< THE ART OF DIAGNOSIS

Transcript

Friday, December 26, 2008

BROOKE GLADSTONE:
There's a saying that goes, "A good book is the best of friends, the same today and forever." But books that are periodically revised can be even better. Consider the *Diagnostic and Statistical Manual of Mental Disorders*, or *DSM*, the catalog of mind-based maladies designated by the American Psychiatric Association.

Plagued by fears or fantasies, bad thoughts or bad behaviors? If the problem's in your head, it's in the *DSM*, charting your psychic pain since 1952.

The next edition, the fifth in 60 years, isn't due out until 2012, but now's the time when new disorders are debated, tested and prepped for their debuts in the *DSM-V*. The world consults this book. This is a very big deal -
DR. DARREL REGIER:
- because the disorder definitions that we provide are used by the FDA to determine whether or not new medication might have an indication for treatment.
BROOKE GLADSTONE:
Dr. Darrel Regier is the vice-chair of the *DSM-V* Task Force.
DR. DARREL REGIER:
It's used by the NIH to assess the type of disorder that somebody is asking to research. It's also used by Medicare, Medicaid and insurance companies to identify the condition that somebody is requesting payment of treatment for.
BROOKE GLADSTONE:
Most important, it's used by doctors to define what's normal and what's not. It was the *DSM* that officially declared homosexuality a mental disorder, and then in 1973 officially undeclared it.

It's defined an ever-expanding range of phobias and addictions that we're still arguing about, but this time, demands for more transparency aim to crack open the window on *DSM-V* deliberations so interested parties can weigh in before they are enshrined – because once they are, the FDA approves drugs to treat them, and any further debate is drowned out in the flood of direct-to-consumer ads.
[CLIPS]:
[MUSIC UP AND UNDER]

WOMAN:
If you are one of the many who suffer from overwhelming anxiety and intense fear of social situations with unfamiliar people -
MAN:
You know when you're not feeling like yourself. You're tired all the time. You may feel sad, hopeless, and lose interest in things you once loved. You may feel anxious.
WOMAN:
You can feel it in so many ways. Cymbalta can help. Cymbalta is a prescription medication that treats many symptoms of depression.
[END CLIPS]
BROOKE GLADSTONE:
One controversial diagnosis up for inclusion is gender identity disorder. For social conservatives and some religious groups, this is a definite thumbs-up for inclusion in the

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FEEDS
On The Media Podcast

DSM. If you think you're a woman trapped in a man's body or vice versa, you have a disorder.

But Dr. Michael First, who worked on the last two editions of the *DSM*, says that for those in the transgender community it's not so simple.
DR. MICHAEL FIRST:
People who want sex reassignment surgery, who are transgendered so much so that they feel like they have to go all the way and actually change their gender - they need to view this as a disorder in order to qualify for the surgery.
BROOKE GLADSTONE:
You mean to get insurance to cover it.
DR. MICHAEL FIRST:
Insurance, and also social acceptance. The people who are against it are people who see being transgendered as a lifestyle choice and part of the normal variation, and they just see the stigma.
BROOKE GLADSTONE:
Similarly, feminists stand on both sides of the debate over a form of PMS affecting five percent of menstruating women that is so severe it impairs their ability to function. It's called PMDD, or -
[CLIP/MUSIC UP AND UNDER]:
WOMAN:
Premenstrual dysphoric disorder, a distinct medical condition. It causes intense mood and physical symptoms right before your period. Doctors can now treat PMDD with Sarafem, the first and only prescription medication for PMDD.
[END CLIP]
STEF PROSE:
When the Sarafem commercials came out was when I got, you know, the ah-ha!
BROOKE GLADSTONE:
Stef Prose was being treated for depression, even though she rejected that diagnosis and felt stigmatized by it. When she saw the Sarafem ad depicting her debilitating mood swings, her rages and her guilt, she finally felt she had a real diagnosis and was deeply relieved and grateful.
STEF PROSE:
Somebody knows actually what I'm talking about. And immediately I called my doctor and said, this is what I have. I want depression [LAUGHS] taken off the record.
BROOKE GLADSTONE:
Like so much in the *DSM*, diagnosis is a judgment call, but Stef Prose, who now blogs about PMDD at Lifewpmdd.com, has no trouble passing judgment on whether it should be in the DSM.

STEF PROSE:
My answer is yes. Trying to go to work every day and getting the energy to do it, it does, it affects you every single day. And to me, that is a disorder.
BROOKE GLADSTONE:
PMDD has languished in the appendix of the *DSM*, signifying that the jury is still out. It is a hot-button issue because, you know, this one's just for the ladies, and it could be used against them – all of them.

