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Psychiatric Epidemiology:

It's Not Just About Counting Anymore

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Over the past 2 decades, the National Institute of Mental Health supported ambitious population-based efforts in psychiatric epidemiology. The landmark 5-site Epidemiological Catchment Area (ECA) study of the 1980s provided the first comprehensive picture of the prevalence of *DSM-III* mental disorders in the United States.¹ A decade later, the National Comorbidity Survey (NCS) was the first study to estimate the prevalence of *DSM-III-R* mental disorders in a nationally representative US sample.² These studies established the methods of modern psychiatric epidemiology in the United States, including the use of reliable lay-administered structured diagnostic assessment tools to ascertain standardized diagnostic criteria,^{3–4} the comparison of clinical interviews with lay interviews to evaluate diagnostic validity,^{5–7} and the application of sampling strategies to identify nationally representative samples. Combined with earlier and richly informative international studies in psychiatric epidemiology,^{8–10} the ECA, NCS, and related surveys demonstrated that mental disorders were highly prevalent in the general population and placed mental illness squarely on the nation's and the world's public health agenda.¹¹

These studies have also changed how we view psychopathology. Most mental illnesses, for example, begin far earlier in life than was previously believed. In addition, findings such as the frequency of comorbidity among the major diagnostic entities have led to systematic studies of their boundaries and renewed questions about categorical vs dimensional approaches to classification. Nonetheless, many critical issues were not addressed by earlier studies. While the overall 12-month prevalence of any mental illness was reported to be in the range of 30%, significant questions about the disability associated with these syndromes remain. How severe are the disorders reported to be present in 30% of the population? What is the economic and public health impact of these conditions? How long is the delay between onset and diagnosis? And to what extent have we made progress in providing appropriate evidence-based treatments to those who are ill?

The 4 articles from the National Comorbidity Survey Replication (NCS-R) published in this issue of the ARCHIVES address each of these questions.^{12–15} The NCS-R uses the international World Health Organization-Composite International Diagnostic Interview (WHO-CIDI),⁶ a fully structured lay-administered interview, to generate *DSM-IV* diagnoses from data collected in a household survey of 9282 respondents (70.9% response rate). Relative to prior studies, methodological innovations include an expanded set of diagnoses; in-depth clinical validation of field research diagnoses based on clinician-administered Structured Clinical Interview for DSM-IV (SCID) reinterviews⁷; dimensional self-ratings on clinically anchored scales^{16–18}; inclusion of subthreshold diagnostic syndromes; assessment of disability and impairment; the use of disease burden metrics linked to marker physical disorders; and assessments of service use, treatment barriers, and adequacy of treatment.

A single study cannot address all pertinent questions so there are several limitations to the NCS-R. The survey did not collect extensive data on relatively low base-rate, disabling disorders such as schizophrenia and autism. In addition, sampling required that all respondents speak English and belong to a household. As a result, non-English speakers, institutionalized, and homeless individuals were not included in this survey. There was a relatively high nonresponse rate (29.1%), but a careful evaluation of nonresponders revealed no systematic

association between nonresponse and psychopathology.¹² In addition, data on age of onset were obtained retrospectively; there was no prospective arm to this study. These limitations aside, the results described in these 4 articles raise several important issues that should concern readers of the ARCHIVES.

First, as reported in earlier population-based studies, mental disorders begin in early life and are common and protracted. As suggested in the WHO Burden of Disease study,¹⁹ mental illnesses are the chronic diseases of the young. Kessler et al¹²⁻¹³ find lifetime history of a mental disorder in 46.4% of their sample; a 12-month prevalence of 26.2%, with half of all cases reporting onset by age 14 and three quarters by age 24. What should we make of these numbers? If one quarter of the population has a disorder each year, are most mental disorders so mild as to be trivial? Or are these disorders serious and more prevalent but underreported?

In the second report, Kessler et al¹³ address the issue of severity by demonstrating that nearly 60% of those diagnosed with a disorder in the previous 12 months are rated as "serious" (22.3%) or "moderate" (37.3%) rather than "mild." Those rated as serious (22.3% of 26.2% = 5.8% of the population in the 12-month sample) reported a mean of 88.3 days when they were unable to carry out their normal daily activities because of mental or substance abuse problems. Ratings of serious were most common among those with bipolar disorder (83%), drug dependence (56.5%), obsessive-compulsive disorder (50.6%), oppositional-defiant disorder (49.6%), and mood disorders (45%). Surprisingly, impulse control disorders, neglected in most previous epidemiological studies of adults, were found in 8.9% (12-month prevalence) and 24.8% (lifetime prevalence) of the population with a greater proportion at the serious level than either anxiety or substance disorders. Corroborating the high rates of comorbidity described in earlier studies, 45% of those with a 12-month disorder met criteria for 2 or more disorders. Severity of illness was strongly related to meeting criteria for more than 1 disorder.

