

Provocative alternatives to understanding madness and treatment, based entirely on first-hand experience, are pioneering new ways of thinking, says [Gail A. Hornstein](#)

Psychiatry is the most contested field in medicine; at every point in its 200-year history it has had more fractious debates, a shakier scientific foundation and an angrier patient population than any other specialty. Fundamental questions of the field have yet to be resolved: What causes mental illness? How can it best be described? What treatments work? But physicians have never been the only ones trying to answer such questions. For as long as psychiatry has existed, there has been a rival literature on madness written by people with first-hand experience. Most of us just haven't had access to it or known how to make sense of its ideas.

illness'. For patients, madness isn't about 'chemical imbalances' or 'new hopes for a breakthrough in the exciting world of brain research'. They talk of captivity and coping, resilience and recovery. Patients see their 'symptoms' as meaningful, not as anatomical defects or the random firing of faulty brain circuits.

In other fields of medicine, patients' accounts don't directly challenge doctors' theories. Someone who writes about having cancer, for example, isn't seen as contributing to oncology. But there's no blood test for schizophrenia, no brain scan that can detect manic depression. No mental

illness can be diagnosed on the basis of an objective measure. Because there's no agreed-upon metric against which to evaluate their claims, psychiatrists have to rely on the power of rhetoric to stake out their domain. *The Diagnostic and Statistical Manual of Mental Disorders (DSM)*, the most widely used system in the field, was created by the American Psychiatric Association to establish diagnostic standards, but it has devolved largely into a political document – written by a committee, with some categories of disorder

decided by vote, its framework so often disputed that a new version of the manual (with a completely different list of disorders) has to be issued every ten to fifteen years. (The next version, DSM-V, is due out in 2012.)

Patient accounts don't simply focus on symptoms. They're often stories of struggle, with people trying to escape their doctors' narrow thinking or having to cure themselves after everyone else gave up on them. It's not surprising that psychiatrists ignore this literature; physicians in every branch of medicine discredit what patients say, and madness, by definition, further calls into question patients' legitimacy. But dismissing these ideas robs the rest of us of provocative insights into how the mind works.

I've spent the last six years immersed in the alternative world that psychiatric patients have created for

But now we can start to do this. More than 700 psychiatric patients have managed to publish narratives of their experiences. (And these are just the ones in English, and just those in print; no one knows how many others have been suppressed, censored or published only in expurgated form or in other languages.) Beyond these written narratives there are now dozens of oral histories, artworks, blogs and other testimonies by people with lived experience of the myriad states of mind psychiatrists call 'mental illness'. And most important, there are now hundreds of peer support groups all over the world, where current and former psychiatric patients work together to unravel the mysteries of madness and help one another recover.

Most first-hand accounts of madness contradict the triumphant stories doctors tell of 'conquering mental

Who owns the mind?



themselves. I've analysed hundreds of published narratives, videotaped oral histories and asylum artworks. I've participated in countless support groups, conferences and peer-led strategy sessions. I've talked with activists in the psychiatric survivor movement from all over the world. What I've learned contradicts everything I assumed about mental illness from my PhD studies and 30 years as a professor of psychology. For the first time in history, there is now a systematic alternative to understanding madness and treatment based entirely on first-hand experience. It offers a powerful challenge to our taken-for-granted ideas.

While psychiatrists continue to fight amongst themselves about which symptoms fit into which diagnostic categories, patients are pioneering new ways of thinking. This is largely a consequence of structural changes in the mental health system over the past 30 years. When patients were institutionalised for long periods, they kept records of their experiences (often in secret). Sometimes, after they got out of hospital (if they ever did), they managed to get these accounts published or privately distributed. But until very recently, such narratives had to be written in isolation; only rarely were patients aware that others had produced similar works. It was impossible for psychiatric patients to meet to discuss their ideas – most were literally locked up. It's only since the closing of the huge state institutions across the US, UK and Europe in the 1970s that patients have finally been able to collaborate and advance their own frameworks.

For three decades there have been debates – economic, moral, political, clinical – about the effects of the massive restructuring of the mental health system that has been taking place. But none of the dozens of books on this so-called 'deinstitutionalisation' focus on a key fact: these changes have created the structural conditions for psychiatric patients to formulate models that can truly rival those of physicians. For the first time in history, people who've been institutionalised in different hospitals, in different geographic regions, even in different countries have been able to meet, recount their experiences, analyse their similarities and differences, and put forward their own frameworks for understanding how the mind works. Helped along by the broader focus on patients as 'consumers' that

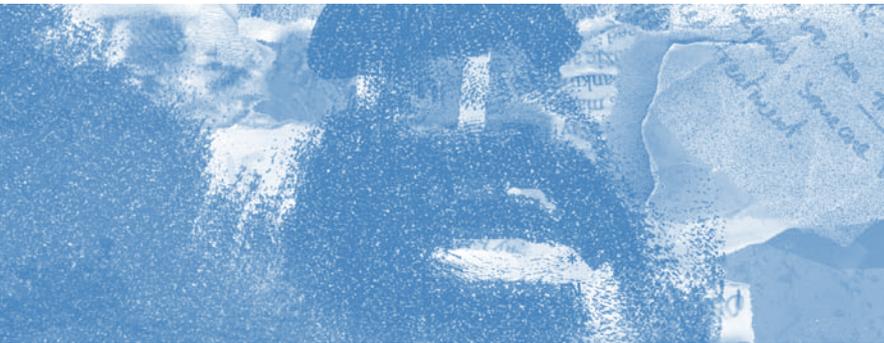
began with the women's health movement of the 1970s, patients are now able to develop approaches that offer real alternatives to those of their doctors.

