10-Year Research Update Review: The Epidemiology of Child and Adolescent Psychiatric Disorders: I. Methods and Public Health Burden

E. JANE COSTELLO, PH.D., HELEN EGGER, M.D., AND ADRIAN ANGOLD, M.R.C.PSYCH.

ABSTRACT

Objective: To review recent progress in child and adolescent psychiatric epidemiology in the area of prevalence and burden. Method: The literature published in the past decade was reviewed under two headings: methods and findings. Results: Methods for assessing the prevalence and community burden of child and adolescent psychiatric disorders have improved dramatically in the past decade. There are now available a broad range of interviews that generate DSM and ICD diagnoses with good reliability and validity. Clinicians and researchers can choose among interview styles (respondent based, interviewer based, best estimate) and methods of data collection (paper and pencil, computer assisted, interviewer or self-completion) that best meet their needs. Work is also in progress to develop brief screens to identify children in need of more detailed assessment, for use by teachers, pediatricians, and other professionals. The median prevalence estimate of functionally impairing child and adolescent psychiatric disorders is 12%, although the range of estimates is wide. Disorders that often appear first in childhood or adolescence are among those ranked highest in the World Health Organization’s estimates of the global burden of disease. Conclusions: There is mounting evidence that many, if not most, lifetime psychiatric disorders will first appear in childhood or adolescence. Methods are now available to monitor youths and to make early intervention feasible. J. Am. Acad. Child Adolesc. Psychiatry, 2005;44(10):972–986. Key Words: epidemiology, services, methods.

The focus of these two 10-year reviews is, unlike most in this series, not on a disorder or treatment but on an approach to thinking about disease. Many years ago, Tony Earls (1979) defined epidemiology as “an exact and basic science of social medicine and public health.” Epidemiology provides the scientific underpinnings for the prevention and control of disease across the spectrum of medicine, from infectious diseases like acquired immunodeficiency syndrome to chronic conditions like diabetes. Here we discuss how epidemiology in the past decade has increased our understanding of psychiatric disorders of childhood and adolescence.

Child and adolescent psychiatry came late to epidemiological research, and in one respect this is fortunate because a tremendous amount of empirical, theoretical, and statistical work has been done in other branches of medicine and psychology, from which we have been able to benefit. In the past 30 years, and outstandingly in the past decade, research in our area has caught up, and even, as in the innovative use of longitudinal epidemiological samples to study gene–environment interactions (Caspi et al., 2002, 2003; Foley et al., 2004), moved to the forefront of epidemiological research.

First, we explain what an epidemiological approach to child and adolescent psychiatry can offer, making clear Earls’s distinction between “public health epidemiology,” whose task is to monitor and reduce the burden of disease on the community, and “scientific epidemiology,” which uses epidemiological methods to...
understand the causes of mental illness (Earls, 1979). Then, we review how far epidemiology has progressed in its “public health” task of monitoring the burden of child and adolescent psychiatric disorder in the past decade. In Part II, we focus on epidemiology’s other task: to build a body of scientific information about what causes psychiatric disorders to occur when and where they do. We describe a major paradigm shift that has occurred in recent years: like child and adolescent psychiatry in general, epidemiology is beginning to incorporate developmental psychopathology into a new approach with a new name: developmental epidemiology.

WHAT IS EPIDEMIOLOGY?

Epidemiology is the study of patterns of disease in human populations (Kleinbaum et al., 1982). Patterns are nonrandom distributions, and patterns of disease distribution occur in both time and space. Whenever we observe a nonrandom distribution, we have the opportunity to identify causal factors that influence who gets a disease and who does not. For example, we observe that depression rises rapidly after puberty in girls, but not to the same extent in boys (Angold and Worthman, 1993). This nonrandom distribution in time suggests that there may be something about puberty in girls that is causally related to depression (Angold et al., 1998a). An example of disease distribution in space can be seen in the Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) study of five sites in the United States and Puerto Rico (Shaffer et al., 1996). Although the prevalence of psychiatric disorders was fairly similar across sites, the likelihood that a psychiatric diagnosis was accompanied by significant functional impairment was much higher in children at the mainland sites than in Puerto Rico. This offers the opportunity to study between-site differences that may result in differences in the level of impairment caused by psychiatric disorders. The task of epidemiology is to understand these observed patterns in time and space and to use this understanding as a basis for the prevention and control of disease.

