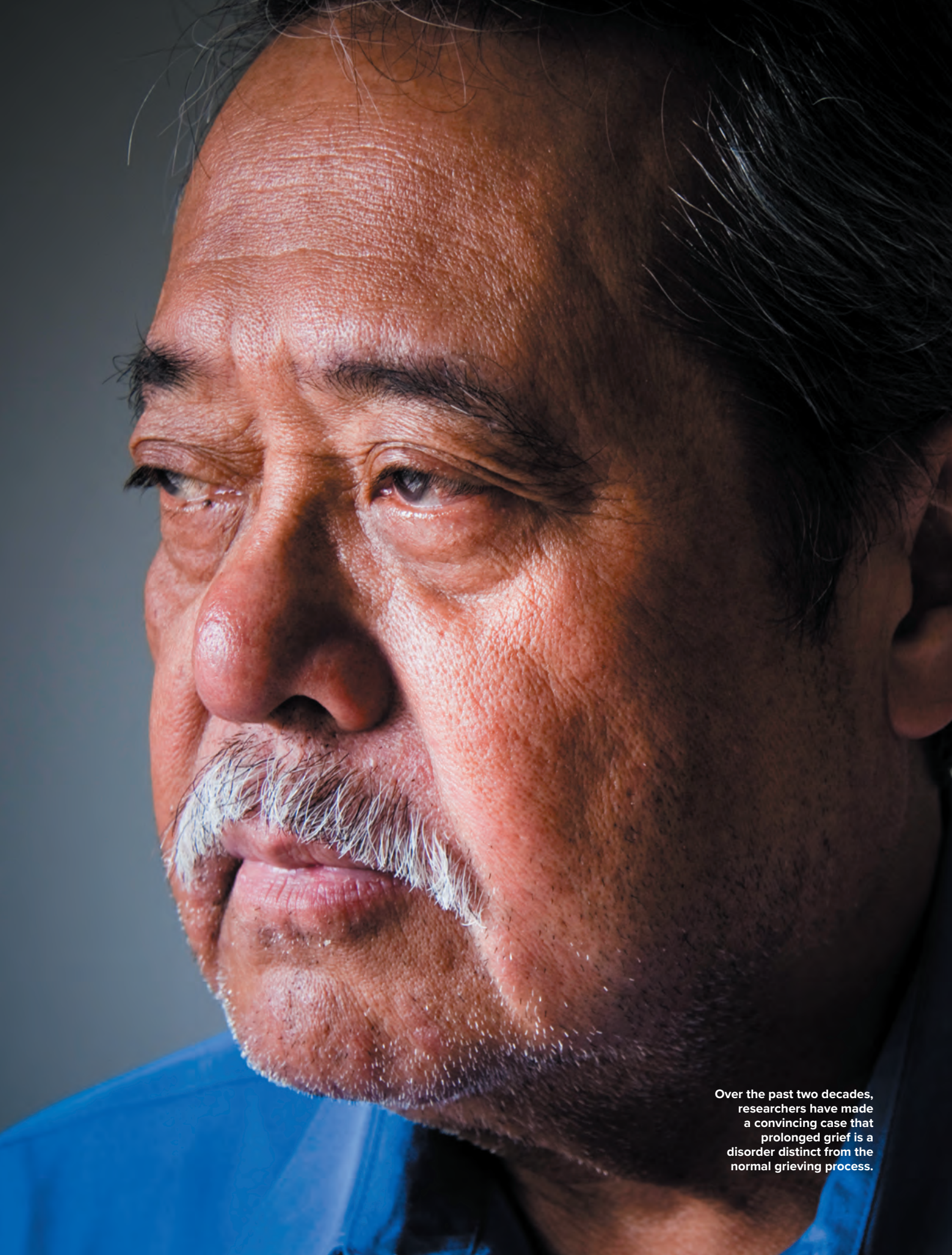




Over the past two decades, researchers have made a convincing case that prolonged grief is a disorder distinct from the normal grieving process.

