

Chapter 2

Epidemiology

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Introduction

This chapter is a brief introductory perspective on epidemiology—in particular psychiatric epidemiology—a field which encompasses the study of both addiction and mental illness. This perspective is in contrast to the typical clinical perspectives held by many social workers whose primary interest is in directly treating or addressing problems at the individual or family level. Clinicians are critically important—but epidemiologists count—literally. This chapter presents some recent data on trends in rates of disorder and unmet treatment need. It concludes by highlighting the critical importance of epidemiology as a perspective focused not just on describing rates but on searching for causes. In particular, epidemiology’s role in articulating the importance of “place” and how multilevel research models—models accounting for both individual and community level risk factors—can facilitate more effective prevention strategies.

Background

Psychiatric epidemiology is the study of the distribution, burden, and causes of mental illness and psychological distress in the community. The key word here is “distribution”; epidemiologists identify and sort cases by time and place in order to ultimately make inferences about causality. From its early days, psychiatric

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epidemiology was focused on the impact of location—the physical and social environment—on the development of psychiatric disorders and symptoms.

According to Susser et al.'s recent comprehensive review (Susser, Schwartz, Morabia, & Bromet, 2006), the Durkheim cross-national European investigation first published in the late nineteenth century of suicide may be considered early example of psychiatric epidemiology. Using official records of recorded suicides, Durkheim found elevated rates in so-called Protestant countries compared with Catholic countries (Durkheim, 1987). Durkheim surmised that behavior was affected by the contrasting patterns of interpersonal connections and social support—the varying social structures—characterizing and countries with different religious orientations (Susser et al., 2006).

In the early part of the twentieth century, the Chicago School of Social Ecology led by Faris and Dunham conducted a series of studies focused on exploring the geographic distribution of mental illness in Chicago neighborhoods. Their research showed that patterns for the distribution of schizophrenia contrasted with patterns for the distribution of manic depression. The highest rates of schizophrenia were in inner city neighborhoods characterized by high levels of residential instability and social isolation and lowest rates in more affluent suburban areas. In contrast, manic depression was highest in the suburban areas and lowest in the inner city neighborhoods (Faris & Dunham, 1939). Thus, as illustrated by the early work of Durkheim and Faris and Dunham, the field of psychiatric epidemiology has its roots in an ecological approach—one that emphasizes community characteristics as opposed to individual level risk factors in the etiology of psychiatric disorders (including both mental illness and substance abuse).

Methodology

Over the course of subsequent decades and continuing to the present, psychiatric epidemiologists have mainly focused on the use of large-scale social surveys to measure rates of distress and psychiatric disorder (Susser et al., 2006). Through responses to these surveys, they have identified individual-level risk factors for these outcomes, such as socioeconomic disadvantage, exposure to stress, impairments in social relationships, or adverse family history and experiences. A number of studies involve surveying randomly selected residents of urban households about drug use, high-risk sexual behavior, and psychiatric symptoms.

Surveys, especially those that involve the collection of data on sensitive topics from randomly selected individuals in a targeted geographic areas, are typically very expensive—costing hundreds of thousands of dollars to execute in a scientifically valid manner. Social surveys are usually long and detailed measures that ask people questions that may seem sensitive and make respondents uncomfortable. For example, respondents often do not provide valid responses to when questioned about issues such as drug abuse history (Fendrich, Johnson, Sudman, Wislar, & Spiehler, 1999). Furthermore, survey researchers are challenged by declining response rates (Groves et al., 2006). It is often hard to get people in the community to answer the door or telephone or

respond to inquiries on the Internet. And once contacted by survey researchers, many people do not want to be burdened with a lengthy set of intrusive questions.

Given these challenges, many clinicians may wonder why epidemiologists do not rely on the collection of treatment information obtained from social service systems. Why don't researchers just approach social service agencies and treatment centers to gain access to clinic records patients for interviews to find out about prevalence, risk factors, and disease course?