Epidemiology has similarities to and differences from clinical medicine. Like clinical medicine, epidemiology is an action-oriented discipline whose goal is interventions to prevent and control disease. Scientific knowledge about the cause and course of disease is another common goal. Epidemiology also reflects clinical medicine in using two methods of attack on disease: tactical methods, concerned with the practical and administrative problems of disease control at the day-to-day level, and strategic methods, concerned with finding out what causes disease so that new weapons of prevention and control can be engineered (Earls, 1980; Susser, 1973). Thus, for example, in their tactical or public health role, epidemiologists can be found reporting on the prevalence of adolescent drug abuse and advising on how to control its spread, whereas others working at the strategic level may be exploring the science underlying environmental constraints on gene expression.

Epidemiology diverges from clinical medicine to the extent that it concentrates on understanding and controlling disease processes in the context of the population at risk, whereas the primary focus of clinical medicine is the individual patient. This does not mean that epidemiology is not concerned with the individual; on the contrary, it is very much concerned with understanding the individual’s illness and the causes of that illness. The difference lies in the frame of reference. Put crudely, clinical medicine asks, “What is wrong with this person and how should I treat him or her?” Epidemiology asks, “What is wrong with this person and what is it about him or her that has resulted in this illness?” Why is this child depressed, but not her brother? If her mother is also depressed, then is the child’s depression a cause, a consequence, or an unrelated, chance co-occurrence? Such questions immediately set the individual child within a frame of reference of other children, or other family members, or other people of the same sex or race or social class.

As the study of patterns of disease distribution in time and space, epidemiology encompasses a great deal more than simply counting noses. “Epidemiology counts” (Freedman, 1984), but it does far more than that. This review of the past decade shows just how much more epidemiology has begun to do in one of its final frontiers: child and adolescent psychiatric disorder.

EPIDEMIOLOGICAL METHODS: ASSESSING CHILD AND ADOLESCENT PSYCHIATRIC DISORDERS IN NONCLINICAL SAMPLES

Counting cases is an important first step toward measuring the social burden caused by a disease and the effectiveness of prevention. For most diseases, simply counting the number of individuals presenting for treatment will produce estimates that are seriously biased by referral practices, ability to pay, and other factors; a particular
problem in child psychiatry because parents, teachers, and pediatricians all serve as ‘gatekeepers’ to treatment (Horwitz et al., 1998). Community surveys are needed to measure the extent of need and unmet need for prevention or treatment.

A major task facing child and adolescent psychiatric epidemiologists is to develop assessment measures that accurately identify ‘true’ cases. In recent decades, this task has been understood as one of translating the disease taxonomies in current use (in practice, the ICD [World Health Organization, 1978, 1987] and the DSM [American Psychiatric Association, 1980, 1987, 1994]) into questionnaires, interviews, and other means for collecting the relevant information from individuals and coding it into diagnostic categories. A decade ago, child and adolescent psychiatric epidemiology was still struggling with the task of developing measures that accurately performed this task for nonclinical samples, preferably for reasons of cost, measures that could be administered without long-term clinical training. The process was made more challenging by the rapid revisions of the taxonomies, which kept moving the target, and by a lack of clarity in many areas of the symptom criteria. Several kinds of measures were needed, ranging in detail from those that mirrored best-practice clinical diagnosis as closely as possible to shorter screening questionnaires for use in the many settings in which full diagnostic assessments were not feasible.