CE

CONTINUING EDUCATION NEW PATHS FOR PEOPLE WITH PROLONGED GRIEF DISORDER

BY KIRSTEN WEIR

Mourning the death of his wife, the 20th-century writer C.S. Lewis described grief as “a sort of invisible blanket between the world and me.” Anyone who has lost a loved one—that is, virtually everyone who has lived to adulthood—has experienced that fog of grief.

For most people, that blanket lifts with time. But for some, the pain lingers for years.

Distinct from depression, prolonged grief is marked by a pervasive yearning for the deceased. It is most common among people who have lost a child or a romantic partner and is more likely to occur after sudden or violent deaths, such as deaths by homicide, suicide or accident. Evidence suggests that about one in 10 bereaved people develops prolonged grief disorder, according to a meta-analysis by PhD candidate Marie Lundorff, at

Aarhus University in Denmark, and colleagues (*Journal of Affective Disorders*, Vol. 212, No. 1, 2017).

Without treatment, the condition can persist indefinitely, leading to problems such as substance abuse, suicidal thinking, sleep disturbances and impaired immune function, according to a review by M. Katherine Shear, MD, a professor of psychiatry and director of the Center for Complicated Grief at the Columbia University School of Social Work (*The New England Journal of Medicine*, Vol. 372, No. 2, 2015).

Now, researchers and clinicians have a new tool for diagnosing that ongoing grief. The World Health Organization is expected to include prolonged grief disorder in its forthcoming 11th revision of the International Classification of Diseases (ICD-11). The ICD-11 describes prolonged grief disorder as persistent and pervasive longing for, or preoccupation with, the deceased that lasts at least six months after loss. In addition, people with the disorder often experience intense emotional pain (such as sadness, guilt or anger), difficulty accepting the death, emotional numbness, a feeling that part of them has been lost, an inability to experience positive mood and difficulty engaging in social activities.

Although some grief researchers still disagree about how best to characterize persistent grief, research has validated the diagnostic

criteria for prolonged grief disorder, and psychologists and other mental health experts are developing evidence-based treatments to help those whose mourning interferes with the activities of living.

Successful treatment is possible, says Robert Neimeyer, PhD, a professor of psychology at the University of Memphis, director of the Portland Institute for Loss and Transition and editor of the journal *Death Studies*. “There are some very useful, practical things that we can do alongside the bereaved that can make a huge difference in whether or not they remain stuck in an endless grieving, or whether they are able to move forward.”

GRIEF BY ANY OTHER NAME

Over the past two decades, researchers have made a convincing case that prolonged grief is a disorder distinct from the normal grieving process. But there are still disagreements in the field in several areas, such as the diagnostic criteria for the disorder, the point at which normal grieving becomes a disorder and even what to call it.

Two decades ago, Holly Prigerson, PhD, now a professor in geriatrics at Weill Cornell Medicine and co-director of the Weill Cornell Medicine Center for Research on End-of-Life Care, and colleagues demonstrated that bereavement-related depression was different from what

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they called “complicated grief” (*The American Journal of Psychiatry*, Vol. 152, No. 1, 1995). Some researchers still use that name, though “prolonged grief” appears to be emerging as the favored term. In 2009, Prigerson and colleagues proposed a set of criteria for prolonged grief disorder. Those criteria differed somewhat from previous definitions of complicated grief and described the primary experience of yearning, as well as several other symptoms: feeling emotionally numb, stunned or that life is meaningless; experiencing mistrust; bitterness over the loss; difficulty accepting the loss; identity confusion; avoidance of the reality of the loss; and difficulty moving on with life (*PLOS Medicine*, Vol. 6, No. 8, 2009).

Seeking a compromise between definitions of complicated and prolonged grief, the most recent Diagnostic and Statistical Manual of Mental Disorders (DSM-5) created yet another condition: persistent complex bereavement disorder, listed in the appendix as a disorder requiring further study. The diagnosis set 12 months as the threshold after which normal grief may become disordered.

