during a cancer journey. Insufficient insurance coverage/high out-of-pocket costs, shortages of certified mental health professionals and fragmented mental health navigation are pressing issues with public policy implications.

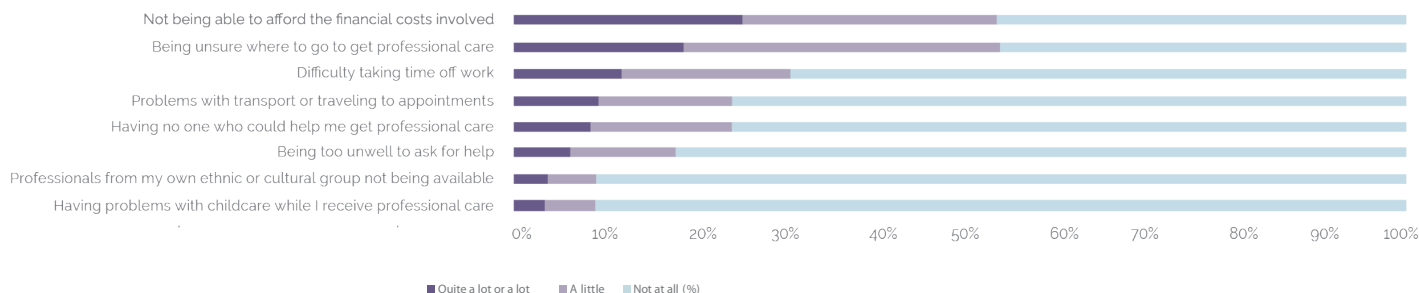
The CSC survey identified barriers to mental health services across three categories:

1. **Attitudinal:** personal viewpoints or beliefs on mental health
2. **Instrumental:** health system constraints
3. **Treatment Stigma:** relating to societal myths or misperceptions

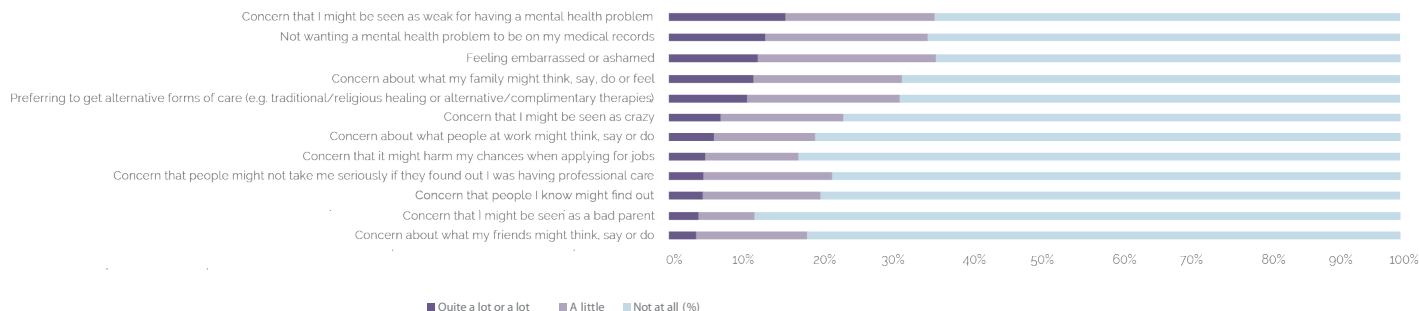
Attitudinal Barriers



Instrumental Barriers



Treatment Stigma Barriers



Information is from Barriers to Access to Care Evaluation (BACE) scale and include citation: Clement, S., Brohan, E., Jeffery, D. et al. Development and psychometric properties the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. *BMC Psychiatry* 12, 36 (2012).

The Importance of Self Care

Another important finding is that patients desire various types of treatment and support for their mental health. Many are looking for other ways to reduce stress in addition to medication and counseling. Fifty-eight percent of respondents received care from a mental health professional. Forty-eight percent of patients were prescribed depression or anxiety medication. Many respondents wanted other services and activities to help reduce distress and improve emotional well-being, such as exercise (66%), meditation (62%), nutrition programs (61%), and support groups (60%).