Even if HIPAA regulations were not a barrier, the need to base conclusions about prevalence, etiology and course on nonclinically derived samples is perhaps best supported by the concept of the clinician's illusion (Cohen & Cohen, 1984). This is the notion—well established in other areas of epidemiology and sometimes called “Berkson's Bias”—that those with a specific type of disorder or illness that actually seek clinical treatment tend to be quite different, especially while they are in the midst of receiving treatment, than others who have the disorder. Compared with other cases, patients in a treatment-based sample tend to be more impaired, to have higher rates of comorbidity, a longer disease course, and, overall, to have a much worse prognosis. Cohen and Cohen (1984) cite as examples the disputed, overly pessimistic prognoses that clinicians typically ascribe to alcoholism, schizophrenia, and heroin addiction. Dire prognoses derived from cross-sectional research employing clinical samples have been consistently contradicted by longitudinal research with nonclinical samples. The most famous example of such a contradiction derives from Lee Robins' study of Vietnam Veterans.

Perhaps even more striking is the view of clinicians, widely shared by the public, of opiate addiction as an incurable state for most if not all users. This view was forcefully contradicted by Robins and associates, who found that of a sample of Vietnam veterans who were addicted to heroin when interviewed after their return to the USA, 71% were drug free 21/2 years later, often without great effort. Of all those who became addicted in Vietnam, even a larger proportion, 88% avoided relapse over the three years following their return (Cohen & Cohen, 1984: p. 1179).

As empirically supported and concisely summarized by Cohen and Cohen (1984), the clinician's illusion is the “attribution of the characteristics and course of those patients who are currently ill to the entire population contracting the illness... it is the consequence of using a prevalence sample as a substitute for an incidence sample” (p. 1180). While it might be far more convenient for me to study a clinic or residential treatment-based population of those treated for opiate addiction, cases in the clinic are not like those in the community. We cannot get a true sense of a disorder's onset, course, long-term prognosis, correlates, or etiology without doing community-based health surveys.

Epidemiological Survey Results

The survey work that epidemiologists do today builds on a tradition started in the middle of the twentieth century, beginning with a number of survey-based community studies—including Srole's “Midtown Manhattan” study and the Leightons'

study of Nova Scotia residents (Leighton, Harding, Macklin, MacMillan, & Leighton, 1963; Srole et al., 1962). Early on in psychiatric epidemiology, researchers did not have the tools to derive precise diagnoses and instead focused on nonspecific indicators of psychological impairment or distress. These studies found that symptoms of psychological distress were quite common, with over 80% of the population reporting them (Susser et al., 2006). About 20% of the population had symptoms that were judged by psychiatrists reviewing the data as indicative of *severe* impairment. Risk factors for impairment included being female, having lower socioeconomic status, and experiencing greater socioeconomic adversity (Susser et al., 2006). These rates seem unreasonably high at first blush, and, accordingly, were met by both researchers and the public with considerable skepticism (Susser et al., 2006).

In the mid-1980s, the technology of survey research developed to the point where diagnostic specific survey tools were available and validated for use by lay interviewers in large-scale community surveys. In the early 1980s, employing one such tool, the Diagnostic Interview Schedule (DIS), the National Institute of Mental Health-supported Epidemiologic Catchment Area study determined the diagnostic status of some 20,000 adults sampled from selected neighborhoods of five U.S. communities. This was followed with two rounds of the Kessler's National Comorbidity Survey (one in 1991–1992; and one in 2001–2002) which employed the Composite International Diagnostic Interview (CIDI) in a national probability sample.

These two sets of studies, when taken together, suggest that somewhere between 15% and 25% of adults ages 18–64 years currently suffer from one or more mental disorders (Susser et al., 2006). The data suggest that disorders are highly comorbid with one another and that many of these disorders typically have symptoms that began in childhood or adolescence. Also note that these diagnostic-focused national studies provided further support for the high prevalence of psychiatric impairment (previously met with public skepticism) and provided additional evidence that gender, social class, family dysfunction, and environmental adversity are key correlates of psychiatric disorder onset.