This is no intellectual exercise on the part of patients. Psychiatric treatments have such poor success rates that there's an urgent need to find other ways to help people. Cancer or AIDS patients may hate the side effects of their medications or the disfiguring surgery they are forced to endure, but they put up with them because they're convinced that their health is being improved or their lives saved. (When they stop thinking this, they stop agreeing to more chemotherapy or another operation.) Mental patients, in contrast, often aren't convinced that the treatments their doctors offer are better than what they can manage on their own or with other patients. Compared to long-term drug regimens for physical ailments – diabetes, heart disease, thyroid problems, etc. – neuroleptic medications (given for schizophrenia and bipolar illness) are blunt instruments. They typically don't work for at least a third of the people to whom they're given, and when they do work, they can reduce people to zombies or cause permanent neurological damage after being taken for long periods. It's no wonder that people forced to take these drugs – sometimes by threats, sometimes by legal action – or those involuntarily given ECT (still a common practice in the USA) are often angry with their doctors and motivated to develop their own approaches.

Patients are particularly critical of doctors' narrow assumptions. By insisting that emotional distress is caused by some (still unknown) genetic or biochemical defect, psychiatrists focus largely on biological processes, ignoring trauma or other facts of life history. In 1902, Emil Kraepelin, the most influential figure in the history of psychiatry, made this claim about psychosis: 'There is usually some insight into the disease, but while the patients appreciate that they have undergone a change, they attribute it to misfortune and abuse rather than to mental illness.'¹ Current attitudes are little changed. The DSM instructs physicians to ask about trauma only if there is a specific reason to suspect post-traumatic stress disorder. (And this exception only made it into the manual because of lobbying by Vietnam veterans, who didn't want every soldier who broke down in

combat to end up being diagnosed 'schizophrenic'.) Many patients feel deeply wounded by the assumption that madness has no link to life experience. As Jacqui Dillon, Chair of the National Hearing Voices Network, England, said at a recent conference, "Pathologising the experience of people like me, who have suffered terrible trauma, only adds insult to injury and protects those who have abused us. Instead of asking, what's wrong with you? people should ask, what's happened to you?"²

First-hand accounts of madness show how the contexts of breakdown can be as important as any internal 'defect' or disease. Politics, racism, and class are often key themes in such narratives; the physical or sexual abuse that countless patients identify as a cause of their symptoms also stand in sharp contrast to the genetics and brain physiology that dominate doctors' theories.



Yet even as they point to painful, even crippling experiences as causes of their suffering, patients remain remarkably optimistic about the potential for full recovery. In the view of many people with lived experience, madness is a crisis or an altered state, not a chronic illness. Their approaches focus on resilience, an idea with provocative and useful implications for all of us. In hundreds of published testimonies and in peer support groups all over the world, people who've been diagnosed 'schizophrenic' or 'bipolar' or 'borderline' have shown again and again that complete recovery is possible no matter how long someone has suffered.

Gail A. Hornstein's new book, *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness* (2009, Rodale Press, ISBN 978-1594865442), is available from Amazon UK. Her *Bibliography of First-Person Narratives of Madness in English* (4th edition) can be freely downloaded from her website at www.gailhornstein.com Gail will be speaking at the 10th anniversary conference of the Critical Psychiatry Network on 22 June 2009 (see www.mentalhealth.freeuk.com/speakers.htm).

One of the most insidious effects of psychiatry's widespread adoption of drug treatment has been the redefinition of the criteria for what will count as data. It's now taken as axiomatic that only 'controlled outcome studies' with hundreds of participants constitute the 'evidence-based medicine' upon which treatment decisions can be based. Research like this may help to determine the effectiveness of a particular drug, but it tells us nothing about madness as an experience or what might help an individual. Patients may lack access to grants or teams of researchers, but that doesn't mean they have no laboratories to test their ideas. The evidence of testimony – in published narratives, in oral histories, and spoken aloud in support group meetings – is as much 'outcome data' as any brain scan or chemical assay. True understanding of anomalous states or distressing feelings can only come from analysing the data of lived experience.

There are important practical implications to these ideas, and all of us can help to implement them. If you teach in a clinical setting or a mental health training programme, work to include first-person accounts of madness in your standard curriculum and make a well-stocked 'recovery library' available to patients at every clinic and hospital. If you're a mental health professional, read first-person accounts and recommend them to your patients, along with contact information for support groups in your local area. If you're in distress yourself, seek out recovery narratives, oral histories and testimonies by those who've faced similar challenges. There are real alternatives to the narrow, pessimistic views psychiatrists have long offered, and many of the most useful ideas are coming from people who've experienced madness themselves.

1. Kraepelin, Emil (1981) *Clinical Psychiatry* (original edition 1907), Delmar, New York: Scholars' Facsimiles and Reprints, p. 286.
2. Dillon, Jacqui (2003) Remarks at 'Beyond Belief: How to Understand and Cope with Hearing Voices', a special one-day conference at the University of London, 10 April.

Testimony is a Mental Health Media project that began in 1999 in collaboration with the British Library to create an audio-visual record of life in institutions based on the old Victorian model. Visit the Testimony website at www.insidestories.org for full access to the transcripts of the Testimony interviews. You can also find out more about the history of the asylum and the development of the service user movement, and you can share opinions in the community section.