

A New Word in Serious Mental Illness:

Recovery

Field begins to engage in debate with major implications for services

Seventeen men and one woman have come together in a small classroom in a handsomely renovated factory building, the Errera Community Care Center of the Veterans Administration (VA) hospital in West Haven, Conn.

For the next hour, they will hash out some of the questions that arise from the intersection of mental illness and addiction to drugs or alcohol, a crossing that

By Colleen Fitzpatrick has sent their lives at one time or another — maybe now — into a tailspin. The meeting organizer, Moe Armstrong, clad in jeans and suspenders, sits off to one side, readying his laptop to make notes should anyone need them later.

A man named Reggie, mellow but focused, stands before a magnetic white board and, marker in hand, prompts the group:

What is relapse? And: if you know the harmful, injurious consequences of ingesting a drink or drug, and you do it anyway, does that constitute mental illness? And: if this circle drawn on the board represents your life, how much of the pie is taken up by mental illness?

And: should we be looking for that Graceland — to be cured?

The last question elicits fewer responses than the others. Yet it gets to the very heart of why these souls are in this room.

Long before the Academy Award-winning “A Beautiful Mind” painted Hollywood’s gloss on one man’s experience with schizophrenia, utterances of

“recovery” have punched through the hard ground of historical and deeply held beliefs about mental illness, like scattered crocuses over a winter landscape.

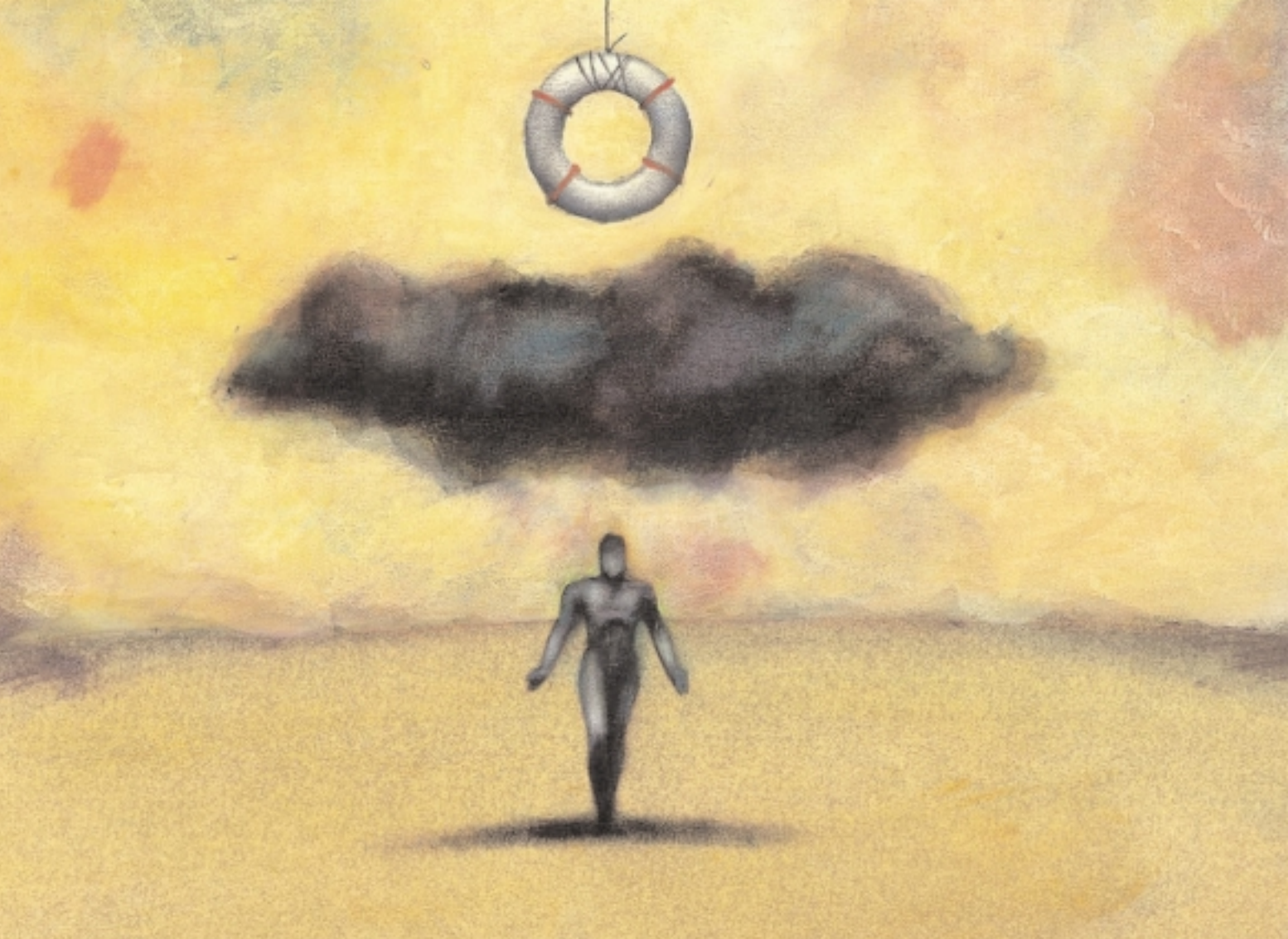
The blooms, though by no means a carpet, are filling in. As mental illnesses become better understood, and new medications are discovered, and consumers of mental health services gain greater traction in the field, discussions increasingly are focusing not on coping with serious mental illness, but on recovering from it.