Increasingly, epidemiologists are concerned with and have documented the prominent role that psychiatric disorders have in the total pattern of morbidity and mortality nationally and worldwide as part of the World Health Organization's (WHO's) Global Burden of Disease initiative. Beginning in late 1990s, a revised version of the CIDI was administered in 30 countries worldwide. Based on these data, the specific burden of mental disorders on the USA was most recently summarized by Buka (2008; p. 977):

...according to the World Health Organization's estimates for 2002 (which have been sustained in more recent updates), mental health disorders are the leading cause of disability in the USA and Canada, accounting for 25% of all years of life lost to disability and premature mortality. Worldwide, it is estimated that mental disorders account for 12% of disability-adjusted life years. In terms of mortality, suicide alone is the 11th leading cause of death in the USA, with approximately 30,000 deaths per year.

Figure 2.1 reflects recent work by Eaton et al. (2008) that summarizes the global burden of psychiatric disorder by first indicating the worldwide 1 year prevalence of

Mental disorder	Median 1-year prevalence	Interquartile range	No. of studies found	No. of studies included
Panic disorder	0.9	0.6-1.9	486	33
Social phobia	2.8	1.1-5.8	296	30
Simple phobia	4.8	3.5-7.3	296	25
Major depressive disorder	5.3	3.6-6.5	3,935	42
Obsessive-compulsive disorder	1.0	0.6-2.0	293	19
Drug abuse/dependence	1.8	1.1-2.7	1,417	11
Alcohol abuse/dependence	5.9	5.2-8.1	1,646	14
Personality disorders	9.1	9.0-14.4	620	5
Schizophrenia	0.5	0.3-0.6	2,637	23
Bipolar disorder	0.6	0.3-1.1	865	16
Dementia (age >65 years)	5.4	3.2-7.1	2,979	25

Eaton et al. *Epidemiol Rev* 2008;30:1-14. Reprinted with permission from Oxford University Press.

Fig. 2.1 Prevalence of mental disorders* in adults in the 12 months prior to interview

major psychiatric disorders by diagnosis; these estimates are based on an extensive review of multiple US and international prevalence studies. Highlighting the most prevalent major psychiatric disorders, the estimates suggest that about 6% of the adult population suffered from alcohol abuse or dependence during the past year, over 5% of the adult population suffered from depression; and among the adult population over 65, more than 5% suffered from dementia.

Eaton et al. (2008) estimated the global burden of disease (GBD) for each of the diagnostic categories listed in Fig. 2.2. This includes an estimate of the GBD disability weight for certain disorders (based on expert rankings of symptom vignettes), as well as an indicator of the percentage of those with each disorder who have marked impairment on the Sheehan Disability Scale (which was administered as part of the WHO collaborative surveys). More importantly, they provide an estimate of the cost per year in the USA for each of the disorders.

Thus, for example, the score of 83 for bipolar disorder indicates that among those who suffer from this disorder, 83% report a severe disability in one or more of the four areas on the Sheehan Disability Scale. With respect to the Global Burden of Disease weight (GBD), for comparison sake, we know that multiple sclerosis has a GBD weight of 0.41, deafness 0.33, and blindness 0.62. The schizophrenia GBD weight of 0.50, the bipolar GBD weight of 0.40, and the major depressive disorder GBD weight of 0.35 underscores the severity of these relatively prevalent psychiatric disorders. The last column of the table highlights the US costs associated with each of these disorders. The costs are staggering. The costs associated with both alcohol abuse/dependence and drug abuse/dependence in the USA exceeds \$200 billion. The costs for major depression approach \$100 billion. By conceptualizing the burden of psychiatric disorders in terms of the years of disability that they cause, the WHO projected that depression will be the second leading cause of disability in the world by the year 2020, right behind cardiovascular disease (Susser et al., 2006; Üstün et al. 2004).

Mental disorder	GBD disability weight*	CPES % severe SDS disability†	Cost per annum in US dollars (billions)
Panic disorder	0.17	47	30.4
Social phobia	NA§	36	15.7
Simple phobia	NA	19	11.0
Major depressive disorder	0.35¶	58	97.3
Obsessive-compulsive disorder	0.13	47	10.6
Drug abuse/dependence	0.25	39#	201.6
Alcohol abuse/dependence	0.16¶	14#	226.0
Personality disorders	NA	NA	NA
Schizophrenia	0.53¶	NA	70.0
Bipolar disorder	0.40¶	83	78.6
Dementia (age >65 years)	NA	NA	76.0

*Global Burden of Disease (GBD) disability weights from Murray and Lopez, annex table 3, untreated form, age group 15-44 years.

