

the epidemic in mental illness: clinical fact or survey artifact?

Do half of all Americans suffer from mental disorders at some point in their lives? Or do surveys misdiagnose the distress that is a normal part of every life?

According to large, community-based research studies that the media report with great fanfare, alarming numbers of Americans suffer from mental disorders. The most frequently cited study, the National Comorbidity Survey, claims that half the population suffers from a mental illness at some point. Moreover, these same studies show that few people diagnosed as mentally ill seek professional treatment.

Policy discussions, scientific studies, media reports, advocacy documents, and pharmaceutical advertisements routinely cite such figures to show that mental disorder is a public health problem of vast proportions, that few sufferers receive appropriate professional treatment, that untreated disorders incur huge economic costs, and that more people need to take medication or seek psychotherapy to overcome their suffering. Awareness of large numbers of untreated, mentally ill people in the community has reshaped mental health policy, justifying efforts to address this “unmet need for treatment”—for example, by training general practitioners or public school personnel to screen for and treat mental disorders.

Despite their rhetorical value, the high rates are a fiction; the studies establish no such thing. In fact, the extraordinarily high rates of untreated mental disorder reported by community studies are largely a product of survey methodologies that inherently overstate the number of people with a mental disorder. The inflated rates stem from standard questions about symptoms with no context provided that might distinguish the normal distress experienced in life from genuinely pathological conditions that indicate an underlying mental illness. Both get classified as signs of disorders. Moreover, because people experiencing normal reactions to stressful events are less likely than the truly disordered to seek medical attention, such questions are bound to inflate estimates of the rate of untreated disorders.

We use depression to illustrate such exaggeration. However, our argument applies equally well to estimates of other presumed mental illness such as sexual dysfunctions, anxiety disorders, or drug and alcohol abuse. Some history will help to frame the problem.

origins of symptom-based diagnosis

All major surveys in psychiatric epidemiology, the field that assesses the patterns of mental illness in a population, attempt to translate as exactly as possible into survey questions the diagnostic criteria published in various editions of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. Often called the “Bible of psychiatry”

Photo by Allan Horwitz



because of its authoritative status and almost universal use by clinicians, researchers, and medical insurers, the *DSM* provides official diagnostic definitions for all mental disorders.

Since its third edition, published in 1980, the *DSM* has attempted to provide precise, reliable, easily applied criteria for diagnosing each mental disorder. This approach was a response to a variety of criticisms of psychiatry common at the time, many of which hinged on the unreliability of psychiatric

diagnosis. That is, different clinicians were likely to diagnose the same individual in different ways. Two problems led to this embarrassing result. First, members of different theoretical schools often conceived of and defined disorders differently, on the basis of their own theoretical concepts, whether psychodynamic, biological, or behavioral. Second, earlier definitions were generally vague and referred to fuzzily defined internal processes. To increase reliability, the third edition of the *DSM* (*DSM-III*) addressed both problems by stating diagnostic criteria strictly in terms of observable or reportable symptoms. Theoretical concepts were left out of diagnosis, which became “theory neutral.” The new definitions used only symptoms that clinicians could precisely describe and reliably ascertain.

The *DSM-III* approach of defining disorders by presenting lists of symptoms is still used in the current edition published in 2000. For example, the definition of depressive disorder requires that five of the following nine symptoms be present during a two-week period: depressed mood, lack of pleasure or interest in usual activities, change in appetite or weight, insomnia or excessive sleep, psychomotor agitation or retardation (slowing down), fatigue or loss of energy, feeling worthless or inappropriately guilty, lack of concentration or indecisiveness, and recurrent thoughts of death, suicide, or a suicide attempt. Cases of normal bereavement after the death of a loved one are exempted from diagnosis, but only if the grief involves no severe symptoms and lasts no more than two months.

using standardized questions in community surveys

Epidemiologists study rates and patterns of disease in order to find clues about causes and determine possible treatments. They eagerly embraced the *DSM*'s symptom-based

For the past thirty years, Allan V. Horwitz has studied various social aspects of mental disorders and normality. Jerome C. Wakefield was trained in philosophy and clinical social work, and writes on the conceptual foundations of the mental health professions. They are now collaborating on a book, The Loss of Sadness, which deals with the transformation of sadness into Major Depression.

approach to diagnosis. Because researchers generally accepted the *DSM* criteria as authoritative, psychiatric epidemiologists could use them without having to do elaborate studies