Enough critical mass has been reached so that Courtenay M. Harding, Ph.D., one pioneer in the United States of recovery research, no longer feels isolated. “Having been a lone voice in the wilderness, I’m glad I’ve lived long enough to see it,” she says of the current discussion about recovery.

Make no mistake: It is a stormy, halting conversation. The question — To what extent can people with serious mental illness recover? — practically invites misunderstanding. What is meant by recovery? What are the expectations surrounding recovery? What is serious mental illness? The answers to these and other questions are all over the board — passionately so.

Yet it is a discussion the field desperately needs to conduct in a more concerted way. The idea of recovery speaks to how mental health systems are structured. It shapes how professionals are trained and it offers options — and hope — to those with mental illness and their families.

“Five years ago, we wouldn’t have used the term ‘recovery,’” says Daniel Fisher, M.D., Ph.D., the most



visible consumer representative to serve on President Bush's new mental health commission.

"We think it's a good step," Fisher says of the word's anchoring in the mental health lexicon. "But it's deceptive. It looks on the surface like everyone's working toward the same goal."

Continuum of views

For simplicity's sake, definitions of recovery might be thought of as stretching along a continuum, with perhaps three discrete stops amid lots of variants.

One stop, the medical model of recovery, roughly holds that serious mental illnesses, once diagnosed, usually require medication to clear up symptoms and often to remain symptom-free. The chances for recovery depend on the diagnosis, the duration of the illness, the illness stage at which treatment begins, and the level of disability.

Another stop, the rehabilitative model, regards mental illness along the lines of a spinal cord injury: Once damaged in such a way, a person will always have had the injury. But by combining pharmacological treatment, skills training and psychological and social support, the person can achieve a life approaching what might have been without the injury.

A third stop, the empowerment model, essentially denies the existence of mental illness as characterized by genetic or brain abnormalities. It maintains that the relatively balanced, connected state that all people are born into can become traumatized during development by overwhelming environmental stresses. Recovery does not refer to specific services, but incorporates peer support, holistic health, empowerment and forming voluntary relationships with people who believe in the mentally ill person's capacity to recover.

In discussing recovery, William A. Anthony, Ph.D., executive director of the Center for Psychiatric Rehabilitation at Boston University (BU), tries to steer clear of the causes of mental illness. He believes that recovery transcends the issue of causation.

"I've stayed away from that because I don't think there are any answers there," he says. "All it really is is a best guess."

Whether its roots are biological, sociological or some combination, Anthony says, mental illness is catastrophic for people. His working definition of recovery is: the development of new meaning and purpose as one grows beyond the catastrophe of mental illness.

For Kathryn Cohan-Haerry, a consumer of mental health services who lives in Rhode Island, recovery means “living well with what you’ve got. ... What constitutes recovery at any moment is tied to duration of effective treatment, good supports and general adult development.”

While at times she still has some “very unusual ideas” and experiences “a flirtation with both edges of the envelope,” Cohan-Haerry says, “I have the hallmarks of a really nice life.” They include a husband, two children, a house, a motorcycle and a good job, as director of consumer education and support with the National Alliance for the Mentally Ill’s (NAMI’s) Center for Education, Research and Practice.

Jeffrey A. Lieberman, M.D., of the University of North Carolina at Chapel Hill (UNC-CH), speaks for many medically trained professionals when he defines recovery as a remission of symptoms and a return to premorbid levels of functioning. Or, he clarifies, at least a level of functioning that allows for living and working independently.

Armstrong, who organizes the Peer Educators Project at the Errera center and many other locations, is director of consumer and family affairs with Vinfen Corp., a mental health services provider in Cambridge, Mass. He prefers to think of “realistic levels of recovery,” whose elements include sanity, stability, sobriety and safety.

The goal, Armstrong says, should be “looking to see how the quality of life is, not the functional assessment. It seems people move in and out of this recovery thing.”

A participant in Armstrong’s meeting in Connecticut offers this definition: “It’s the way you felt when you were five.”