† Percentage with marked or extremely severe impairment according to the Sheehan Disability Scale (SDS), as used in the Collaborative Psychiatric Epidemiologic Surveys (CPES). The SDS estimate for bipolar disorder was based on the most severe of the SDS rating for depression and mania. Bipolar disorder and its SDS estimate were present in the National Comorbidity Survey Replication (NCS-R) and National Survey of American Life (NSAL) components of the CPES. Obsessive-compulsive disorder and simple phobia and their SDS estimates were present in only the NCS-R component of the CPES.

§ NA, not applicable.

¶ Disability weights from Mathers et al. (2006); depression level is "moderate."

Dependence only.

Eaton et al. *Epidemiol Rev* 2008;30:1-14. Reprinted with permission from Oxford University Press.

Fig. 2.2 Disability and cost associated with mental disorders

The WHO report also underscores the extent to which treatment need is not met. Strikingly, the report points out that in developed countries, between 36% and 50% of those who were identified as having serious mental illness on the CIDI survey were untreated in the year before their interview; the gap is even greater in developing countries where over three quarters of serious cases received no treatment (The WHO World Mental Health Survey Consortium, 2004).

The cross-national variation is informative for another reason: it reminds us that when we aggregate across countries we may lose sight of critical differences that may relate to specific countries and specific diagnoses (recalling Durkheim), so it might be best to refocus with some U.S. specific data, and if possible, on specific disorders.

For example, the review by Mojtabai et al. (2009) suggests that with respect to those meeting the criteria for a diagnosis of schizophrenia in the USA 40% report not having received mental health treatment in the previous 6–12 months. Among those who report getting treatment, these authors indicate that their treatment falls short of the benchmarks set by evidence-based practice guidelines and that a lack of meaningful psychosocial treatments (as opposed to medication treatment) and a lack of continuity of care are particularly striking.

Epidemiologists have produced specific estimates related to prevalence of serious mental illness and unmet treatment need in the US general population in the

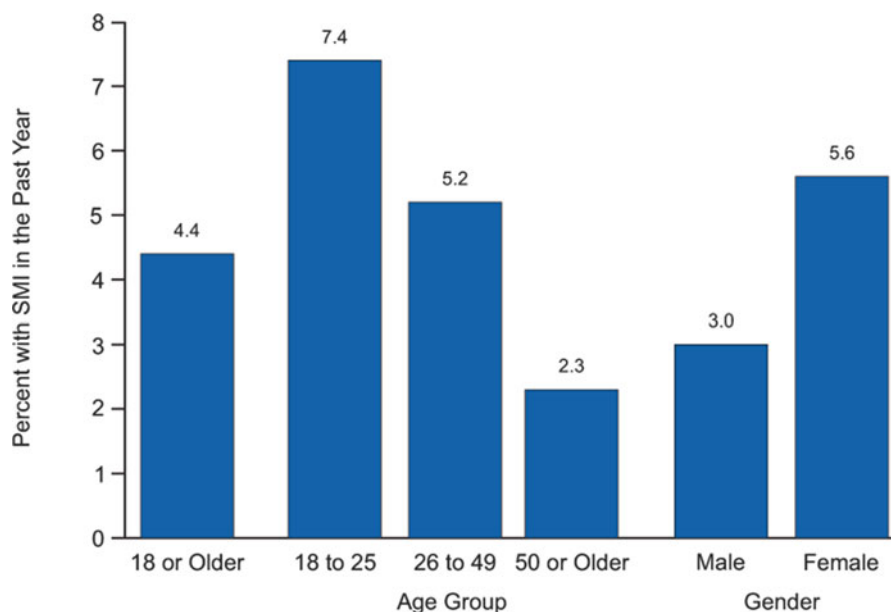


Fig. 2.3 Serious mental illness in the past year among adults aged 18 or older, by age and gender: 2008. <http://www.oas.samhsa.gov/nsduh/2k8nsduh/2k8Results.cfm#8.1.1>