The third report by Wang et al¹⁴ demonstrates, as extensively described in reports from the President's New Freedom Commission on Mental Health²⁰ and the Surgeon General's report,²¹ that mental health care in America is ailing. Over a 12-month period, 60% of those with a disorder (recall that nearly 60% of these are "rated" serious or moderate) receive no treatment. Indeed, for those with impulse control and substance abuse disorders, nearly half of all lifetime cases have never been treated. Among those with any of the disorders who do report obtaining care, only 32.7% report service that meets criteria of minimally adequate. While the survey can only crudely estimate adherence to evidence-based standards and adequacy of treatment, the sources of care are informative. Those with a mental or substance use disorder were more likely to receive help from a general medical professional (eg, primary care physician or nurse) or a complementary-alternative source (eg, internet support group) than a psychiatrist. Even for major depressive disorders, respondents were nearly as likely to receive services from a non-health care source, such as a religious or spiritual advisor, as to be treated by a psychiatrist, yet the survey found that the overall quality of treatment is much higher in mental health specialty care (minimally adequate in 48.0% of specialty mental health vs the 12.8% of general medical and the 13.1% for non-health care sources).¹⁴

Finally, a systemic and unacceptable failure in the provision of care is also reflected in very substantial delays between illness onset and first diagnosis and treatment.¹⁵ Even for mood disorders, with considerable effort expended to increase public awareness of detection and treatment, the delay to first treatment contact ranged from 6 to 8 years. With anxiety disorders, the delay was even longer, ranging from 9 to 23 years. A number of factors predict delayed diagnosis, including early onset, male gender, less education, and racial-ethnic minority status.

Collectively, these articles provide a stark challenge for psychiatry as a public health discipline. Most of the disorders assessed by the NCS-R have evidence-based treatments, but the data

suggest that these treatments are rarely provided in the community. Most psychiatrists practice in office-based specialty settings, yet most patients obtain care in the general medical sector. How do patients who receive psychiatric care differ from those who do not? How can we improve care outside of the mental health specialty environment? Given that mental disorders are often lifelong illnesses that begin in childhood or adolescence, how can we ensure care for these patients equivalent to the care for children with juvenile-onset diabetes or cystic fibrosis? Regrettably, data from the NCS-R indicate that we most often fail to identify illness sufficiently early to intervene and minimize the damaging effects of psychiatric illness on young peoples' developmental trajectories. With respect to the detection and appropriate treatment of mental illness in the United States, the NCS-R quantifies the distance yet remaining along the path to ensuring that all Americans have access to timely and high-quality mental health care.

The findings reported here are the first fruit of what promises to be a bountiful harvest; the NCS-R is one element in a coordinated program of new psychiatric epidemiological studies that will be completed over the next several years.¹ These include the NCS-A study of adolescent mental health in the United States that has assessed nearly 10 000 youths aged 13 to 17 years; the NCS-2, a 10-year follow-up of the original NCS, that will allow assessment of the natural history of illness and treatment in a representative sample of the US population; and the National Study of African American Life and the National Study of Latino and Asian Americans that have sampled nationally representative groups of nearly 6000 and 5000 individuals, respectively. Because these studies use identical diagnostic instruments and share a common core of predictor, symptom, disability, and service use probes, it will be possible to combine samples to document, understand, and potentially remedy mental health disparities in the United States. Beyond the United States, NCS-R methodology has been adopted in epidemiological studies under way in 27 other countries under the aegis of WHO in the WHO World Mental Health Survey initiative.²² When completed, over 200 000 individuals will have been surveyed, making this the first and largest international study of mental disorders ever attempted.

Quantifying the prevalence of mental disorders, the disabilities associated with them, and the adequacy of service provision forms the foundation for national and international mental health policy. But psychiatric epidemiology is no longer just about counting.²³ The NCS-R results will yield much-needed information about the burden of disease, medical comorbidity, and global patterns of illness. Because it includes subthreshold diagnostic information, which we know from studies of hypertension and diabetes can be highly predictive of future diseases, the results may be informative for studying the effect of early intervention. Both the sample and findings may also be informative for future case-control studies of specific subgroups and population-based genetic studies, as well as a source of empirical evidence for prevention.

Diagnosis has confounded psychiatry for the past century, with the *DSM* approach enhancing diagnostic reliability but not validity. By empirically defining clusters of symptoms found in population-based samples, studies such as the NCS-R may point the way to more valid diagnostic entities. Certainly they reveal that those we provide diagnosis for in a clinical setting represent a small fraction of those with disorders, and they remind us that psychiatry faces one of the greatest public health challenges in contemporary medicine.

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