CATEGORY #4		YES (1)	NO (5)
D9. Have you ever had 2 weeks or more when nearly every night you had trouble falling asleep?	(#6)	<input type="checkbox"/>	GO TO D11
D10. Have you ever had 2 weeks or more when nearly every night it took you at least 2 hours to fall asleep?	(#7)		
D11. Have you ever had 2 weeks or more when nearly every night you had trouble staying asleep?	(#8)	<input type="checkbox"/>	GO TO D13
D12. Did you ever have 2 weeks or more when nearly every night you lay awake more than one hour?	(#9)		
D13. Have you ever had 2 weeks or more when nearly every morning you woke up too early?	(#10)	<input type="checkbox"/>	GO TO D15
D14. Have you ever had 2 weeks or more when nearly every morning you would wake up at least 2 hours before you wanted to?	(#11)		
D15. Have you ever had 2 weeks or longer when nearly every day you were sleeping too much?	(#12)	<input type="checkbox"/>	
D15a. INTERVIEWER: IF ANY <input checked="" type="checkbox"/> RESPONSE IN D9-D15, CHECK "SADNESS" CATEGORY #4 BOX ON REFERENCE CARD.			

Examples of screening questions for depression from the National Comorbidity Study

of their own to establish their validity. Moreover, the approach seemed to resolve a series of problems that plagued contemporary community studies of mental disorder.

Early studies in psychiatric epidemiology had simply surveyed various treatment settings and relied on the diagnoses contained in medical charts to determine rates of mental disorder. But it soon became apparent that the number of treated patients did not reliably indicate the degree of mental disorder in a community for a variety of reasons, such as lack of access to appropriate treatment, people's reluctance to seek professional help because of stigma or cost, and variations in diagnostic practices. Community studies of mental disorders try to get around these problems by attempting to determine directly how many people in the community have various mental disorders, regardless of whether they have undergone treatment. This requires interviewing many normal as well as disordered people.

In contrast to respondents in treatment studies, most of the people in community studies have never been diagnosed with mental disorders. Thus, to establish rates of disorders in the overall population, community surveys must collect thousands of cases. This poses formidable challenges. For one thing, psychiatric or other professional interviewers are expensive. For another, unless questions are carefully standardized,

there is a danger of unreliability in the way the interviews are conducted. Additionally, valid analysis of qualitative data such as psychiatric interviews is extremely difficult.

The *DSM's* symptom-based diagnostic criteria offered a solution to these problems. Epidemiologists conducting community studies simply translated the *DSM's* symptoms into closed-format questions about symptoms experienced by respondents. This yielded a questionnaire that nonprofessionals could be trained to administer, allowing cost-effective collection of data from large numbers of people. Computer programs using the *DSM* criteria could determine if a disorder was present.

Accurate estimates of prevalence require that different interviewers ask these questions in exactly the same way. As one study notes, "The interviewer reads specific questions and follows positive responses with additional prescribed questions. Each step in the sequence of identifying a psychiatric symptom is fully specified and does not depend upon the judgment of the interviewers." Without such standardization, even minor variations in wording or in the interviewer's probes or instructions can lead to different results. The resulting standardized interview format excluded any discussion of the reported symptoms and their context. The rigid approach of structured interviews improves the consistency of symptom assessment across interviewers and research sites and thus the reliability of diagnostic decisions. Note, however, that the decision to use decontextualized, symptom-based measures in community studies assumes an uncritical acceptance of the *DSM's* symptom-based criteria and is based largely on considerations of practicality and cost, not on independent tests that prove the accuracy of such methods in identifying disorders in the community.

are survey-based diagnoses equivalent to clinical diagnoses?

The diagnoses of particular disorders in surveys, however reliable they may be, provide poor measures of mental illness in community populations. The core assumption in community studies is that tightly structured questions allow researchers to obtain diagnoses that are comparable to those of a psychiatrist, since the questions match the *DSM's* symptom criteria. This assumption rests in turn on the assumption that those criteria are valid for identifying disorders. However, those diagnosed as having mental disorders in community populations differ in two fundamental ways from those who seek mental health treatment.

First, people seeking help are highly self-selected and use all sorts of contextual information to decide for themselves if their feelings exceed ordinary and temporary responses to stressful events. David Karp, for example, found that

depressed people sought help from psychiatrists only after they attributed their symptoms to internal psychological problems and not to stressful situations:

[O]nce it becomes undeniable that something is really wrong, that one's difficulties are too extreme to be pushed aside as either temporary or reasonable, efforts begin in earnest to solve the problem. Now choices to relieve pain are made with a conscious and urgent deliberation. The shift in thinking often occurs when the presumed cause of pain is removed, but the difficulty persists. Tenure is received, you finally get out of an oppressive home environment, a destructive relationship is finally ended, and so on, but the depression persists. Such events destroy theories about the immediate situational sources of depression and force the unwelcome interpretation that the problem might be permanent and have an internal locus. One has to consider that it might be a problem of the self rather than the situation.

People who enter treatment thus have already decided that their problems go beyond normal reactions.

