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Out of the Blue

Depression is often a silent partner to HIV

April 4, 2016 By Mark Leydorf

You'll never forget the day you learn you're HIV positive. The experience of walking out of the clinic in a fog and collapsing into sobs is all too common. For most of us, a period of depression followed our diagnosis, but for a lot of us, depression predates the bad news.

Mary Ann Cohen, MD, a clinical professor of psychiatry at Mount Sinai Hospital in New York and a private practitioner, says HIV incidence is 10 to 20 times higher in people with mental illness. "It's a triad—depression, substance use and violence—that can lead to HIV/AIDS," she says.

Studies have found that people with mental illness are up to five times more likely to get HIV. In a 2009 study of people who'd recently contracted HIV, 85 percent had a history of substance use, and 53 percent had a depressive or bipolar disorder. Other studies suggest that 35 to 40 percent of all people with HIV have had a major depressive disorder, compared with 15 percent of the general population, and that alcohol and drug use are two to five times as common among people with HIV.

Even for those without a history of mental illness, depression often comes after an HIV diagnosis. "People with HIV go through a long period of adjustment," says Paul Bellman, MD, a former board member of GMHC who retired in 2013 after 28 years of treating people with HIV at his Manhattan practice. "There's a lot of variability, but everyone pretty much struggles with it—they do better, then they struggle again."

How do we cope? Below are the stories of three people living with HIV who have found a way to coexist with, and even overcome, their depression.

Chad Taylor does not recall being depressed growing up in Richmond, Virginia; at least he never had a need to see a doctor for it. Regardless, his 1990 HIV diagnosis—he was in the Army, stationed at Fort Benning, Georgia—changed everything. "I felt alone and doomed," he says. Soon he stopped saving money, forgot about finding a career, and became cavalier about sex and drugs.

In 1999, he moved to New York and dove headfirst into the crystal meth scene. He found a bit of relief from his terror and isolation in the "peculiar fraternity" of HIV-positive men having anonymous, drug-fueled sex. He remembers meeting someone who'd survived for 12 years. "I was amazed and inspired by him," he says. "I never imagined I'd be a long-term survivor."

Ultimately, drugs were a flawed solution, leaving him to vacillate between despair and giddiness. Finally, Taylor sought psychiatric treatment. His doctor diagnosed him with bipolar disorder and put him on a mood stabilizer and antidepressant, but they didn't help much.

"The problem was that I was actively using drugs by then, drugs that affect [pleasure chemicals in the brain such as] dopamine and serotonin," Taylor says. His story underscores the importance of being diagnosed properly: If he'd been honest about his substance abuse, his doctor might have come to a different conclusion.

Eventually Taylor did get sober, but it took years of emotional seesawing to settle on the correct treatment, a low dose of Prozac (fluoxetine), which he still takes. But more important to him than medication has been his 12-step recovery program, which taught him to rethink his response to conflict and perceived rejection. "Recovery has given me tools to put those feelings into perspective and frame them in a different way," he says.

Taylor pays a lot of attention to his diet; with his doctor's help, he became a vegan four years ago. He'd like to work out more, but finding time is a challenge. He began teaching three years ago, and his job keeps him very busy. "I poured myself into my work, was outgoing and friendly with my colleagues, doted on my students and formed relationships with their parents."

Now sober for around seven years, Taylor says his work life has eclipsed his social life—but he doesn't mind. "I spend my days interacting with adolescents, which is invigorating." Last year, he was elected Teacher of the Year.

Susan Rodriguez tested positive after her husband was diagnosed with AIDS in 1995. "My three children—Samantha, Christina and Joseph—had to be tested," she says. "It turned out Christina, my middle child born in 1991, was also HIV positive."

Rodriguez, 56, who lives in Upper Manhattan, never suffered from depression in her youth, but the dual HIV diagnoses—and her husband's AIDS-related death a year later—left her reeling. "All I could think about was dying and what would happen to my kids." In 1996, she quit her job as a legal secretary. "It was too much for me," she says. "I just couldn't concentrate anymore. This probably was my darkest hour."

