A hard reality:

Some patients will die

BY ALISON KNOPF

Treatment programs often fail to validate their clinicians' legitimate feelings of loss

Patients who go to treatment for substance use disorders are getting help for a chronic, potentially fatal disease. And sometimes, they die—usually after they have been discharged, and all too frequently because they have relapsed. Sometimes the death is caused by another illness, such as HIV/AIDS or cancer. Sometimes they take their own life deliberately. And recently, there has been a tragic trend toward fatal overdose when people return to using opioids after abstinence-based treatment.

How can and should treatment providers respond when a patient dies? Professionals shared their own personal experiences with us for this article, and experts offered advice and words of caution. When a patient dies, the people who treated that patient need to mourn, providers say.

Shirley Beckett Mikell has seen many patient deaths over the course of more than three decades as a treatment provider, mainly in the field of methadone maintenance. She remembers two deaths with particular poignancy: one patient who committed suicide and one who died from hepatitis C.

"There were many, but these were the most traumatic to me," says Mikell, who is a consultant to NAADAC, the Association for Addiction Professionals, where she was the longtime manager of the certification program and the general overseer of professional ethics.

Intense reactions

The patient who committed suicide was "a pillar of society" who did not want his status as a methadone patient to be known publicly, says Mikell. This occurred in South Carolina 10 years ago, in a methadone clinic where Mikell served as the man's counselor. As in many states even today, opioid addiction and treatment with methadone were highly stigmatized.

"We tried to shield him from the community at large," sayst Mikell, a social worker. "But after a year, it became obvious to him that people were going to find out." He had take-home doses, and needed to go to the clinic only once a week to get them, but this was still a challenge.

"When his suicidal thoughts became more complex in the clinical sense, I had a safety plan for him," she says. But what was traumatic was the way that he died, on the same day she had her last session with him. "I believe he ran his car into an 18-wheeler," Mikell says. "They say it was an accident. But I knew the state of mind that he was in. There was an agreement that he would meet his wife and son five minutes from our facility. A psychiatrist and myself had a 45-minute session with him, and had him re-sign his safety contract." The plan was for the patient to transfer to another methadone clinic, so that he would not face as much exposure in his town.

"They labeled his death as an accident to make it easier for his family and for the community at large," says Mikell. Calling it an accident instead of suicide meant there would be no problems with life insurance. It made it easier for the clinic too. "We didn't have to say that one of our opioid-dependent clients committed suicide, or have that as a public pronouncement," she says. Like many methadone clinics, this one already had been subjected to neighborhood opposition to its presence.

"I knew in my heart of hearts the state of mind he was in, and that somehow he maneuvered that accident," says Mikell. For months, she mulled over what she could have done differently. "Should I have kept him there? Should I have insisted to the psychiatrist that he be committed for evaluation? Should I have insisted to the family that they come to the clinic rather than let him drive?"

Ultimately, her supervisor said she had to go into therapy herself to deal with these issues.

The first patient of Mikell's to die was a patient with hepatitis C. "We didn't know back then that it was hepatitis C, because everything was HIV, but when he died, I went to the funeral," she says. Like the other patient, this patient's methadone treatment status was not known to the community. So Mikell asked her supervisor whether she should acknowledge the death in any way—by sending a card, or attending services. Her supervisor told her to call the family and ask.

"The family was so relieved when I called," she says. "They wanted me there, but they were scared to ask."

Mikell, however, was "devastated" by the death, and felt that "if I had known more, he would still have been alive." She had been a counselor in the methadone clinic for less than two years, and this was the first death for the program. Afterwards, it was hard for her to talk to any patient without bursting into tears.

"Every time I saw a sore, or when someone seemed in bad health, I kept wondering if they would die," she says. It took her a year to work through her supervision with a psychiatrist, who told her it was OK for her to talk to her patients about it—other patients in the clinic knew that the man had died. This proved therapeutic, not only for her but for her patients.

"They started to understand that I had concerns for them, that I was empathic, and they started to take better care of themselves," Mikell recalls.

Secondary trauma

"The main issue with patient deaths is secondary trauma to counselors," says Marvin Ventrell, JD, executive director of the National Association of Addiction Treatment Providers (NAATP). "Some treatment centers deal with this better than others." If affected counselors don't get proper care, they won't be able to provide good care themselves, says Ventrell.

In addition, secondary trauma is amplified in the addiction treatment field because of disclosure, which is allowed to a certain extent (unlike the case in much of the mental health world). "The cardinal rule in therapy is it's not about the therapist. Don't tell your client about yourself, that's a breach of the boundary," says Ventrell. "But in addiction treatment, we say that's not true, we can disclose a little bit—such as saying, 'I get it, I'm in recovery too.'"