Second, clinicians as well as patients make contextual judgments of symptoms when they diagnose mental illness in treated populations. Psychiatrists have long recognized that symptoms such as depressed mood, loss of interest in usual activities, insomnia, loss of appetite, inability to concentrate, and so on might naturally occur in response to major losses, humiliations, or threats to one's meaning system, such as having a marriage unravel, losing one's job or pension, or failing a test that has serious implications for one's career.

Such reactions, even when quite intense, are part of normal human nature. Applying the *DSM's* symptom-based criteria literally, with no professional judgment, would result in classifying such normal reactions as disordered. Clinical diagnosis has a built-in backup system for catching such potential misdiagnoses: the clinician takes a psychiatric history in an interview that includes questions about context. The clinician is free to deviate from the literal *DSM* criteria in arriving at a diagnostic judgment and is responsible for doing so when the criteria erroneously classify a normal reaction as disordered. How often clinicians actually use this corrective option is unknown, but at least it exists in principle.

Thus, in treated populations, contextual judgments by both patients and clinicians precede clinical diagnosis. In contrast, the diagnostic process in community studies, which involves neither self-evaluation by respondents nor clinical judgment, ignores the context in which symptoms develop. Survey interviewers are forbidden to judge the validity of responses or to discuss the intent of questions, and they neither exercise clinical discretion nor use flexible probes about responses. Even if the respondent seems to misunderstand a

question, the interviewer is instructed to repeat the question verbatim. The absence of interviewer probes can produce seriously misleading results. For example, when asked, "Have you ever had a period of two weeks or more when you had trouble sleeping," a person might recall a time when ongoing construction across the street interrupted her sleep. In such a case, she can disregard the literal meaning of the question, self-censor her response, and not report the "symptom." Or she can give an answer that is literally true, with the result that her troubled sleep will be counted as a potential symptom of a mental illness. The lack of clinical judgment based on exploring context can easily inflate reported rates of pathological conditions.

the prevalence of depression

The most widely cited estimates of the prevalence of depression in the United States in the scientific, policy, and popular literatures stem from the National Comorbidity Survey (NCS) conducted in the early 1990s, with a ten-year follow-up, and from a similar study, the Epidemiologic Catchment Area (ECA) study undertaken in the early 1980s. The NCS uses two steps to obtain diagnoses of depression based on *DSM* criteria. First, respondents must answer yes to at least one of the following stem questions at the beginning of the interview: (1) "In your lifetime, have you ever had two weeks or more when nearly every day you felt sad, blue, or depressed?"; (2) "Have you ever had two weeks or more when nearly every day you felt down in the dumps, low, or gloomy?"; (3) "Have there ever been two weeks or more when you lost interest in most things like work, hobbies, or things you usually liked to do?" and (4) "Have you ever had two weeks or more during which you felt sad, blue, depressed or where you lost all interest and pleasure in things that you usually cared about or enjoyed?" Since these questions are so broad and do not allow for reference to the circumstances in which the moods arose, it is no surprise that 56 percent of the population replies yes to at least one of them. Later in the interview, these respondents are asked questions about symptoms derived from the *DSM* criteria for Major Depressive Disorder. To be diagnosed with depression, community members must report having depressed mood or inability to feel pleasure along with four additional symptoms, such as loss of appetite, difficulty sleeping, fatigue, or inability to concentrate on ordinary activities.

The NCS estimates that about 5 percent of subjects have a

current (30-day) episode of major depression, about 10 percent had this condition in the past year, about 17 percent at some point in their lives, and about 24 percent report enough symptoms for a lifetime diagnosis of either depression or dysthymia, a related disorder. It also finds that relatively few people diagnosed with these conditions have sought professional help: only about a third of those with survey-identified Major Depressive Disorders had sought professional treatment, and far fewer sought any kind of help from mental health professionals.

Are the many cases of Major Depressive Disorder uncovered in such community studies equivalent to treated clinical cases? In contrast to clinical settings, where the judgments of both lay persons and clinicians distinguish ordinary sadness from depressive disorders, symptom-based diagnoses in community studies consider everyone who reports enough symptoms as having the mental disorder of depression. A respondent might recall symptoms such as depressed mood or insomnia that lasted longer than two weeks after the breakup

Community studies, rather than uncovering high rates of depressive disorders, simply show that the natural results of acute or chronic stressful experiences could be distressing enough to fit the *DSM* definition of a disorder.

of a romantic relationship, during a loved one's serious illness, or the unexpected loss of a job. Although these symptoms might have dissipated as soon as a new relationship developed, the loved one recovered, or another job was found, this person would be counted among the many millions who suffer from the presumed disorder of depression each year. For example, in the ECA study the most commonly reported symptoms are "trouble falling asleep, staying

asleep, or waking up early" (33.7 percent); being "tired out all the time" (22.8 percent); and "thought a lot about death" (22.6 percent). College students during exam periods, people who must work overtime, who are worried about an important upcoming event, or who take the survey soon after the death of a famous person would all naturally experience such symptoms.