Making matters worse, Rodriguez was diagnosed with breast cancer not long after she started antiretrovirals (ARVs) in 1999. She began chemotherapy that November, immediately after she turned 40—"Happy birthday to me!" she jokes—and between that and her ARVs, she dealt with months of side effects, including losing her hair. Undaunted, she stayed on all of her meds. And it paid off on both counts: She's been cancer-free and has had an undetectable viral load since 2000. Apart from a mini-stroke in 2007, she's been in great health.

Rodriguez saw a series of therapists and took antidepressants for the next several years. In addition to psychotherapy, she says, "What gave me the most control was taking better care of myself. Eating healthy and staying active became part of my treatment regimen, not only for HIV but for me, mentally.” Walking a few miles with her dogs, Ollie and Mork, is central to her sanity. “That’s one of the reasons I have them,” she says. “And they’re fun to be with.”

But like Taylor, Rodriguez says finding support and a passion—hers is activism—turned things around. When she was diagnosed, she picked up a copy of Body Positive, a now-defunct HIV/AIDS magazine, and was inspired by what she read. “It gave me some kind of hope.”

She then saw a woman on the cover of POZ magazine. “It was Michelle Lopez with her daughter,” she says. “I thought, ‘Wow, how could she do that?’ It was a time when I couldn’t tell anybody!” This was around the time she quit her job. “I really had no community.” But the magazines directed her toward one: The PWA Health Group.

In 1998, with help from her new friends, Rodriguez founded SMART: the Sisterhood Mobilized for AIDS/HIV Research & Treatment. “First, we came up with the name ‘SMART’; then we came up with what the acronym would mean,” she laughs. “I don’t know what possessed me!”

She started going to HIV/AIDS conferences. Her life really turned around when she spoke in front of an audience for the first time. Each subsequent speaking opportunity gave her even more confidence. “I would get up to a mic and say, ‘I am living with HIV.’ I didn’t realize what that power was.”

Fairly reserved when talking about herself, Rodriguez explodes when the topic turns to SMART, which celebrates its 18th anniversary this year. “I have the most wonderful team,” she says. Paging through a glossy cookbook the organization produced, she starts talking about its Food for Life project. “This keeps me energized, hopeful and positive about SMART moving forward, beyond HIV.” She adds, “I never thought of SMART as part of my recovery, but I guess it has been.”

Peter Robinson was 11 years old and playing with a cap gun when his friend fired a shot that ricocheted off a Quaker Oats box and hit Peter in the eye. “It was that thing you always hear,” Robinson says. “It’s fun until someone loses an eye.”

Going through life with only one eye hasn’t limited his vision at all. “I’ve been making art—doing something—since I was a kid.” Robinson, a photographer in New York, has always had what he calls “a pioneering spirit,” and began traveling when he was 22. Now 69, he’s been around the world close to 50 times. Working in international trade has meant he’s often traveled to Asia. “When Nixon signed the deal opening China up, I was in Hong Kong waiting for the train,” Robinson remembers. “I was the only black person in all of China, probably, apart from a newspaper reporter.”

In addition to leading the way in his travels, Robinson has been an AIDS pioneer. He spent much of the 1980s in hospitals, volunteering for buddy programs and caring for sick friends before they died. One of those men’s deaths stands out in his memory. “He was so angry,” he says. “I was living, and he knew he was dying.” Robinson learned in 1986 he had the virus. “Finding out I was positive eased my guilt.”

He had been sure his partner, Gary Jacinto, would have the virus, but he himself would not. When it turned out they were both positive, “of course I was shocked,” Robinson says, but he wasn’t the type to get depressed.

Although he’s been HIV positive for more than 30 years, Robinson doesn’t think of himself as a survivor. “Did we really make it?” he asks. “I don’t know. I’m a witness. I’ve seen a lot happen.”

Like many people who came through the plague years, he struggled with post-traumatic stress disorder (PTSD). At his East Village apartment in the 1990s, he’d put up pictures of his friends as they passed away, filling both walls of a long hallway. “It was my way of dealing with the loss,” he says. “I finally realized I had to take down the pictures—they kept me in a constant state of mourning.”