Many researchers take issue with that cutoff point, however. “If you are suffering for one year, by that point the psychopathology is a downward spiral,” says George A. Bonanno, PhD, a professor of psychology at Teachers College of Columbia University who studies loss and trauma. “The point of diagnosis is to capture people earlier on, but the recent DSM is not allowing that.” He and other experts are hopeful that the

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ICD-11’s simplified description of prolonged grief, which sets the threshold at six months after loss, will help the field coalesce around a more functional definition.

REWARDING GRIEF

Despite the untidiness surrounding the clinical diagnosis of persistent grief, those who study it have a lot to agree on.

It’s clear, for instance, that prolonged grief differs from sadness and depression. For people with prolonged grief, emotions often run high. They experience intense longing and a preoccupation with memories of their loved one, Shear says. People with depression, by contrast, typically feel their emotions have been muted. “They do not tend to have longing and yearning for much of anything,” Shear adds.

The differences also show up in the brain. Mary-Frances O’Connor, PhD, at the University of Arizona, and colleagues studied bereaved women with and without what was then known as complicated grief. They found those with complicated grief showed increased activity in the nucleus accumbens, the brain region associated with reward (*Neuroimage*, Vol. 42, No. 2, 2008). “For those with complicated grief, reminders of the deceased still activate neural reward activity, which may interfere with adapting to the loss in the present,” the authors suggest.

People with depression show no such activity in their reward centers, Prigerson adds. “In many respects, prolonged grief is more like an addiction,” she says. “There is a reward that people feel that’s related to wanting to

maintain a connection with someone they love and who made them feel safe and secure.”

There’s another important clue that prolonged grief isn’t just a form of depression: Unlike clinical depression, it doesn’t tend to improve much with antidepressants, Shear adds. Fortunately, she’s developed another treatment approach that can help those who are stuck.

Shear’s complicated grief treatment (CGT) draws from interpersonal therapy and from treatments for post-traumatic stress disorder (PTSD), since, like PTSD, prolonged grief symptoms can include disbelief, intrusive images and avoidance behaviors. Her treatment also targets unique features of prolonged grief, such as yearning for the deceased. The 16-session protocol focuses on seven core themes: understanding grief, managing painful emotions, thinking about the future, strengthening relationships, telling the story of the death, learning to live with reminders and remembering the person who died. Across studies, Shear says, she’s found that about 70 percent of people with prolonged grief improve with the treatment.

In one randomized controlled trial, participants with complicated grief received either interpersonal psychotherapy or CGT for 16 sessions. Both groups showed improvements, but those who received the targeted grief therapy had significant improvement in their symptoms of complicated grief, and responded more quickly, than those who received interpersonal therapy (*JAMA*, Vol. 293, No. 21, 2005).



In a more recent trial of nearly 400 bereaved men and women, Shear found that adding the antidepressant citalopram to CGT did not significantly improve symptoms of prolonged grief, though it did help reduce depressive symptoms in those patients who had co-occurring depression (*JAMA Psychiatry*, Vol. 73, No. 7, 2016).

The treatment includes specific procedures focused on helping people adapt to the loss, Shear says. “You have to accept the reality of the loss, and to be able to envision a future with the possibility for joy, satisfaction, purpose and meaning,” she says. “[With CGT], we’re trying to promote the processes involved in those two goals.”

RE-ENGAGING WITH LIFE

While CGT is effective, researchers say more studies are needed to further understand each component of the treatment. Is it possible

to pull out certain elements of the therapy to create a tool that is still effective but also less expensive and more accessible than the current 16-session protocol?

Some scientists have questioned whether the exposure therapy aspect of CGT is necessary, for instance. Exposure therapy is common in treating PTSD. But revisiting the circumstances of a loved one’s death can be upsetting, both for the patient and for the psychotherapist. Some clinicians might be tempted to skip that difficult step—but research suggests that would be unwise.