Diagnostic Interviews

The decade since DSM-IV appeared has been marked by what could be seen either as surrender in the face of an insoluble problem or as a more mature approach to assessment. It became clear that (1) there is a limit to the degree of test-retest reliability achievable in psychiatric interviews, caused to a considerable extent by problems at the level of the taxonomy (what does ‘often loses temper’ really mean?); (2) diagnostic instruments now available, whether for parents, adolescents, or children older than 8 years, match the test-retest reliability of comparable instruments for adults (Angold and Fisher, 1999; Shaffer et al., 1999); (3) different informants will disagree not because the measuring instrument is faulty but because they really do see different aspects of a child (Kraemer et al., 2003); (4) there is no single best way to identify psychiatric disorders using face-to-face psychiatric interviews. All of the various types of diagnostic interview (e.g., respondent-based interviews, interviewer-based interviews, best-estimate diagnostic interviews) have shown similar levels of test-retest reliability and validity (Angold and Fisher, 1999). Statistical methods are being developed for optimally combining data from multiple informants (Kraemer et al., 2003) and across studies (Festa et al., 2000).

A result of these developments is that the National Institute of Mental Health (NIMH) has ended its period of special support for the development of a single psychiatric interview (the Diagnostic Interview Schedule for Children [DISC; Shaffer et al., 2000]). Researchers should decide which diagnostic interview to use based on the core questions that they want to answer in their study and the resources are available; for example, will the interviewers come from a survey research company or will they be trained and supervised by the research team?

The former tend to be good at conducting respondent-based interviews such as the DISC, in which each question is fixed. When more intensive training and supervision of interviewers are possible, it has been shown that lay interviewers using a structured interview such as the Child and Adolescent Psychiatric Assessment (CAPA; Angold and Costello, 2000) are capable of making what would once have been called ‘clinical judgments’ about the presence and severity of symptoms and are less likely to overidentify rare symptoms, such as those of psychosis (Breslau, 1987).

Are clinically qualified ‘best estimators’ available to make a final judgment if the fixed questions leave the interviewer unsure of how to code a symptom? If so, then it is feasible to use an interview such as the Development and Well-Being Assessment (DAWBA; Goodman et al., 2000), which combines highly structured questions with additional material, if necessary.

Do the Study Questions Require Categorical Diagnoses or Symptom Scales or Both? All of the interviews described here generate diagnoses. Most also produce symptom scales created by adding the number of positive symptoms. These can be useful provided that the focus is on the symptoms that go into a formal diagnosis and not on any other related symptoms, or on the frequency, duration, or intensity of symptoms. If this kind of information is needed, however, the choice is between instruments such as the CAPA, which incorporate these features, and interviews designed for clinicians, such as the Schedule for Affective Disorders and Schizophrenia for School-Age Children (Ambrosini, 2000; Shane et al., 1997).

Extensions of Psychiatric Interviews

A great deal of progress has been made in expanding the range of instruments and modalities available for making formal psychiatric diagnoses. Here, we describe some of these developments.

Assessing Psychiatric Disorders in Preschool Children. Just as in the 1980s, child and adolescent psychiatrists discovered that it was possible to generate reliable diagnostic information from structured interviews with school-age children, so in the past decade, they have discovered that structured interviews with parents of children 2 to 5 years old yield reliable responses that map onto DSM-IV diagnostic categories.

Major efforts have been made to create a clear taxonomy of early childhood disorders (Angold and Egger, 2004; Boris et al., 2004; Luby et al., 2003; Scheeringa et al., 2003; Stafford et al., 2003). Several new instruments have been developed for this age group (Carter et al., 2003; Egger and Angold, 2004; Wakschlag et al., 2002). A young child version of the DISC is under development (see http://www.c-disc.com). Work is also going on at several sites to integrate these parent measures with reliable assessments of affect and behavior that can be used directly with young children, such as the MacArthur Story-Stem Battery (Emde et al., 2003) and the Berkeley Puppet Interview (Ablow and Measelle, 1993; Measelle et al., 1998).

