

Understanding Cancer in the Mind and the Heart

CU Cancer Center researchers and clinicians are leading the way in treating cancer as a disease that affects mental and emotional well-being alongside physical health.

June 21, 2023 By University of Colorado Cancer Center

Cancer, the author Susan Sontag wrote, is “the disease that doesn’t knock before it enters.”

It’s the scary C-word that a large and continually growing body of research demonstrates has effects far beyond its physical symptoms. A cancer diagnosis, especially one made in the later stages of the disease, often impacts a person’s mental and emotional health in ways that can be unexpected and broad-reaching.

“As humans, we are spiritual and emotional as well as physical beings, and that’s how cancer needs to be treated,” says [Stacy Fischer, MD](#), co-leader of the [University of Colorado Cancer Center Cancer Prevention and Control Program](#). “We can have suffering across all those domains of who we are, but it’s not easy to ask about and not easy to address. As cancer treatment has evolved into a more whole-person approach, though, we’ve recognized that mental and emotional distress is a huge problem.”

CU Cancer Center clinicians and researchers are at the forefront of treating cancer holistically and recognizing cancer as a mental and emotional health diagnosis, not just a physical one. Patients receive care from [multidisciplinary teams](#) whose members include mental health specialists and social workers, and researchers are studying groundbreaking mental health interventions for people diagnosed with cancer, particularly late-stage disease.

One such study, led by Fischer and [Jim Grigsby, PhD](#), a professor of psychology at CU Denver, along with researchers at New York University, is researching the use of psilocybin-assisted psychotherapy in advanced cancer. The study, anticipated to open by June, is being closely followed by scientists and members of the public alike for its innovative approach to addressing the depression and anxiety that people with late-stage cancer can feel.

“We’ve made incredible advances in cancer therapeutics, so that people who receive a cancer diagnosis are living longer and physically healthier lives,” says CU Cancer Center member [Joanna Arch, PhD](#), a professor of psychology and neuroscience at CU Boulder. “We’ve been hearing more and more from patients and practitioners that patients with advanced cancer are in dramatic need

of supportive mental and emotional health care services at a level we simply hadn't imagined before."

"Working with a sense of urgency"

In the 1950s, building on centuries of observed distress following or related to the symptoms and side effects of cancer, clinicians began approaching the mental health impacts of the disease as a serious and urgent area of study.

In 1956, New York clinician Arthur Sutherland, MD, [wrote that](#) "the cancer patient must be seen as a person under a special and severe form of stress. ... Such stress may threaten or disrupt important patterns of adaptation which the patient has evolved."

However, even with this early clinical recognition that people diagnosed and/or living with cancer may be experiencing mental and emotional distress, research and treatment are still largely focused on the physical aspects of cancer.

"It's really in the past several decades that we've been working with a sense of urgency to develop psychosocial interventions for people living with cancer," says CU Cancer Center member [Kristin Kilbourn, PhD](#), an associate professor of psychology at CU Denver who is involved in the training of counselors and therapists guiding sessions in the psilocybin-assisted therapy research, as well as a project providing psychosocial support to rural and historically marginalized individuals diagnosed with lung or head and neck cancer. She leads the [Psychosocial Oncology Lab](#) on the CU Denver downtown campus, focusing on research to improve the experience of patients and caregivers across the cancer care trajectory.

"I remember as an undergrad in the '80s, there was this idea of 'mind over matter' that was so prevalent," Kilbourn recalls. "It was this idea that if you didn't think negative thoughts and just focused on visualization to improve your immune system, that somehow it would help you cure your cancer. The other side of it was that if the cancer didn't go away, people felt responsible."

There is growing recognition that even the common language of cancer can have negative consequences for those living with a cancer diagnosis, Fischer says — "this idea that you're 'fighting' cancer, and if cancer causes your death, then you've 'lost the fight.' More and more, we're recognizing that the way we talk about cancer shouldn't blame the person for having it, and that we fight for all kinds of things, not just beating cancer. We fight for quality of life, or for control, or to have things happen on our own terms. And it's not about whether you won or lost."

More than a physiological disease

Such recognition contributes to the expanding body of research demonstrating the many ways in which what has long been considered a physiological disease is also a mental and emotional one. [Data show](#) that about 35% to 40% of all cancer patients have a diagnosable psychiatric disorder,

and rates are higher in those with advanced stages of the disease or who are accessing palliative care. Rates are [not significantly lower](#) among cancer survivors, evidence shows.

“It’s true that the majority of people who receive a cancer diagnosis are not clinically anxious or depressed,” Arch says, “but it’s a large minority who are.”

The mental and emotional impacts of cancer can impact the whole of a person’s life, Arch says, and can include fears that stem from confronting mortality and death, the loss of dreams and expectations, feelings of guilt for “doing this” to loved ones or for leaving them, loss of physical or mental function, anger at the unfairness of the diagnosis and the unrelenting vulnerability it brings, and fear of the unknown.

“Often when we treat anxiety disorders in the community, we help people test whether their beliefs are actually true and how bad their worst-case scenarios could actually be,” Arch says. “But in advanced cancer, people’s worst-case scenarios are often realistic, so we’re looking at how we can take a different approach.”