Ventrell says that solid boundaries in therapeutic relationships do protect the counselor from being emotionally affected by the outcome of treatment. "We aren't our clients' parents—we have to have a professional relationship," he says. "A counselor's health shouldn't depend upon whether the client drinks or uses—once you deliver the medicine, it's the patient's job to use it, and the relationship ends."

However, when a patient dies, that's different. "I'm not going to say, 'If you have a good boundary, it's not going to bother you,'" Ventrell says. "Talk to your peers, to someone in your institution, someone who is trained in the counseling of the counselor."

Acknowledging death

At the Marworth treatment organization, based in Waverly, Pa., patient deaths are acknowledged in staff meetings, says medical director Margaret Jarvis, MD. "The overwhelming majority of deaths have been post-discharge, and there are some that we don't ever hear about," she says. "But we don't keep it a secret."

"Addiction kills people," Jarvis adds. "You get to know someone, they die, and it hurts." The line between normal sadness and "a pathology for the caretaker" isn't that easy to draw. "You need to have people around who can help you," she says.

Even in the medical arena where some specialties regularly face patients with terminal illness, being human is allowed. "Most of the oncologists I know often get close to their patients, and it's not an easy thing to lose patients, whether it's expected or not expected," Jarvis says.

Marworth has what Jarvis calls "rituals" that help staff cope with patient deaths. These focus on "acknowledging it, talking about it, not being afraid to bring it up," she says.

In the last several years, because of the opioid epidemic, deaths have been more and more "present in our day-to-day work," says Jarvis. "Some of this has to do with the fact that the counseling staff who get the young opioid-dependent patients know that these are the patients who are most likely to end up overdosing and dying, and these counselors are the most likely to have burnout as a result," she says. "They might need a break, need different kinds of supervision, need encouragement to make sure they are taking care of themselves."

Expert providers are out there

Some counselors are particularly adept at working with patients at risk of serious health problems, says Shirley Beckett Mikell. Typically, these counselors have been in the profession for a long time, and have had exposure to sickness and death as nurses. But more important, Mikell points out, is "the heart of the individual."

Mikell once volunteered in an HIV clinic in Washington, D.C., and saw these counselors at work. "I cannot tell you how special that person becomes," she says. "They don't have the background of a highly credentialed counselor, but they have the hope for the individual with HIV or AIDS to have a good life today." That counselor comes to work every day bringing that hope, and making patients' lives better, "even if they go to six funerals in a month," she says.

Sometimes a facility will designate a grief counselor to work with counselors when a patient is facing death from AIDS or cancer. Facilities also can send a staff counselor to grief counselor training, so that he/she can be available to facilitate work with other counselors.

Marworth also has moved to try to prevent post-discharge deaths, stepping up its use of medication-assisted treatment with Vivitrol, the extended-release form of naltrexone that prevents opioids from having any effect.

The importance of supervision

Good clinical supervision is key to ensuring that the counselor who is bereaved—because that's what it feels like for many—is able to continue providing treatment. And for addiction counselors who do not have specialized training in mental health, it is essential to bring in a psychologist or psychiatrist to address suicidal thoughts, says Mikell.

It is natural for counselors to wonder what they did wrong after a patient dies, so those internal questions and feelings should not be denied, says Mikell. The clinical supervisor can help. But in today's healthcare settings, the supervisor has to play three roles: manager, administrative supervisor, and clinical supervisor. When you have to manage payroll and other administrative functions in a facility, it's hard to be sensitive to what all the counselors are doing.

The supervisor can say "I'm always available" to the counselors. "But if the counselors know that in five minutes the supervisor may be called into a meeting or have to leave to deal with the cleaning crew, they may not feel they have the freedom to talk about these issues," says Mikell.

What could go wrong if the counselor's issues aren't addressed? A lot, Mikell believes. "That's when they start resisting patients who have severe health issues—they'll distance themselves rather than becoming fully engaged," she says. "They'll protect themselves." This hurts the patient, who may not even know that it's happening.

Some counselors will just leave the field, victims themselves of a lack of care for issues in which their field is supposed to specialize.

Attending a funeral

Counselor and social worker Dinny McClintock, director of adult services at Hope House in Albany, N.Y., says she has lost "numerous" patients to overdose, suicide and cancer. The first time a patient of hers died, the man's mother asked her to attend the funeral—she had found McClintock's business card in her son's wallet.

"This was handled so badly by my co-workers, who didn't acknowledge my emotions," McClintock tells *Addiction Professional*. "For human service workers, we can be very inhumane."

