

Helen C. Carey Memorial Lecture

Epidemiology of Substance Use and Mental Illness: Treatment Implications

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September 23, 2009

Introduction

I am honored to be asked to present a lecture named for a dedicated social worker who devoted her life to helping those who are neglected in so many ways in our society – the seriously mentally ill. I thank Diane Miller very much for all of her work arranging the details for this event. I want to thank my colleagues from University of Wisconsin-Milwaukee and the busy staff at Milwaukee County Behavioral Health and those from other local agencies who have taken time out of their busy day to attend today's lecture. I also want to thank Dean Stojkovic for inviting me to speak and for his kind introductory remarks.

I asked Stan to give me some background information about Helen Carey. Stan told me that as the site coordinator for field placements, Helen Carey was someone who created strong linkages between UWM social work trainees and Milwaukee County Behavioral Health. In my role as a faculty member and director of a research center at UWM (CABHR), I hope that today's event serves as an opportunity not only to reinforce those well established training linkages but to build and create new research collaborations and interests. I note that I have already had the pleasure of working with Walter Laux and Michael Nunnally in the design of an evaluation for a SAMHSA grant focused on expanding the Milwaukee County Drug Court. We recently heard that this project has been funded, so the basis for new collaborations has already begun.

I am going to talk to you today from my unique perspective as a survey researcher on addictions with training in psychiatric epidemiology. I want to contrast my way of

thinking with the typical clinical perspectives that many of you might have. Clinicians are critically important – but epidemiologists count –literally. I will present some recent data on trends in rates of illness and unmet treatment need. I will conclude by highlighting the critical importance of epidemiology as a perspective focused not just on describing rates but on searching for causes. In particular, I want to underscore epidemiology’s role in articulating the importance of “place” in risk for psychiatric illness and how multilevel research models – models accounting for both individual and community level risk factors can help to move us forward.

History

Let us begin with a definition and follow with some history: Psychiatric epidemiology is the study of the distribution, burden, and causes of mental illness and psychological distress in the community. The key word in that sentence is “**distribution;**” epidemiologists identify and sort cases by time and place in order to ultimately make inferences about causality.

The history that follows is adapted from the Susser et al.’s recent comprehensive review (Susser et al., 2006). The 1897 cross national European investigation of suicide conducted by Frenchman Emile Durkheim, may be considered one of the earliest examples of psychiatric epidemiology. Looking at official records on recorded suicides, Durkheim found that suicide rates were higher in so-called Protestant countries than they were in Catholic countries; in other words, rates varied by location (Durkheim, 1987). Durkheim concluded that it was not the countries’ religious orientation that was the key factor in the differences. He suggested that the patterns in suicide rates were due to

differences in the countries' social structure and the individual's place within it. In the early part of the 20th century, the so-called Chicago School of Social Ecology led by Farris and Dunham conducted a series of studies on the geographic patterns of mental disorders in Chicago neighborhoods. A key finding was that the concentration of schizophrenia was highest in inner city neighborhoods characterized by high levels of residential instability and social isolation and lowest in more affluent suburban areas; the reverse pattern was found for what was then called manic depression (Faris and Dunham, 1939). Thus, from its early days, psychiatric epidemiology was focused on the looking at how place influenced the distribution of rates.

Methodology

Over the course of subsequent decades and continuing to the present, epidemiologists have mainly focused on the use of large-scale social surveys to measure rates of distress and psychiatric disorder. 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. Indeed, this has been what much of my work in the area of substance abuse has involved over the past twenty years. Surveying randomly selected residents of urban households about drug use, high risk sexual behavior, and psychiatric symptoms. As you can imagine, there are numerous obstacles to our data collection efforts – I will not discuss them here – but it begs the question – why don't we just focus on collecting data from social service systems? Why do we have to go out into the community to recruit respondents and ask them all of these questions? As many of you may know, social

surveys are usually long and detailed measures that ask people about very uncomfortable things. 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 you contact people, they often do not want to be burdened with a lengthy set of intrusive questions. Why don't we just come down to Milwaukee County Behavioral health or Aurora's Dewey Center and use clinic records and interview patients to find out about prevalence, risk factors, and disease course?

Even if HIPAA were not a barrier, the need to base conclusions about prevalence, etiology and course on non-clinically derived samples is perhaps best supported by the concept of the clinician's illusion (as clearly articulated in a 1984 article by Jacob and Patricia Cohen; Cohen and 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 and 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 non-clinical samples. The most famous example of such a contradiction derives from Lee Robins' study of Vietnam Veterans: Quoting from Cohen and Cohen (1984):

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 United States, 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. (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 can not get a true sense of a disorder's onset, course, long term prognosis, correlates or etiology without doing community-based health surveys.

The problem, however, is that it is much easier for clinicians than it is for researchers to derive precise diagnoses, So early on in the field, researchers focused mainly on measures of non-specific distress.

Epidemiological Survey Results

The survey work that we do today, builds on a tradition first begun 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 (Srole et al., 1962; Leighton et al., 1963). 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). Susser and colleagues (2006) indicate that the findings of these original community surveys were met by both researchers and the public with considerable skepticism. Many thought that these rates seemed too high.

In the mid-1980's, 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 1980's, 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.

As summarized by Susser et al., (2006), these two sets of studies, when taken together, suggest that somewhere between 15 and 25% of adults ages 18-64 currently suffer from one or more mental disorders. 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 1990's, a revised version of the CIDI was administered in 30 countries worldwide. Based on these data, the specific burden of mental disorders on the U.S. was most recently summarized by Buka (2008):

...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 United States 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 United States, with approximately 30,000 deaths per year...