Richard Bryant, PhD, at the University of New South Wales in Australia, and colleagues treated people with prolonged grief in a randomized clinical trial with 10 group therapy and four individual therapy sessions. Half of the bereaved participants received grief-focused cognitive-behavioral

People with prolonged grief experience intense longing and a preoccupation with memories of their loved one.

therapy (CBT) that included exposure therapy, while the other half received grief-focused CBT alone. While both groups showed improvement, those who participated in the exposure therapy group had fewer psychological symptoms, better social functioning and better quality of life than those who did not. And despite the belief that exposure therapy can be distressing for patients, the study participants didn’t experience any adverse reactions as a result of treatment (*JAMA Psychiatry*, Vol. 71, No. 12, 2014).

In addition to confronting the loss, clinicians treating patients with prolonged grief should also help them re-engage with life. “A lot of bereaved people need help connecting with others. Even if they want to socialize, they are often stuck and just don’t have the energy to engage,” Prigerson says.

To that end, support groups can be helpful for people with prolonged grief. For example, William E. Piper, PhD, at the University of British Columbia in Canada, and colleagues have developed short-term, research-based group therapy models to treat people with complicated or prolonged grief (“Short-Term Group Therapies for Complicated Grief: Two Research-Based Models,” 2011). But for groups to be most effective, it helps if the bereaved people can truly identify with the other members of the group, Prigerson has found. “Mothers who lost a child to a drunk driver don’t feel like they can identify with a combat vet who lost a buddy,” she says. “One of the main issues with bereavement is social isolation, and there needs



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Psychologists are key to identifying those at risk of prolonged grief.

to be at least that much connection for support groups to work."

Prigerson and her colleagues are also developing an online intervention to help people suffering from the loss of a loved one. The intervention, called Finding Your Way, will offer a screening tool to determine whether visitors meet the criteria for prolonged grief disorder, and will provide web-based tools to help the bereaved work through their grief.

A RESPONSIBILITY TO THE BEREAVED

Prigerson and her colleagues have also developed a tool known as the Bereavement Challenges Scale, which identifies specific thoughts and behaviors that may make adjustment more difficult and pose a risk for prolonged grief (*Journal of Palliative Medicine*, Vol. 21, No. 4, 2018).

Identifying those at risk of prolonged grief is an important next step for the field, Bonanno says. "It's clear there's a group of people who are not recovering [from

grief]. After a certain period of time, you don't need a diagnosis. The person is suffering; it's not such a mystery," he says. The puzzle scientists need to solve, he adds, is how to identify these people, and intervene, early on.

That goal runs into a challenge, however: In the first weeks and months after losing a loved one, grief is a healthy and normal reaction. It's only when it persists that it becomes problematic. "Bereavement is a normal event," Prigerson says. "To start calling bereaved people mentally ill is a really risky thing that you need to handle very delicately."

Indeed, many of those who work with people who are dying or are bereaved are wary of the prolonged grief diagnosis, says Neimeyer, who is also working to develop a checklist of risk factors to identify those at risk of prolonged grief. "If your child dies in a vehicular accident or you come home to find your spouse dead by suicide, many would say that it's entirely normal to have [an extreme

or prolonged] response," he says. "There's a pushback against that diagnosis, which does pose the risk that grief becomes simply the province of specialists, rather than the responsibility of caring communities."

In fact, he adds, most bereavement care is practiced outside the province of psychology and other helping professions. "The great majority of bereavement care is provided by volunteers in hospice settings or people in pastoral care, typically with fewer formal preparations, who undertake this work for humanitarian rather than professional purposes," he says. And while those people provide a valuable service, he adds, there's more that skilled psychologists could add. "We as professionals have largely abdicated our responsibility to the bereaved, and we tend

to ignore or misclassify their suffering," he says.

Psychologists and other trained clinicians, including psychiatrists, counselors and social workers, can play a significant role in helping bereaved people move beyond their suffering. "The good news about bereavement is that although it can leave us brokenhearted, it can also break our hearts open to levels of greater compassion," Neimeyer adds. "And therapists can be in a place to make a great contribution to those positive outcomes."

Working with bereaved people is difficult, Shear acknowledges. "You have to confront death, and it's hard. But when you do it day in and out, you get good at it and see that you can really help people," she says. "For most of us, that trumps everything else." ■

FURTHER READING

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