annual National Survey on Drug Use and Health (NSDUH). In the last decade, the NSDUH survey has added questions about depression and serious psychological distress (via the K6 Scale) to its extensive and comprehensive national assessment of substance use problems in children and adults. In 2008, further modifications and enhancements were made to the survey (including additional questions about disability and follow-up clinical interviews with a sample subset) that facilitated estimates of what the US Office of Applied Studies terms “serious mental illness.” The NSDUH surveyed over 67,500 people ages 12 and older in randomly selected households in the USA using audio computer-assisted self-interviews (Substance Abuse and Mental Health Services Administration, 2009). In 2008, NSDUH estimated that about 4.4% of the adult population ages 18 years and older experienced serious mental illness (having a mental disorder plus “impairment” in functioning) during the past year (based on model estimates; see Fig. 2.3). That represents about 9.8 million adults. The figure shows that among the subgroups in the population, the 18–25 years old group experienced the highest rates and that women experienced higher rates than men. Also, not shown, the rates of SMI were higher among adults who were unemployed (8%). Respondents meeting the criteria for serious mental illness (SMI) reported significantly higher rates of substance dependence or abuse. Among adults with SMI in 2008, 25.2% were dependent on or abused illicit drugs or alcohol—this compares with 8.3% for non-SMI adults.

Overall, the NSDUH survey indicates that 2.5 million adults were estimated as having had both SMI PLUS substance abuse and dependence during the past year

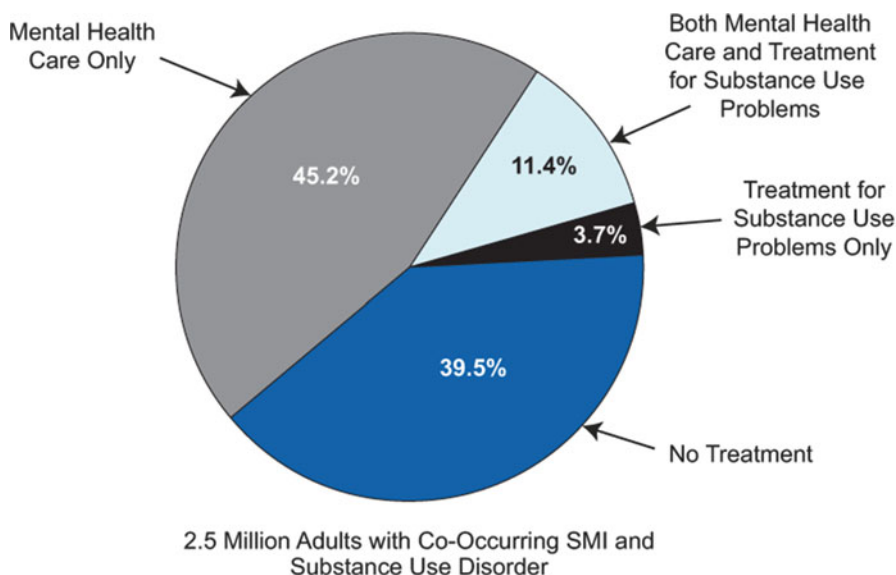


Fig. 2.4 Past year mental health care and treatment for substance use problems among adults aged 18 or older with both serious mental illness and a substance use disorder: 2008. <http://www.oas.samhsa.gov/nsduh/2k8nsduh/2k8Results.cfm#8.1.1>

in 2008. The pie chart in Fig. 2.4 underscores the limited nature of treatment being provided to those most in need of it. Nearly 60% reported receiving some type of treatment during the past year—most of the treatment was restricted to mental health services (i.e., their substance abuse was not directly addressed). Most strikingly, nearly 40% of this group with dual diagnosis issues received no treatment at all during the past year. While the rates of serious mental illness in this study are somewhat lower than we have seen in CIDI-based studies, these findings regarding unmet treatment need are consistent with the WHO data presented earlier.