Assessing Psychiatric Disorders in Young Adults. When participants in a longitudinal study are interviewed with a measure designed for children one year and one designed for adults the next, year-to-year differences may reflect changes in method as much as developmental changes. Two diagnostic interviews for children and adolescents have developed instruments relevant to adolescents moving out of the home and into independent lives. The DISC has a young adult version in preparation (see http://www.c-disc.com) and the CAPA has a version available for adolescents living away from home and for young adults (the Young Adult Psychiatric Assessment [Angold et al., 1999]). Both are designed to be used with the participant alone, without supporting information from a parent, as is customary with younger individuals.

Alternative Methods of Data Collection. The standard method of data collection until recently has been, as in the clinical field, the face-to-face interview with the child and/or parent. The interviewer usually asked questions from a printed schedule and recorded responses the same way; the latter were then entered into computer
files and coded using specially written algorithms that followed the logic of the diagnostic taxonomy (DSM or ICD). Many alternatives are being developed and tested. First, most interviews have or are developing computerized versions of the standard interview. These may simply transfer the paper-and-pencil interview to a laptop computer, so that the interviewer reads the same questions from the screen as he or she would from the paper schedule and keys to the responses. The advantage here is that the data are entered directly into a database, cutting out an expensive and error-prone phase in data collection. These programs may also prevent the interviewer from entering out-of-range information and guide him or her through sets of branching questions. Examples of computerized interviews are the DISC, a version of the Diagnostic Interview for Children and Adolescents (Reich, 2000), and the Preschool Age Psychiatric Assessment (Egger and Angold, 2004).

A second development has been to provide the child or parent with direct access to the computerized interview, cutting out the interviewer. The respondent may read the questions on the screen or listen to them through earphones, or both. Examples of this approach are the “voice DISC” (see http://www.c-disc.com), and the audio-CASI (computer-assisted self-completed interviewing) sections of the CAPA (see http://devepi.mc.duke.edu). There is evidence that respondents will report more information, particularly about sensitive topics such as abuse and drug use, than they will face to face with an interviewer (Des Jarles et al., 1999; Metzger et al., 2000; Taylor et al., 1999).

Third, investigators have been working on adding visual cues to the verbal forms of questioning in the hope that this will improve the validity of psychiatric interviewing with younger children or those with lower levels of cognitive development. Picture interviews based on the verbal forms of questioning in the hope that this will improve the viewer (Des Jarles et al., 1999; Metzger et al., 2000; Taylor et al., 1999).

Third, investigators have been working on adding visual cues to the verbal forms of questioning in the hope that this will improve the validity of psychiatric interviewing with younger children or those with lower levels of cognitive development. Picture interviews based on the verbal forms of questioning in the hope that this will improve the viewer (Des Jarles et al., 1999; Metzger et al., 2000; Taylor et al., 1999).

Other Languages. Most of the major assessment instruments have now been translated into Spanish. The DAWBA, which was used for the recent national survey of British children, has online versions in English, Norwegian, Portuguese, and Spanish (http://www.dawba.com/b0.html), and the DISC is available in at least 10 languages (Web site under construction), whereas the CAPA and Preschool Age Psychiatric Assessment also exist in several languages, including Spanish and French. International comparisons are becoming a real possibility.

Screening for Psychiatric Disorder

Brief lists of questions or questionnaires completed by the child, teacher, parent, and/or clinician are widely used to assess psychopathology, much more so than are full psychiatric interviews. Screening instruments are often used in schools, primary care pediatric offices, and with high-risk groups such as children in juvenile justice settings, as well as in national surveys. Thus, it is important to review progress in this field.

Screens have two main types of use: to estimate prevalence rates of a given problem at the level of the population and to identify individual children as being at high risk of a disorder so that they can be selected for further evaluation, clinical services, or preventive interventions. Evidence from the past decade has shown that there are important differences in the utility of brief screens, depending on the purpose for which they are used.