Characteristics of illnesses

Indeed, the notion of recovery incorporates value judgments that stem from experiences, knowledge and training, among other factors. It carries expectations, and it includes the attributes that people give to illnesses.

The medical community, and others as well, say that the chances for recovery depend on the kind of serious mental illness, whether schizophrenia, bipolar disorder, major and recurrent depression or obsessive-compulsive disorder. They also depend on the disorder’s duration and when treatment begins, they say.

Consider schizophrenia, the most chronic and disabling of the severe mental disorders. The brain disorder’s causes are unknown, but they likely involve a genetic vulnerability with behavioral, developmental, environmental and other

factors at play. Its onset typically occurs during adolescence or early adulthood. Symptoms include hallucinations, delusions, disordered thinking and social withdrawal. Up to one in 10 persons with schizophrenia commits suicide.

The nihilistic, historical view held that schizophrenia is a progressively debilitating disease from which there is no recovery. More recently, the American Psychiatric Association’s (APA’s) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV), the field’s most widely used diagnostic book, states that an accurate summary of the long-term outcome is not possible.

It goes on to say: “Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability.”

Lieberman believes that while it is an overstatement to say that schizophrenia is a necessarily progressive illness, treatment theory holds that it is the rare patient who is free of symptoms and functioning well.

Lieberman is vice chairman of the department of psychiatry and director of the Mental Health Clinical Research Center at UNC-CH. He also is principal investigator of the National Institute of Mental Health’s (NIMH’s) CATIE Schizophrenia Trial. CATIE stands for the Clinical Antipsychotic Trials of Intervention Effectiveness project. It involves studying 1,600 patients with schizophrenia who may be changing their medication because of efficacy or tolerability.

It is possible for symptoms to remit, Lieberman says, and early treatment, in the form of antipsychotic medication, is key. Symptom remission rates are as high as 80 percent among patients who take medication within three to five years of the onset of the illness, and before a second episode occurs, Lieberman said. The problem, he says, is that people are not encouraged to remain on medication for extended periods.

If and as the disorder continues untreated, patients become less responsive to medication, he says, acknowledging that this view holds little hope for recovery among people who have lived with schizophrenia for years.

Harding, on the other hand, a colleague of Anthony’s at BU, believes that some people with schizophrenia can be symptom-free without medication. But that’s hard to know for sure, she says, because as a rule the mental health system’s first treatment response is drugs.

Harding directs the BU center's Institute for the Study of Human Resilience. She has taught at several academic institutions, and conducted NIMH-funded longitudinal studies of schizophrenia involving patients at state hospitals in Maine and Vermont.

In Vermont during the 1950s, a hospital director, George Brooks, treated residents with the then-new drug Thorazine (chlorpromazine). Finding that it alone did not enable many patients to leave the hospital successfully, Brooks helped design a psychosocial rehabilitation program to help residents develop social and work skills, cope with daily living and regain confidence. Many patients who had not responded to the drug became well enough to go back to their communities.

During the 1980s, these former residents were tracked down for a University of Vermont study. The researchers found that 62 to 68 percent had significantly improved or recovered. A full 45 percent no longer had signs or symptoms of any mental illness, according to Harding.

Pathways to recovery include having a home, job and friends and becoming integrated in the community. These, in turn, contribute to a sense of hope, relearned optimism and self-sufficiency, she says.

Harding also says that the aging process — when dopamine levels drop and serotonin levels increase, and brain chemicals otherwise recombine — aids in recovery. “Mother Nature’s normal processes happen to be helpful to people with schizophrenia,” she says. “After age 40, Mother Nature is doing all these things to their brain.”

But while Harding declares that recovery is a given and is now recognized as such, Lieberman just as emphatically dismisses the recovery-dovetailing-with-age premise, as well as some of Harding’s statistics and the underlying research.

“All of these notions are just plain inaccurate,” he says. “It sounds harsh to say this because it is dashing any kind of hope people can have for recovering from these sorts of illnesses.”

Consumer perspectives

Hope, and the need for it, is one of the main drivers of the recovery discussion. Its earliest, most vocal and ardent advocates are, not surprisingly, consumers.

Recovery-oriented writings by consumers gained wider circulation during the 1980s, and found an outlet through organizations such as NAMI. These developments paralleled the advent of more effective medications for treating mental

illness, as well as research gains into understanding mental illness.

Consumers, of course, do not speak with a single voice. Fisher and Laurie Ahern, who co-direct the National Empowerment Center (NEC) in Lawrence, Mass., are among those seen as pushing the envelope on recovery and its implications.

Fisher believes that hundreds, if not thousands, of people unknown to or undiagnosed by the research and medical communities have recovered from what society calls schizophrenia.