Figure 2.5 is based on follow-up questions regarding reasons for not seeking treatment among those who self-identified as having an unmet need for treatment or counseling who also reported not receiving mental health services during the past year. Among the 5.1 million adults who reported an unmet need for mental health care and who *did not* receive mental health services in the past year (see Fig. 2.5), the primary barrier to care—affecting nearly 43% of these respondents—was affordability. Interestingly, nearly one in five within this group cited not knowing where to go for care as a reason for not receiving needed services.

Clearly, there may be important differences in location that may influence the nature of psychiatric disorders; it may not be completely valid to aggregate data across the 50 states. NSDUH provides statewide estimates of elevated rates of serious psychological distress (based on the average of multiple survey years) and of major depression alone (based on K6 algorithms; Hughes, Sathe, & Spagnola, 2009).

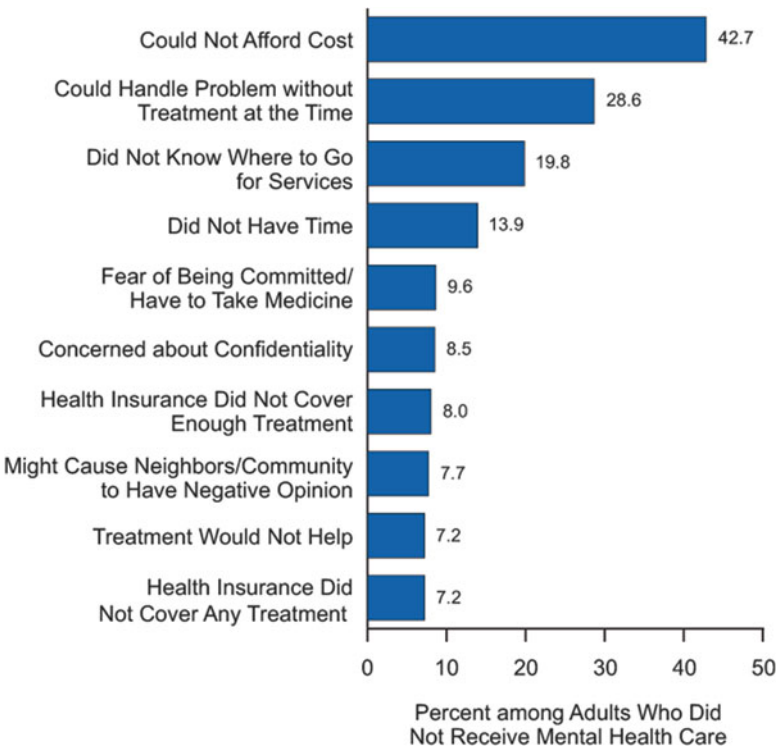


Fig. 2.5 Reasons for not receiving mental health services in the past year among adults aged 18 or older with an unmet need for mental health care who did not receive mental health services: 2008. <http://www.oas.samhsa.gov/nsduh/2k8nsduh/2k8Results.cfm#8.1.1>

The declining budgets in State Mental Health and Substance Abuse Systems treatment services locally and nationally have also been well documented. The [National Association of State Mental Health Program Directors \(NASMHPD\)](#), based on a survey of 42 states, determined that state mental health budget cuts of at least nearly 5% are evident in 32 states for FY 2009 and over 8% for FY 2010. We are also seeing increasing reports in the media that the criminal justice system is bearing a great deal of the burden for mental health care. A recent report in the New York Times documented the fact that juvenile justice systems around the country are being flooded with youths with severe mental illness—youths who previously may have been treated through their states’ mental health systems (Moore, 2009).

The Search for Cause: The Importance of Place

A core focus of epidemiology —part of the definition provided earlier—is the search for causes. We use that search to guide prevention strategies so that ultimately we can have an impact in reducing rates and preventing serious mental disorder

from occurring or persisting. Importantly, there has been renewed attention to the importance of this search. As part of this search, there has been renewed concern about the importance of “place” in the variability and distribution of disorder. This is reflected in three recent comprehensive summaries of the psychiatric literature appearing in the 2008 volume of *Epidemiological Reviews*. One paper focuses on the role of “place” in psychosis (March et al., 2008). Another focuses on neighborhood and depression (Kim, 2008). A third shows variability in rates of schizophrenia by region (McGrath, Saha, Chant, & Welham, 2008). These papers return the discipline of psychiatric epidemiology to its Durkheimian roots.