But the political ramifications don't worry Stef Prose.
STEF PROSE:
I hadn't really thought about it. I guess the way I look at it is, it is kind of a sexist disease. [LAUGHS]
BROOKE GLADSTONE:
Sarafem, just Prozac in pink, is still available, but the FDA demanded that Eli Lilly pull the ads because they described the symptoms of PMDD so broadly they were virtually indistinguishable from what most women experience as PMS, a condition not currently up for inclusion in the DSM.
DR. JONATHAN METZL:
If we are in the business of treating PMS with psychiatric drugs, in part what we're saying is that there is a level of insanity to the suffering of [LAUGHS] PMS.
BROOKE GLADSTONE:
Jonathan Metzl, psychiatrist and author of *Prozac on the Couch: Prescribing Gender in the*

Era of Wonder Drugs.
DR. JONATHAN METZL:
Historically speaking, psychiatric drugs have been used to convey the message that if you're not just suffering from an illness but if you're not a good mother, if you are not a good wife, these are all conditions that can be treated with psychiatric medications.

And I can say that historically the blurriness of that line has gotten psychiatry into a lot of trouble. The "mother's little helper" phenomenon in the '70s is one example of that.
BROOKE GLADSTONE:
Valium.
DR. JONATHAN METZL:
Correct. We know that when the industry drives diagnosis, there's a process that happens that Peter Kramer, in *Listening to Prozac*, beautifully described as "diagnostic bracket creep." People start to come into doctor's offices and say, I know this drug is indicated for a particular illness, but I've kind of got that. And the doctor says, that sounds good enough. We'll give you this medication.

And what happens over time is that the diagnostic boundaries expand and expand and expand so that a drug that was indicated for a very small subset of people over time becomes indicated and used for a much wider category.
CHRISTOPHER LANE:
Fifty percent of the population defines itself as shy.
BROOKE GLADSTONE:
Christopher Lane is the author of *Shyness: How Normal Behavior Became a Sickness*.
CHRISTOPHER LANE:
An enormous number of people have a profound dislike of speaking in public but that doesn't mean they suffer from a psychiatric condition. And the effort on the part of these psychiatrists and the APA to broaden the net and include Internet addiction and compulsive buying disorder and apathy disorder, relational disorder, all of these are basically codes for everyday experiences and fears and anxieties that should not be represented in a psychiatric bible.
BROOKE GLADSTONE:
Lane says the media compound the problem by reporting only the upper range of the estimate of those who may suffer from a potential disorder and by failing to report the size of the field studies, which often are quite small.
CHRISTOPHER LANE:
I mean, one of the studies – it was a telephone survey to 526 urban Canadians – came out with self-reported accounts of social anxiety that ranged from 1.9 percent to 18.7 percent, but only the higher figure was reported in the subsequent media literature.

And what happens is then the public reads that, or hears it on the radio, and decides this is potentially a problem, certainly with social anxiety disorder because the drug maker in question, GlaxoSmithKline, spent over 94 million dollars on what it called a "public awareness campaign" for the disorder in question.

It wanted people basically to rethink whether they were suffering from just shyness and to ask themselves whether it might be something more serious, like social anxiety disorder.
DR. MICHAEL FIRST:
The issue with all mental disorders is they're defined in terms of symptoms that we all experience every day as part of normal living.
BROOKE GLADSTONE:
Dr. Michael First, who worked on the third *DSM* and was an editor on the fourth.
DR. MICHAEL FIRST:
Sadness, anxiety, palpitations, these are all normal phenomena. It's only when they're sufficiently severe enough and clustered together that they begin to look like they're a potential mental disorder. So if you add a mental disorder to the *DSM* and it's defined in terms of everyday symptoms, you always run the risk of labeling someone who is normal with having a disorder.
BROOKE GLADSTONE:
The *DSM* Task Force is keenly aware of the risk of what are called "false positives," a risk driven home in 1972 by psychologist David Rosenhan, who conducted a study in which eight mentally healthy people gained admission to 12 psychiatric hospitals in five states by

claiming to hear a voice saying “empty” or “hollow” or “thud.” That was their only deception. Otherwise, they behaved normally. All but one was diagnosed as schizophrenic.

After admission, they said they felt fine, and their behavior reflected it, but it took them from 7 to 52 days to be discharged, with a diagnosis of “schizophrenia in remission.”

When the study was published, two psychiatric hospitals agreed to undergo the same test. Could they identify the fakers? In fact, they identified dozens of them, only none had actually been sent.

DR. MICHAEL FIRST:

One of the big challenges of psychiatric diagnosis is the fact that it’s still descriptive. It’s based upon the way patients present.

BROOKE GLADSTONE:

Is this why we're all desperate for genetics to come up with, hey, you have a super-short, you know, Q gene, therefore that’s the cause of your condition?

DR. MICHAEL FIRST:

We're desperate for that. It’s never going to happen, I think. The reason why we haven't discovered the gene for schizophrenia is there is no gene for schizophrenia. It’s a complex interaction of so many different factors. I would have imagined that after 15 years of research, given all of the advances, we'd have to have a lab test by now.

And, in fact, there was a series of research conferences before work on the *DSM-V* actually started, and one question that was put to every single research group is, are we ready to have lab tests or genes or neuro-imaging as a diagnostic test? And every single time that question was raised we always got the same answer, which is while this is interesting, while there’s data, it’s not good enough to help us make a diagnosis. So we're going to have to wait til, you know, who knows when, but certainly not now.

BROOKE GLADSTONE:

So, diagnosis is still an art.