He deduces that partly from research into alternative medical treatments done by Loren Mosher, M.D., among others. With NIMH funding, Mosher studied over 12 years the virtually drug-free treatment of people with first-break schizophrenia at a San Francisco Bay Area center called Soteria House. The results showed that they achieved the “same level of reduction in global pathology and a lower level of recidivism than in a general hospital using neuroleptic medications,” according to Fisher and Ahern, writing in an article published in the April 2001 issue of the *Journal of Psychosocial Nursing*.

In Fisher’s view, mental illness is a label and “is not primarily based on some biological difference. ... There is no proof of a [genetic] marker that separates out a population” for mental disorders, he says. Rather, mental illness is severe emotional distress combined with the loss of a social role, he says.

In recounting how he transcended the label of schizophrenia that was placed on him, Fisher lists ingredients for recovery: learning how to cope with distress, having somebody who believes in you, and being an accepted part of the community, which means having a valued social role.

One goal, he says, is to prevent a label of mental illness because once that occurs, recovery is doubly difficult. People then must recover both from “their developmental barriers and from the role of a person labeled with mental illness,” and the trauma and stigma associated with the illness, Fisher and Ahern write.

They also refer to a similar drug-free approach espoused by Lars Martensson, M.D., who has called the use of narcoleptics “forced chemical lobotomy.” He considers psychosis a crisis to be overcome, and advocates that hospitalization should be avoided.

Such statements cause the overwhelming majority of mental health professionals to nearly convulse with alarm. It is

the rare professional — and consumer — who would advocate banning medication from the array of tools available to help people with mental illness.

“The last thing we need is a raft of people going off their meds,” says Paul Seifert, director of government affairs with the International Association of Psychosocial Rehabilitation Services (IAPRS).

Seifert cites a study in the 1999 U.S. Surgeon General’s report on mental health that found that more than half of people with schizophrenia were receiving incorrect doses of medication. “This is not good,” he says. “Nor is it good to pull people off their meds. Anyone who says that is toying with life. ... For some, all the peer support in the world is not going to make a difference without medication.”

Many consumers eschew certain aspects of the empowerment model as well. Armstrong believes he has a mental illness; he and Cohan-Haerry believe medication can be a support to recovery.

Message not heard

Though the numbers of people and the pathways may be in dispute, the fact remains that people with mental illness are recovering, says BU’s Anthony. But many in and out of the behavioral health field are having a hard time hearing that message, he adds.

The reasons for that are many.

Harding suggests that among mental health professionals, there is a discrepancy between what the day-to-day case-load feels like and what long-term studies show. Those most closely connected to treatment “are systematically deprived of outcomes,” she says, so many professionals continue regarding mental illness through the historical and pessimistic lens of diminished expectations for recovery.

Skepticism on the part of people outside the experience of mental illness also contributes, says Cohan-Haerry.

“It’s the nature of mental illness for persons with mental illness not to be viewed as expert,” she says. “The experience of mental illness casts aspersions on a person’s judgment and ability, a person’s worth as a contributor.” This is a critical point in how well a consumer-driven movement is received.

Also working against any changes in response to the message are “destructive social forces like prejudice, discrimination and poverty, as well as overzealous cost containment in

public and private insurance coverage,” Harding wrote in a March 10 op-ed article published in *The New York Times*.

“Public dialogue is mostly about people taking their medication, with little said about providing ways to return to productive lives. We promote a self-fulfilling prophecy of a downward course and then throw up our hands and blame the ill person, or the illness itself, as not remediable,” she writes.

There are other systemic obstacles. Recovery implies less dependence on mental health providers and more responsibility on the part of people with mental illness, including possible changes to the social systems aimed at helping them.

At the advent of the 1990s, Anthony began referring to the decade as the “decade of recovery,” rather than the decade of the brain. He has identified several assumptions that a recovery-oriented mental health system needs to build in. They include:

- Recovery can occur without professional intervention.
- A recovery vision is not a function of one’s theory about the causes of mental illness.
- Recovery can occur even though symptoms recur.
- Recovery does not feel like a linear process.
- Recovery from the consequences of illness is sometimes more difficult than recovering from the illness itself.
- Recovery from mental illness does not mean that one was not “really mentally ill.”

Mental health systems, by and large, have barely acknowledged in their programs and services these emerging concepts of recovery.

Nonetheless, Harding for one is thrilled that such a dialogue even exists. “It’s great. It’s finally on the table. It’s very hard to give up a belief system, but people keep showing us this is possible.”

That’s important, she says, because “it certainly changes how clinicians can be trained, what they tell families and patients and how we construct systems of care.”

Because these are such high stakes, adds Cohan-Haerry, “The lions have got to lie down with the lambs on this. We really need to respect what it takes, what is necessary, because people’s lives depend on it. We have an ethical responsibility to people with mental illness, to help them live well. ... It’s a trite phrase, but it does take a village to get people well. I think we’ve got to respect that.” ☺

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