That he might die never occurred to him until the early ’90s, when Kaposi’s sarcoma lesions turned up in his stomach. “It became real when I had to tell my family,” he says. But even this didn’t depress him. It wasn’t until 1995, when his father and his partner were both told they had lymphoma, that Robinson finally experienced a prolonged bout of despair. His father died, and it seemed as if his partner would soon go, too. “Gary and I had buried all our friends, and he wasn’t long for life.”

To cope, Robinson went online—AOL was just becoming a thing—to find a community. “I went out on AOL as Black Man Looking for Friend, BMLKG4FRND.” His openly HIV-positive profile began attracting other positive people. “Some of those people are still friends today.” The chat rooms gave him something to do, a place where he could deal with reality.

Robinson had never actually talked about HIV to anyone. Online he began to come out of his shell. Thankfully, his partner survived lymphoma and a host of other illnesses. Although marriage for same-sex couples wasn’t legally recognized at the time, they tied the knot in 1998. Unfortunately, a different kind of setback lay ahead.

Robinson’s career had evolved to where he was giving international commerce seminars at the World Trade Center. He lost his business when the buildings came down on September 11, 2001. The depression that set in then hasn’t gone away completely, he says. He started going to therapy in 2001 when he closed his company, and stuck with it until 2009.

“The issues I have are so different now. Photography has changed my purpose.” He started taking pictures to document his travels, but later began selling the prints. His work has since been shown at several exhibits and galleries, including Visual AIDS, the Leslie-Lohman Museum of Gay and Lesbian Art and the New York Center for Photographic Art.

This last year has been hard, and Robinson, practical as always, says he’s thinking of reaching out to his old therapist. He fell down last winter pulling another animal off his dog—Clyde is a rescue from Long Island, who, like his owner, has one eye—and rehab from those injuries has taken almost a year.

He still can’t venture far from his studio in Battery Park City. But that’s OK. He wakes up every morning and goes to bed at night looking out a picture window up the Hudson River. “I guess it’s God’s way of telling me, ‘This is what you’ll see.’ I amaze myself with what I see.”

Offering further insight on how to cope with depression, Mary Ann Cohen and Paul Bellman point out that all too often, we ignore our depression, are afraid to mention it or only reveal part of the story—and that doesn’t work.

“The denial aspect is huge,” Bellman says. “If someone doesn’t tell you they’re depressed, it can be pretty hard to know.” With people like Taylor who have substance use problems, it’s usually more obvious they’re depressed. “The two work together in a negative way,” Bellman says.

Cohen believes a combination of therapy and medication is the best treatment for a depressive disorder. “If you look at functional MRIs [brain scans], like 40 percent or 50 percent improvement can be clearly documented whether you give talk therapy or psychiatric medication,” Cohen says. “But if you give both—it’s like 90 percent improvement.” Finding the right therapist is key. “The one thing I can’t overemphasize enough is that if it’s not working—try someone else!” Bellman says.

Bellman and Cohen, who’ve been working with people living with HIV since the beginning of the epidemic, both lament that the number of support groups has dwindled since the ’90s. In this respect, people in recovery from substance use have a unique advantage: the community they find in 12-step groups.

“They’re there because of an addiction issue, but then they get this other benefit,” Bellman says. “I often wonder, ‘What about people who don’t have a 12-step group?’” He also extols the benefits of fitness and exercise. “Do yoga, join a team, get your endorphins going. Find out what works for you.”

Cohen agrees that social and mental engagement, a good diet and exercise, and a spiritual practice can all mitigate depression. She also emphasizes the value in having a job: “Someone who’s continuing to work has a much better prognosis,” she says. “People get so much better when they feel passionate about something.” Bellman concurs: “If a person is just withdrawn, they tend to become homebound,” he says. “And that creates a vicious cycle.”

“A person who’s self-isolating, or has been cut off by their family—and it still happens, even in 2016—has a much harder time overcoming depression,” Cohen adds. “I try to help people create a network. Work is important, and love is important.”