DR. MICHAEL FIRST:

Still an art, but it’s also an art in the rest of medicine as well. I think anyone who’s ever had back pain or an ill-defined medical illness will see how similar the rest of medicine can be to psychiatry.

BROOKE GLADSTONE:

Similar, but not the same. First concedes that the diagnoses of medical disorders rarely affect the culture as intensely as mental disorders do.

DR. MICHAEL FIRST:

The *DSM* is an amalgam of social values and the science. I think the decisions made by the people in the *DSM* have direct impact on everyone.

BROOKE GLADSTONE:

That’s why this veteran of *DSM-III* and *DSM-IV* stands with the many *DSM* critics who are calling for more public deliberations.

DR. MICHAEL FIRST:

You want to see how did this group of individuals who are making these decisions come up with their decisions, and, more importantly, you want to have advanced warning so that if a proposal starts pushing its way through, people are aware of what that proposal is, and if they see a problem with it they'll write in and say, you know, you haven't considered this.

It’s the interaction and the give and take with the entire both scientific community and the community at large which can produce the best DSM. That’s the big problem in not having full transparency. It really robs the book of very, very important input at the earliest possible stages.

BROOKE GLADSTONE:

The *DSM* website offers some updates, but no details of the closed-door deliberations over proposed disorders. What’s more, members of the Task Force sign a contract pledging not to divulge any confidential information, defined as, quote, “all work product, unpublished manuscripts and drafts and other pre-publication materials, group discussions, internal correspondence, information about the development process and any other written or unwritten information in any form that emanates from or relates to my work with the APA Task Force or Workgroup.” Not exactly the model of transparency.

Dr. Darrel Regier, vice-chair of the current *DSM-V* Task Force.

DR. DARREL REGIER:
This particular section was written by the intellectual property attorneys, and their concerns were that individuals who have inside access to the entire process don't use this for personal gain.
BROOKE GLADSTONE:
Nevertheless, Regier does disagree with the critics. He believes it's best that raw data, rough drafts and internal discussions stay behind closed doors.
DR. DARREL REGIER:
Otherwise, it would just be cacophony and mass confusion.
BROOKE GLADSTONE:
I think that some of them wouldn't mind what you call cacophony in order to be able to have some input into the process before it is so well underway.
DR. DARREL REGIER:
Well, it has been underway since 1999. And we put up in 2004 the DSMV.org website, where people could provide their input. And, in fact, we've had quite a bit of input coming in from the general public. The general public actually doesn't get that involved until it's clear what the disorders are and what the impact might be. But –
[OVERTALK]
BROOKE GLADSTONE:
That's because they don't know what is under consideration.
DR. DARREL REGIER:
Well, [LAUGHS] I think that you've seen a number of presentations in the press of people speculating about what might be under consideration.
BROOKE GLADSTONE:
Do you ever personally wonder that too much of the wide range of human behavior is being pathologized?
DR. DARREL REGIER:
I worry about that a lot. And when I went into the field of psychiatric epidemiology, which is my research area, I was very concerned that in 1950s there was a book out called Midtown Manhattan Study that identified something like 84 percent of folks in Manhattan as having a mental disorder.

So, [BROOKE LAUGHS] I've been concerned since that time of having something that is certainly much more credible. I think the DSM-III criteria enabled us to narrow down on what is really a disorder and what is within the normal range of human, you know, emotional expression.
BROOKE GLADSTONE:
I think if you took the wide swath of depression disorders that are in the *DSM* and add them to the wide swath of anxiety disorders that are in the *DSM*, and throw in quite a few of the attention disorders that are in the *DSM*, you could easily find that 84 percent of New Yorkers have a mental disorder.
DR. DARREL REGIER:
I don't think you can.
BROOKE GLADSTONE:
Let's assume that the only goal of the *DSM* is to reduce the sum of human suffering. Under consideration for inclusion in the global compendium of psychic pain include apathy disorder, compulsive shopping disorder, relational disorder, Internet addiction and binge eating. Who among us cannot find ourselves somewhere in the DSM, which prompts the question not how much suffering is too much – we know mental illness destroys lives – but how much suffering is too little?

Psychiatry has lowered our threshold for pain and has raised the bar for normal. Maybe the expectation that there is a "normal" is the most insidious disorder of all.
BOBBY McFERRIN, SINGING:
Here's a little song I wrote.
You might want to sing it note for note.
Don't Worry, Be Happy.
[SONG UP AND UNDER]
BOB GARFIELD:
That's it for this week's show. On the Media was produced by Megan Ryan, Jamie York, Mike Vuolo, Mark Phillips and Nazanin Rafsanjani, and edited – by Brooke. We had technical direction from Jennifer Munson and more engineering help from Zach Marsh. We also had

help from Deena Prichep and Andy Lanset. Our webmaster is Amy Pearl.
BROOKE GLADSTONE:
Katya Rogers is our senior producer and John Keefe our executive producer.
Bassist/composer Ben Allison wrote our theme. This is On the Media from WNYC. I'm
Brooke Gladstone.
BOB GARFIELD:
And I'm Bob Garfield.
BROOKE GLADSTONE:
Happy New Year, Bob.
BOB GARFIELD:
Happy New Year, Brooke.

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