Arch currently leads two ongoing studies focused on mental and emotional health in advanced cancer. One study, funded by a CU Cancer Center pilot grant, looks at adapting a written exposure therapy originally developed by Denise Sloan, PhD, and Brian Marx, PhD, for post-traumatic stress disorder (PTSD). Arch is studying an adaptation specific to the traumatic stress those with advanced cancer can experience.

“What this written exposure therapy does is ask people with PTSD to write about the most traumatic event across five sessions,” Arch explains. “They write as if it’s a story with a beginning, middle, and end. They write factual details, but also their feelings, thoughts, and beliefs that are occurring during and after the event.

“In advanced cancer, people often are most fearing the future and not what happened in the past,” she continues. “So, in consultation with Dr. Sloan, we are having people identify and write about their worst-case future scenario.”

Arch says the 18 study participants so far enrolled have written about having to say goodbye to their children, about being found unconscious and dying alone, about embarrassing physical symptoms and loss of control, about abandoning beloved pets, and other worst-case fears.

“We ask them to imagine the image or event or situation that’s most haunting them, and have them write for two or three sessions about that event, incorporating their deepest feelings,” Arch explains. “Then we ask them to evaluate whether that worst-case scenario is actually realistic – is that actually going to happen, based on what you know? If it is realistic, we spend several more sessions writing about how to cope with it, and if it’s not realistic, we then ask them to write about what is.”

The intervention is happening via telehealth, so people from across Colorado are able to participate. “It’s different than journaling, because we’re having them identify a specific worst-

case event and write systematically from a very powerful writing prompt,” Arch says. “Then we’re able to coach them and give them feedback between sessions. We don’t have data yet, but anecdotally we’re seeing the effect of people putting their fears on paper and not just having to live with them inside their heads. It’s not an easy treatment because it requires people to name their deepest fears about cancer, but we’re hopeful.”

Leading multi-faceted research

Arch also is leading a larger study, funded by the National Institutes of Health, in which people with stage 4 solid tumors of any cancer type who are experiencing elevated anxiety, distress, or depression symptoms are randomized to receive an online Zoom group intervention. This behavioral approach is based on acceptance and commitment therapy, and one of its aims is to help people “connect with who they are and what’s important to them outside of cancer,” Arch explains.

The sessions are led by trained social workers, which is especially important because it has become increasingly common for people who receive a cancer diagnosis to seek information from unvalidated online sources or to join online support communities that are not moderated by trained professionals, Arch says.

Kilbourn also acknowledges that while the internet has evolved as a vital source of information and support for those living with advanced cancer, it can impact their mental and emotional health as well.

“The internet has certainly made some things more accessible, but now the challenge is how clinicians advise people what to look at and what not to look at,” Kilbourn says. “How do we help people judge whether something is valid or efficacious, especially people dealing with late-stage cancer, where there may not be many treatment options?”

“People may be hearing stories about successful treatments, stories that may not even be accurate, and feeling bad that they’re not responding that well themselves, or they may be participating in these online or social media communities that only talk about the worst-case scenarios without recognizing all of the folks who are thriving after cancer. These types of things can really bias people’s perceptions of their disease, potential treatments, and the side effects. They are creating inaccurate ideas about what ‘should’ be happening.”

The challenges of cancer treatment and cancer survivorship are among the many areas that researchers are studying to better understand. They are working to develop interventions that address the specific types of mental and emotional distress experienced by those with different types of cancer. Some research is even working to understand how mental health can be impacted by physiological factors.

Kilbourn and Grigsby, as well as CU Cancer Center member [Virginia Borges, MD](#), contributed to [research published in November 2022](#) that explored associations between chemotherapy

treatment for breast cancer, disruption in the diversity and community composition of the gut microbiome, and self-reported cognitive impairment, anxiety, and depression. The data gathered in the study were consistent with the hypothesis that the composition of the gut microbiome impacts a woman's experience with breast cancer and treatment, and they suggest that microbiome-based interventions have the potential to improve quality of life outcomes in women receiving treatment for breast cancer.

Giving space to feelings

Kilbourn also is contributing to research on how interventions can address racial and economic disparities associated with the mental and emotional health impacts of a cancer diagnosis, including a stepped-care intervention to reduce disparities in mental health services among rural underserved lung and head and neck cancer patients. [This study](#) is led by [Evelinn Borrayo, PhD](#), associate director of community outreach and engagement in the CU Cancer Center.

"There are so many more targeted therapies that help people to live longer, but that doesn't necessarily make it easier for doctors to predict how much longer," Arch says. "People may be living longer, but with greater uncertainty. They may be many months or years into survivorship, but they may also be thinking, 'Is this going to come back?'"

A significant portion of this ongoing research is benefitted by changing norms in how late-stage cancer is not only studied and treated, but talked about, says Fischer, who also conducts palliative care research. There's a growing awareness of the need to discuss not just the physical symptoms, but the mental and emotional ones.

"One of the things we encourage our fellows and trainees to watch is an excerpt from the movie 'Inside Out' where Bing Bong's rocket gets shoved over the edge at the dump, and Sadness is saying, 'It must be really hard,' and Joy's telling her, 'You're making it worse!'" Fischer says. "It's the idea that we have to give people space to feel what they're feeling, that when you have cancer, what you're feeling in your head and your heart can be just as profound as what you're feeling in the rest of your body."

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