“

Advocate for yourself! You can get help, but you have to ask and sometimes keep asking for it. There will be ups and downs regardless of mental health treatment, but you don't have to do it alone.”

– Patient

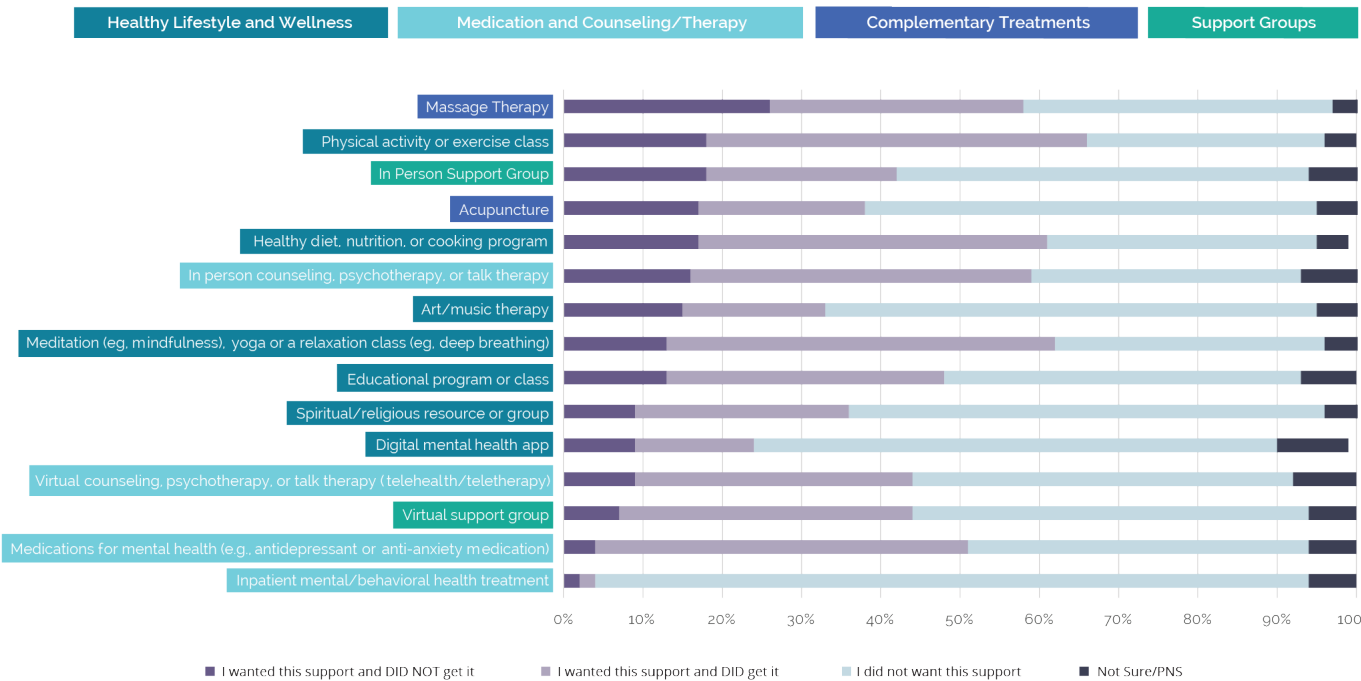
The Significant Mental Health Toll of Cancer Caregiving

Caregivers play a significant role in the cancer patient care continuum. While the CSC survey highlighted the unmet mental health needs of cancer patients and survivors, the lifestyle changes, time demands, financial burden and fear that accompanies cancer diagnoses have a deep emotional impact on caregivers as well. Previous research has shown a correlation between cancer caregiving and the development of anxiety and depression. In fact, studies suggest that cancer caregivers may suffer similar or even higher rates of post-traumatic stress disorder (PTSD) than cancer patients themselves.^x

Who is a caregiver? Caregivers are partners, relatives, and friends who provide assistance (i.e., physical, emotional) to patients with cancer.