Show slide #1 (prevalence rates). The accompanying slide reflects recent work by Eaton and colleagues (Eaton et al., 2008) that summarizes the global burden of psychiatric disorder by first indicating the world wide one year prevalence of 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.

Show slide #2 (disability and cost). Eaton and colleagues (Eaton et al., 2008) estimated the global burden of disease for each of the diagnostic categories listed in the accompanying slide. 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 US 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 .41, deafness .33, and blindness .62. The schizophrenia GBD weight of .50, the bipolar GBD weight of .40, and the major depressive disorder GBD weight of .35, underscore 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 US exceed \$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; Usten et al., 2004).

Show slide #3 (unmet need). 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 (**see slide #3**; WHO World Mental Health Survey Consortium, 2004).

The cross national variation shown in slide 3 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 recently published review by Mojtabai and his colleagues (Mojtabai et al., 2009) suggests that with respect to those meeting the criteria for a diagnosis of schizophrenia in the U.S. 40% report not having received mental health treatment in the previous 6 to 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 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 US 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 during the past year (**based on model estimates; show slide #4: SMI prevalence table; this has to do with having a disorder plus significant impairment**). That represents about 9.8 million adults. The accompanying slide shows that among the subgroups in the population, the 18-25 year 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 (8.0 percent). 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.

Show Slide #5: Overall, the NSDUH survey indicates that 2.5 million adults were estimated as having had both SMI PLUS substance abuse or dependence during the past year in 2008. The accompanying pie chart underscores the limited nature of treatment being provided to those most in need of it. Nearly sixty percent reported receiving some type of treatment during the past year – most of the treatment was restricted to mental health services (that is., 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.

The next slide in the series (**show slide #6: unmet need reasons**) 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 slide #6**), 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.

Does it make sense to aggregate our data? Aren't there important differences by "place" that need to be accounted for even within the US? Additionally as service providers in Wisconsin, many of you may be interested in learning about how the potential demands for service directly affect your state and your city. Briefly, 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 et al., 2009). I will show you three maps that provide some Wisconsin specific data. **Show Maps here: (Slide #7, 8, 9)**. For adults, our rates of serious psychological distress and past year prevalence of major depressive episodes are under 12 and 9%, respectively; these rates are in the mid-range compared with other

states (**slides #7 & 8**) . More importantly, however, when we focus on adolescents, ages 12-17, prevalence of past year major depressive episodes of around 9%, stands out as considerably elevated compared with the rest of the United States (**slide #9**).

The data regarding psychiatric disorder prevalence and unmet service need are particularly bleak, especially in light of the increasingly limited public resources available for treatment. We all know about the huge proportion of citizens in our country lacking adequate health insurance that could pay for needed mental health services. And locally, even with the availability of Badger care and federal mental health parity guidelines, there are many holes in the system which limit the degree to which adequate care can be compensated (for example, the Badger Care plan does not fund *any* residential psychiatric treatment – something that may be necessary for acute psychiatric conditions).

The declining budgets in State Mental Health and Substance Abuse Systems treatment services locally and nationally have also been well documented (**see Slide #10: Service Cuts by State**). 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 FY2010. The map shown on the accompanying slide summarizes this and underscores that Wisconsin is very much part of this overall pattern. 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).

[A visit to an emergency mental health intake department here on a busy summer night – something that I experienced first hand earlier this summer when I accompanied a loved one – shows crowded, antiquated facilities, with patients literally sleeping in chairs as they wait many hours to be evaluated. Following an evaluation, patients may wait additional hours for transfer to an increasingly scarce inpatient bed. Patients were entertained by surrealistic black and white television blaring local programming featuring science fiction, Mr. Ed., and Patty Duke between the hours of 2 and five in the morning. The staff is extremely dedicated and hard working. This is not, however, a physical structure or treatment system that is built to accommodate any more people than are already being served.]

To paraphrase the late John F. Kennedy – I am not here to curse the darkness – but rather to light a candle. First of all – consider our prior discussion of the clinician's illusion: Things might not be as bad as they seem. Some portion of those classified via surveys as having serious mental illness may actually remit without interacting with the formal treatment system. Many or most in need get some treatment (usually psychotropic medication). Many patients will remit for long periods of time as a result.

The Search for Cause: The Importance of Place

But also consider that a core focus of epidemiology – part of the definition I gave 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, I note that 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. Three recent comprehensive summaries of the psychiatric literature appearing in the 2008 volume of *Epidemiological Reviews* – including one titled “Psychosis and Place,” (March et al., 2008) another “Blues from the Neighborhood? Neighborhood Characteristics and Depression” (Kim, 2008.) and an additional paper pointing out considerable variability in rates Schizophrenia by geographic region (McGrath et al., 2008) return our discipline to its Durkheimian roots.

In his review of neighborhood and depression, Daniel 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).

Additionally, I note that 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” (earlier this year, CABHR sponsored a two day workshop on this topic). Previously, our 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).

Our techniques for modeling causation at the individual level, however, have now advanced to the point where we 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). This is work we are extending at CABHR. Epidemiological researchers are advancing the field to search for causes through more complex models that systematically and centrally incorporate “place.”

Thus, our 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. Unfortunately, here

in Milwaukee, these real places have problems that may be rooted in economic disparities in a city that most recently was ranked as the seventh poorest in the nation.

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 (as sociologist Robert Putnam defines it). 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.

Epidemiologist 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 of you are probably well aware of pockets of strength, where supportive community networks thrive despite dismal socioeconomic conditions.

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.

Regarding this last point – it is heartening to note that the importance of direct community engagement is increasingly being recognized by research funders at the federal level, including NIH. This week, multiple RFAs were issued from the National Institutes of Health that actually contained the word “community” in the titles.

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. Thank you.

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