In his review of neighborhood and depression, Kim notes, “Across studies, the evidence generally supports harmful effects of social disorder and, to a lesser extent, suggests protective effects for neighborhood socioeconomic status” (Kim, 2008: p. 101).

An extensive and growing body of social science research underscores the conclusion that the qualities and characteristics of our neighborhoods can powerfully influence our life course. Recent research suggests that neighborhoods not only can affect the onset and course of severe mental illness, but they can also affect long-term academic achievement, sexual risk behavior and the prevalence of sexually transmitted diseases, the use of illicit drugs such as marijuana and cocaine and even high-risk drinking behavior among college students.

This focus on place—and other macro-level variables is coming at a time of great methodological and statistical advancement that has been facilitated by a set of methods called “multilevel modeling.” Previously, the approach to modeling risk factors for psychiatric outcomes had been primarily targeted toward individual level risk factors—variables that were measured at the person level—or characteristics of individual persons for whom behavioral outcomes were being studied (e.g., socioeconomic status, relationships with family members, personality characteristics and sociodemographic variables such as age, gender, and race/ethnicity).

Techniques for modeling causation at the individual level, however, have now advanced to the point where researchers can explore both individual and macro-level neighborhood influences simultaneously. For example, in recent work on high-risk college drinking outcomes in college students, researchers have used multilevel models to explore the influence of exposure to prevention programs, student achievement, and the availability of alcohol outlets and venues in the areas around campus (so-called alcohol outlet density; e.g. Scribner et al., 2008). Epidemiological researchers are advancing the field to search for causes through more complex models that systematically and centrally incorporate “place.”

Thus, the data and methodology are beginning to point to the notion that improving “place” or changing neighborhoods may be critical to transforming lives. This may be easier said than done. Neighborhood boundaries are subjective, complex, and unstable. In this era of twitter, texting, cell phones, blogging, and the Internet, the notion of what constitutes “place” is even more confusing and challenging. These new cyber communities may actually create new barriers, challenges, and risk for those with serious mental illness and those with limited access to technology. And these cyber places are distinct from the “real” places which desperately need our attention.

We can move forward in reducing the ever growing and seemingly insatiable demand for psychiatric services in the long run by understanding the mechanisms of neighborhood impact and the processes that lead to neighborhood improvement. This is not completely reduced to a monetary resource issue. Policy makers, researchers, and service providers are increasingly discussing strategies for improving local levels of “social capital”—community characteristics that promote participation in groups, activities and social networks for mutual benefit (see Putnam, 2002). Neighborhoods high in social capital are those where residents have high levels of trust in one another and where there are an abundance of activities characterized by voluntary efforts and reciprocal exchanges. Epidemiologists need to continue to develop, and refine this concept, systematically track social capital’s level and variation across neighborhoods and thoroughly investigate—through multilevel modeling procedures—its association with health and behavioral outcomes.

The idea of connecting those with serious mental illness in treatment or those who are reentering from treatment facilities (and prisons) to supportive networks and meaningful voluntary activities in the community—an idea that is clearly consistent with social capital theories—is probably as old as the discipline of social work itself. Many social workers are probably well aware of pockets of strength, where supportive community networks thrive despite dismal socioeconomic conditions.

Conclusions

Treatment providers’ insights regarding social capital are valuable to epidemiologists as we focus our work on describing neighborhood level risk and protective factors and statistically assessing their impact on mental health and other behavioral outcomes. As researchers we need to continue to clearly communicate our findings to you—to describe how variation across places and individuals affect the onset and course of psychiatric disorder. We also need to communicate our findings to the communities where we do the research and directly engage communities as much as possible in our research. The joint and collaborative efforts of epidemiologists, clinicians and social work practitioners, and community members, supported by enhanced federal funding for epidemiological and intervention research, may provide sufficient conditions for genuine improvements in the quality of place, ultimately *reducing* the burden of mental illness in our community.

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