Screening as Epidemiological Tools. Brief screening measures are widely used as components of nationally representative “surveillance studies,” discussed later in this section. They may be completed by parent, teacher, or child or some combination of these. When children themselves have completed such questionnaires in school settings, these have tended to be anonymous surveys (e.g., Alcohol and Drug Defense Program, 1991; Johnston et al., 1996; Stevens et al., 1995; Swanson et al., 1992).

Screening or “indicator” measures may be used in several ways in studies of representative population samples. They may be used as a substitute for, or approximation of, psychiatric interviews, in studies short on time or trained staff. If the sensitivity (proportion of true cases identified) and specificity (proportion of true noncases identified) of the screen in relationship to an accepted criterion, such as a psychiatric interview, are acceptable, then it can be used to estimate population prevalence rates. Screens are used in this way, for example, in the National Longitudinal Survey of Children and Youth (Bennett and Offord, 2001) and the Dutch national survey (Verhulst et al., 1997). Work to develop a screen for use in conjunction with the National Health Interview Survey in the United States is in progress (Bourdon et al., 2005). They may be used as the first stage in a multistage protocol designed to increase the number of likely “cases” for more detailed assessment at a later stage, e.g., Isle of Wight study (Rutter et al., 1970), the Great Smoky Mountains Study (Costello et al., 1996b), Caring for Children in the Community (Angold et al., 2002), the Pittsburgh Youth Study (Loeb et al., 2001). They may be used for follow-up of subjects in longitudinal protocols where frequent contact is required (Farmer et al., 1999) and where change in symptom levels may be more important than change in diagnostic status.

Screening instruments make two sorts of errors: they identify children as cases when they are not (false positives) and they miss true cases (false negatives). Nevertheless, when a screening instrument has good test-retest reliability and validity relative to the criterion measure, it can do three useful things:

1. It can provide a useful approximation of population prevalence, even when it makes errors, provided that the false-positive and false-negative errors are reasonably balanced.

2. Screens tend to be inexpensive and intensive interviews expensive. It is sometimes possible to screen a large sample and randomly select a certain proportion with different screen scores for detailed assessment. With the right sampling design, this can help to reduce sample size (and cost) without too great an increase in variance; indeed, if correctly used it can reduce variance and increase power (Erkanli et al., 1997, 1998, 1999).

3. A screening questionnaire can reduce subject burden, which is particularly important in nonclinical and longitudinal studies.

In short, screens can be useful epidemiological tools, if carefully used.

Screening as Tools for Identifying High-Risk Children. Physicians, social workers, teachers, and other professionals working with a broad range of children are anxious for epidemiologists to use their expertise in instrument development to produce “indicators” for service use (Kohler and Rigby, 2003). The idea is that primary care professionals and others can use a brief measure to identify children who should be offered treatment or referred for specialist evaluation. Screens are often used by nonpsychiatric professionals who have a responsibility, whether legal (mandatory) or professional (ethical), to identify children who they believe could be helped by psychiatric or social work treatment. Front-line professionals are uniquely well placed to serve as gatekeepers to specialty care (Gardner et al., 2004; Sayal and Taylor, 2004). They deserve all of the help that
we can give them. Surprisingly little work has been done recently to examine the validity of the measures that they most often use to identify high-risk children or the decisions that they may base on them (Armbuster and Kazdin, 1994; Cassidy and Jellinek, 1998; Farrington et al., 1996; Horwitz et al., 1998; Stancin and Palermo, 1997) or to develop new, more sensitive instruments for them.