Symptoms that neither respondents nor clinicians would see as requiring treatment may nevertheless qualify as signs of disorder in community surveys. Moreover, the duration criteria only require that the symptom last for a two-week period, so that many transient and self-correcting symptoms are counted as disordered. In other cases, reported symptoms could be normal responses to long-standing conditions of poverty, oppression, or injustice. Diagnostically oriented community studies, rather than uncovering high rates of depressive disorders, simply show that the natural results of acute or chronic stressful experiences could be distressing enough to fit the *DSM* definition of a disorder.

why are the high rates perpetuated?

The exaggerated rates of mental disorder in community surveys do not mean that untreated psychiatric disorders are not a significant problem. Nor do they mean that people who experience normal distress may not sometimes benefit from drugs or psychological treatments. It does, however, contribute to a pervasive medicalization of many problems that we might view more constructively as expectable results of social circumstances.

Community surveys could more adequately separate normal responses to stressful situations from mental disorders by including questions about the context in which symptoms develop and persist. Interviewers could ask, for example, if symptoms of depression emerged during periods of intense stress and disappeared as soon as these crises were over. Clinical interviews often include such probes, which are also compatible with basic principles of survey methodology; psychiatrists have always recognized the need for such considerations. The decision not to include contextual criteria in community surveys may involve not only the efficiency and practicality of decontextualized, standardized methods but also resistance to change by groups that benefit from the reported high rates of mental illnesses.

During the 1960s the National Institute of Mental Health (NIMH) promoted an expansive agenda of community mental health and sponsored projects that attempted to alleviate poverty, combat juvenile delinquency, and promote social change, but political changes in the 1970s forced the NIMH to change its focus from social and economic problems to specific diseases. This was more politically palatable than addressing controversial social problems. In addition, the rise of the biological paradigm in psychiatry naturally shifted emphasis from the social circumstances that can produce mental illness toward internal sources. The NIMH funded the epidemiological studies in the 1980s and 1990s in an effort to show that presumed disease conditions were widespread yet untreated. The resulting belief in high prevalence rates, which became the focus of well-known and widely disseminated documents such as the Surgeon General's Report on Mental Health, insulated the agency from political pressures, expanded its mandate, enhanced the importance of the problem it addressed, and protected its budget. Political support is more likely for an agency devoted to preventing and curing widespread disease than for one that confronts controversial social problems.

Pharmaceutical companies have also capitalized on these survey findings, which create a broader market for their products. Their ads focus on symptoms such as sadness, loneliness, exhaustion, and anxiety that are common among normal peo-

ple. These ads also routinely feature the alleged numbers of people who suffer from particular mental disorders, sending the message that potential consumers are not unique but share their problems with millions of others. The explosive growth in sales of antidepressants shows the effectiveness of this appeal.

Family advocacy groups such as the National Alliance for the Mentally Ill embrace claims about the prevalence of mental disorders, which allow them to equate the millions of people that community surveys identify with the far smaller number of people with truly serious mental disorders. This presumably reduces the social distance between the mentally disordered and others, and lowers the stigma of mental illness, potentially aiding efforts to obtain more funding for treatment.

These groups promote high prevalence rates in the belief that if they can convince politicians that mental illnesses are widespread, they can gain more funding for mental health services. But their efforts to get more treatment for currently untreated cases are just as likely to shift resources from people who truly need professional mental health services to those who might be distressed but are not disordered. Moreover, such high rates may make the problem of mental illness seem so overwhelming and potentially costly that it will not be addressed. Erasing the distinction between normal and disordered conditions and calling both mental disorders may harm the truly disabled.

recommended resources

Allan V. Horwitz. *Creating Mental Illness* (University of Chicago Press, 2002). This book describes how and why the general pathologies of psychoanalysis changed into the specific mental disorders of the DSM-III in 1980.

Lee Robins and Darrell Regier. *Psychiatric Disorders in America: The Epidemiological Catchment Area Study* (The Free Press, 1991). The best compilation of conventional views regarding psychiatric epidemiology.

U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General* (National Institute of Mental Health, 1999). A government report shows how epidemiological findings are used for the purposes of public policy.

Jerome C. Wakefield. "The Measurement of Mental Disorder." In *A Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems*, ed. Allan V. Horwitz and Teresa L. Scheid (Cambridge University Press, 1999). This chapter indicates how symptom-based diagnostic categories inflate estimates of the amount of mental disorder in epidemiological studies.