Unmet Needs

Unmet Needs, Met Needs, and Non-Needs



Where Do We Go From Here?

As this survey shows, across stakeholders there is an opportunity for the broader cancer, healthcare, and public policy communities to come together in a meaningful and achievable way to improve mental wellness during the cancer journey. Together, we can consider ways to:

Raise Public Awareness

- Increase public awareness and discussion about the intersection of cancer and mental health.
- Complement efforts of other stakeholders to debunk mental health-related stigmas.

Improve Treatment Access

- Integrate mental health and wellness into quality, comprehensive cancer care as well as treatment guidelines for practitioners.
- Advance public policy to ensure all individuals impacted by cancer have equitable and affordable access to mental health support.
- Champion mental health workforce development initiatives.

Support Cancer Care Providers

- Encourage healthcare providers to screen for mental health concerns proactively and routinely during cancer care appointments to identify specific issues and triage patients to tailored care, thus preventing acute mental health crises.
- Empower healthcare providers with information and resources to address their patients' mental health concerns by increasing awareness of and connection to external mental health resources (e.g., local support groups, local mental health professionals).
- Implement collaborative care models to help improve coordination between cancer care and mental health care providers, particularly in hospital settings.
- Refer patients to advocacy organizations like the CSC, CancerCare, and Leukemia and Lymphoma Society which offer direct patient services.

Empower Patients and Caregivers

- Equip patients and caregivers with information and resources that support and encourage meaningful conversations with their healthcare teams and help them to effectively advocate for their needs.
- Foster educational initiatives to address attitudinal barriers (misconceptions about mental health and support for mental health concerns) and inform patients and caregivers of evidence-based support tools available to them.



Conclusion

Beyond Treating Disease

Through our *Talk About It* program, we are collaborating with broader healthcare and policy stakeholders to elevate the important conversation around mental health and cancer and drive solutions with the cancer community.

Thanks to the insights from the survey, we are all one step closer to supporting the needs of those living with cancer. Advocacy organizations like CSC have been engaged in this work for quite some time. We are committed to working with them and other stakeholders to identify and provide solutions that address the holistic needs of patients.



“

By bringing visibility to the importance of mental health and cancer care, *Talk About It* takes an important step toward improving health outcomes for cancer patients by looking at the patient holistically.”

– BeOne Leadership

Word of Thanks

Talk About It activities are guided by an advisory panel of experts in mental health, oncology, patient advocacy, and behavioral science who share BeOne's intention to systemically integrate mental health and wellness into quality cancer care. We would like to thank the panel members for their participation and insights that guided this important work to support the emotional wellness and mental health of those impacted by cancer.

- **Allison J. Applebaum, PhD**, *Associate Attending Psychologist, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center*
- **Elizabeth Archer-Nanda, DNP, APRN**, *Psychiatric Clinical Nurse Specialist, Norton Cancer Center Institute, Behavioral Oncology Program*
- **Terry Evans**, *Trained Patient Advocate and Cancer Survivor; Director, CLL Society Support and Education Network*
- **Joseph Greer, PhD**, *Co-Director, Cancer Outcomes Research and Education Program, Massachusetts General Hospital Cancer Center*
- **Heather Honoré Goltz, PhD, LCSW, MEd**, *Professor of Social Work and Interim Assistant Department Chair, Department of Criminal Justice and Social Work, University of Houston-Downtown*
- **Nicole Peeke, LCSW, ACHP-SW**, *Licensed Clinical Social Worker; Patients, Partners & Providers Working Together: A Strengths-Based Brain Cancer Program*
- **Alexandra Zaleta, PhD**, *Vice President of Research, Cancer Support Community*

A special thank you to our research partner, the Cancer Support Community, and the work led by Principal Investigator Melissa F. Miller, PhD, MPH, Senior Director of Research

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