Different traditions of screening have grown up in school and primary care clinics. Screens in schools tend to use an adult as informant (e.g., Teacher’s Report Form [Achenbach, 1991], Rutter B Scale [McGee et al., 1985], Conners Teacher Rating Scale [Conners et al., 1998], or to use child self-report, as for example in screening for suicidality [Shaffer et al., 2004]). On the whole, teachers have done better at identifying children with behavioral problems than children with emotional problems (Kolko and Kazdin, 1993; Verhulst et al., 1994). The evidence that suicide screens are adequate for case identification is not encouraging (Patton et al., 1997; Pfeffer et al., 2000; Shaffer et al., 2004). For example, using the Columbia Suicide Screen, of 100 youths identified as high risk on this screen, only 7 met the DISC criterion of suicidal ideation or attempt, plus depression or dysthymia or substance abuse/dependence (Shaffer et al., 2004).

Primary care research, in contrast, has tended to employ parents as informants (Campos et al., 1999; Horwitz et al., 1992; Jellinek et al., 1999; Lavigne et al., 1993; Merritt et al., 1995; Riekert et al., 1999; Simonian et al., 1991). Some pediatricians are beginning to experiment with adolescent screens for drug or alcohol abuse, and, less frequently, depression (Ellen et al., 1998; Middleman et al., 1995; Schwartz and Wirtz, 1990).

The usefulness of available brief questionnaires as “indicators” of service need is under review in an NIMH-funded study (A. Erkanli, personal communication). An NIH work group is exploring the feasibility of using analyses of existing data sets to develop a brief set of “indicators” of need for mental health referral, for use by parents, teachers, or primary care providers (Jensen, personal communication). The demands on screening measures used to identify individuals are much higher than the demands on those used for prevalence studies. They must accurately indicate that this particular child is at high risk. False positives and false negatives do not cancel out in this case but do compound the inaccuracy of the screen.

Evidence about the value of available screens for identifying high-risk individuals is depressing. As would be expected when the task is to identify uncommon disorders in the general population, most measures show good ability to select out noncases (i.e., good predictive value negative), but they identify far too many children as potential cases who do not meet full diagnostic criteria at interview (poor predictive value positive). They also miss a substantial proportion of those with the disorder (poor sensitivity), even when they are good at identifying those who do not have the disorder (good specificity). However, even good specificity can be dangerous if it is not good enough. If a disorder is rare, then most of the cases identified by even a pretty good screen will be false positives. There are financial, emotional, ethical, and possibly legal costs to both false positives and false negatives.

An example of the pitfalls of screens as indicators at the individual level is presented by Patton et al. (1999), who screened adolescents for depression using modules of a self-completion computerized version of the Clinical Interview Schedule, a structured psychiatric interview (Monck et al., 1994). The criterion measure was the widely used Composite International Diagnostic Interview (Wittchen et al., 1991). Even using a highly detailed screen, only 49% of those identified were true cases, whereas the screen missed 82% of the adolescents with diagnosed with depression by the Composite International Diagnostic Interview. This level of accuracy throws serious doubts on our ability at present to use brief screens to identify individual children at risk, however useful they may be at the level of population estimates. This is a critical area of work for epidemiology in the next decade.

SURVEILLANCE FOR CHILD AND ADOLESCENT PSYCHIATRIC DISORDERS: ESTIMATING THE BURDEN OF DISEASE

In the past decade, progress has been made not only in epidemiological methods but also in using them to assess the prevalence of child psychiatric disorder. In a world of scarce healthcare resources, it is important to understand the size of the burden to the community caused by these disorders. Burden, in terms of numbers affected, has an impact on the individual, and cost to the community is a crucial factor in the battle for resources for treatment and prevention. One of the most important developments in epidemiology in the past decade is not specific to child and adolescent psychiatry but extends to the way the burden of illness in general is perceived and measured. In 1996, the World Health Organization (WHO), together with the World Bank and the Harvard School of Public Health, published the first volume of *The Global Burden of Disease* (Murray and Lopez, 1996), whose subtitle is *A Comprehensive Assessment of Mortality and Disability From Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020*. Until this publication, diseases tended to be ranked in public health importance in terms of their impact on mortality rates. The WHO project has undertaken the task of weighing the impact of diseases in terms of nonfatal as well as fatal health outcomes. The unit of measurement adopted is disability-adjusted life-years (DALYs), which measure the number of expectable years of life lost (to death) or lived with disability.