She says her supervisor questioned whether it was appropriate for her to attend the funeral. "It was viewed as if I had too much transference, and not recognizing that we're supposed to form these intimate relationships with people," she says. "I at least needed someone to say,

Dangers of drug-free treatment

Headline after headline reads of young people who have died from opioid overdoses, often after going to multiple rounds of treatment in drug-free programs. At a September briefing with the American Society of Addiction Medicine (ASAM) on new medication-assisted treatment guidelines for opioid use disorders, Don Flattery talked about his 26-year-old son Kevin, who died from an opioid overdose a year ago after many cycles of treatment and relapse.

"Painfully I have learned about evidence-based treatment, and the most significant lesson was about medication-assisted treatment," said Flattery, who is a member of the Virginia Governor's Task Force on Prescription Drug and Heroin Abuse. He tells everyone he can to "avoid abstinence-only facilities, which are only contributing to opioid overdose deaths."

However, "People think they're saving the lives of young people by not letting them have buprenorphine or methadone, and it's the same attitude that's been around since the 1970s," says Shirley Beckett Mikell. "It's the attitude that people can white-knuckle it and come through, and they ask why should we get a young person dependent on medication. But they are already dependent—that's why they went to treatment in the first place."

Marworth medical director Margaret Jarvis says many treatment programs are feeling "helpless" about overdose deaths post-discharge. "These are not places that aren't doing a good job—they are providing what would be considered quality care—but what is missing is the medications," she says.

Another aspect of patient deaths from overdoses is being judgmental. "There's this voyeuristic need to know what the exact circumstances were," says counselor Dinny McClintock. "It doesn't matter. I don't care how he died. The fact is that he's dead and I'll miss him."

Counselors who say that "he did it to himself if it was an overdose" seek to distance themselves from death, she says. "It becomes very shame-based." It also shows a lack of understanding of addiction, she says.

Professionals working in the field need to understand that this is a fatal disease, says Jarvis. "We've always talked about jails, institutions, and deaths, but the number of deaths now are really whacking us upside the head," she says. "To not acknowledge how hard this is, is asking for trouble."

'This must be tough for you.'"

By contrast, last year a former patient who had been out of treatment for a long time but had stayed in touch with McClintock died from an overdose. She didn't feel comfortable going to the funeral, but afterwards, when she heard from the mother, she detected that in fact the family had wanted her to be there.

"Maybe I should have handled it differently," she said. "You can't always do it right."

NAATP's Ventrell believes going to a patient's funeral is not the counselor's role. "I don't know that there's any blanket rule that a therapist could not attend a funeral," he says. "But heart surgeons perform life-saving heart surgery, and sometimes the patients die. They don't go to the funerals."

Ventrell doesn't think counselors should be prohibited from attending, however. "The response needs to be compassionate," he says. "I would advise that you tell the counselor, 'I'm not sure that's the best idea, but clearly this is important to you, you wouldn't be human if this didn't affect you.'" The message needs to be one of support and communication, he says.

At Marworth, because so many patients come from long distances for residential treatment, it may not be feasible for staff to attend funerals, says Jarvis. But frequently, staff members will talk to family members on the phone. In the event that a funeral were local, the staff would be able to go, she says.

"I can't imagine that anybody here would have a problem with the counselor going to the funeral," Jarvis says. "They would just say, 'If it would make you feel better, go ahead.'"

Don't bury feelings

Because of recent increases in opioid overdose deaths across the country, counselors are "feeling a little fried, very tired, and kind of scared for the people we care about," says McClintock. "People are going to die, and even if they don't die from their addiction, they're going to die because that's how life goes."

If patients are told that they need to be able to process loss and grief, isn't that what counselors should do themselves? McClintock describes a past workplace where a pet cat was thrown down a landing. "I had to take the cat to the vet and have him put to sleep," she says. "Even with this cat, nobody was able to process it, nobody was able to say that they missed the cat." For some of the employees, the cat's death was "extremely upsetting," she says. After this, McClintock became overly worried about another pet at the agency, an iguana. "I became almost irrational that this pet has to go, if we can't guarantee an animal's safety," she says.

Clinicians are "too afraid of appearing unprofessional by having feelings," says McClintock. This can hurt their work even in areas not related to deaths. For example, on one occasion McClintock's house was robbed. "I'm thinking I'm going to work with 72 felons. This is grist for the mill, to be explaining to them that you can't just rob somebody's house and not have any effect on them," she recalls. Her supervisor was concerned that this would not be an appropriate thing to say, but trusted her to give it a try. Afterwards, a few patients told her they had never thought of robbery "from the other side," she says. "That's all I wanted—not for me, but for them."

It is important to stay in touch with feelings, even the bad ones. And when someone dies, it's appropriate to be sad, says McClintock.

"Some people are so numb to it all; there have been so many losses," she says. "But you have to take the risk, you have to connect."

The best way for counselors working with a high-risk population to do this is to "have people in your life who are supportive and caring if you have a loss," McClintock says. ■

Alison Knopf is a freelance writer based in New York.