Using this unit of measurement has revealed a drastically different picture of the global burden of disease from that seen when only mortality is counted. Above all, it has demonstrated the public health burden of psychiatric disorders. For example, Table 1 shows the 10 leading causes of DALYs in developed regions of the world, for the age range 15–44 (data for children older than age 4 years are not available separately). Unipolar major depression has the highest number of DALYs associated with it, and all but one (osteoarthritis) of the 10 leading causes of DALYs is either a psychiatric disorder (schizophrenia, bipolar disorder, obsessive-compulsive disorders) or strongly associated with psychiatric disorder.
in the epidemiological literature (alcohol use, road traffic accidents, self-inflicted injuries, drug use, violence). Together the nine psychiatry-related conditions cause more than 50% of all DALYs. Thus, policymakers are being forced to pay serious attention to psychiatric disorders as leading causes of suffering, lost opportunity, and economic cost to their communities.

As we discuss in Part II, there is ever-increasing evidence that many psychiatric disorders are already present, or nascent, in childhood and adolescence. Attempts to reduce the burden of mental illness must out of necessity pay attention to the early years. It is also clear from the population-based studies reviewed later in this article that a large number of children and adolescents suffer from psychiatrically induced disability. This has become a focus of much research in the past decade (Canino et al., 1999; Costello et al., 1996a; Ezpeleta et al., 2000; Foley et al., 2003; Giaconia et al., 2001; Hodges and Gust, 1995; Pickles et al., 2001), especially since WHO published the International Classification of Functioning (World Health Organization, 2001), a radical revision of its 1980 International Classification of Impairments, Disabilities, and Handicaps (World Health Organization, 1980). Work is progressing on a screening questionnaire for children and adolescents to accompany WHO’s brief Disability Assessment Schedule for adults (Janca et al., 1996).

Public Health Surveillance of Child and Adolescent Psychiatric Disorder

For most medical conditions, it is the public health agencies, chiefly the Centers for Disease Control and Prevention (CDC), who keep tabs on the impact of diseases on the public health. CDC is the surveillance arm of medicine, producing regular reports on morbidity, mortality, and, in some cases, risk factors. In the past 10 years, and especially after the publication of the Global Burden of Disease, the CDC has paid a great deal more attention to child and adolescent mental disorder. Since 1991, the CDC’s Youth Risk Behavior Surveillance System has surveyed suicidality, drug use, and risk-taking behaviors, using anonymous questionnaires administered in schools. The data are useful for tracking rises and falls of these problems, at least as reported by youths attending school. On the whole, rates have been fairly steady since 1991 (see http://www.cdc.gov/HealthyYouth/yrbs/factsheets.htm). For example, rates of physical violence have decreased somewhat, and 12-month rates of attempted suicide have remained constant at around 8%, whereas rates of contemplating or planning suicide have fallen. Reported cigarette use has fallen steadily, use of marijuana rose through 1997 and has since fallen, whereas use of cocaine doubled through 1999 and has since held steady. This kind

<table>
<thead>
<tr>
<th>Rank</th>
<th>Disease or Injury</th>
<th>DALYs (thousands)</th>
<th>Cumulative %</th>
<th>Disease or Injury</th>
<th>DALYs (thousands)</th>
<th>Cumulative %</th>
<th>Disease or Injury</th>
<th>DALYs (thousands)</th>
<th>Cumulative %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Unipolar major depression</td>
<td>7,574</td>
<td>12.3</td>
<td>Alcohol use</td>
<td>4,677</td>
<td>12.7</td>
<td>Unipolar major depression</td>
<td>4,910</td>
<td>19.8</td>
</tr>
<tr>
<td>2</td>
<td>Alcohol use</td>
<td>5,477</td>
<td>21.2</td>
<td>Road traffic accidents</td>
<td>4,167</td>
<td>23.9</td>
<td>Schizophrenia</td>
<td>1,450</td>
<td>25.7</td>
</tr>
<tr>
<td>3</td>
<td>Road traffic accidents</td>
<td>5,304</td>
<td>29.7</td>
<td>Unipolar major depression</td>
<td>2,664</td>
<td>31.1</td>
<td>Road traffic accidents</td>
<td>1,137</td>
<td>30.3</td>
</tr>
<tr>
<td>4</td>
<td>Schizophrenia</td>
<td>3,028</td>
<td>34.7</td>
<td>Self-inflicted injuries</td>
<td>2,072</td>
<td>36.8</td>
<td>Bipolar disorder</td>
<td>1,106</td>
<td>34.7</td>
</tr>
<tr>
<td>5</td>
<td>Self-inflicted injuries</td>
<td>2,641</td>
<td>38.9</td>
<td>Schizophrenia</td>
<td>1,578</td>
<td>41.0</td>
<td>OCDs</td>
<td>933</td>
<td>38.5</td>
</tr>
<tr>
<td>6</td>
<td>Bipolar disorder</td>
<td>2,241</td>
<td>42.6</td>
<td>Drug use</td>
<td>1,404</td>
<td>44.8</td>
<td>Alcohol use</td>
<td>801</td>
<td>41.7</td>
</tr>
<tr>
<td>7</td>
<td>Drug use</td>
<td>1,829</td>
<td>45.5</td>
<td>Violence</td>
<td>1,196</td>
<td>48.1</td>
<td>Osteoarthritis</td>
<td>783</td>
<td>44.9</td>
</tr>
<tr>
<td>8</td>
<td>OCDs</td>
<td>1,652</td>
<td>48.2</td>
<td>Ischemia heart disease</td>
<td>1,160</td>
<td>51.2</td>
<td>Chlamydia</td>
<td>599</td>
<td>47.3</td>
</tr>
<tr>
<td>9</td>
<td>Osteoarthritis</td>
<td>1,634</td>
<td>50.9</td>
<td>Bipolar disorder</td>
<td>1,135</td>
<td>54.3</td>
<td>Self-inflicted injuries</td>
<td>569</td>
<td>49.6</td>
</tr>
<tr>
<td>10</td>
<td>Violence</td>
<td>1,507</td>
<td>53.3</td>
<td>HIV</td>
<td>911</td>
<td>56.7</td>
<td>Rheumatoid arthritis</td>
<td>549</td>
<td>51.8</td>
</tr>
</tbody>
</table>

Public Health Surveillance of Child and Adolescent Psychiatric Disorder

For most medical conditions, it is the public health agencies, chiefly the Centers for Disease Control and Prevention (CDC), who keep tabs on the impact of diseases on the public health. CDC is the surveillance arm of medicine, producing regular reports on morbidity, mortality, and, in some cases, risk factors. In the past 10 years, and especially after the publication of the Global Burden of Disease, the CDC has paid a great deal more attention to child and adolescent mental disorder. Since 1991, the CDC’s Youth Risk Behavior Surveillance System has surveyed suicidality, drug use, and risk-taking behaviors, using anonymous questionnaires administered in schools. The data are useful for tracking rises and falls of these problems, at least as reported by youths attending school. On the whole, rates have been fairly steady since 1991 (see http://www.cdc.gov/HealthyYouth/yrbs/factsheets.htm). For example, rates of physical violence have decreased somewhat, and 12-month rates of attempted suicide have remained constant at around 8%, whereas rates of contemplating or planning suicide have fallen. Reported cigarette use has fallen steadily, use of marijuana rose through 1997 and has since fallen, whereas use of cocaine doubled through 1999 and has since held steady. This kind
of tracking is important for deciding whether a problem
is becoming more or less of a public health burden and
can also be used on occasion to check the effects of a pre-
ventive intervention. Other sources of information for
tracking risk behaviors are CDC’s National Health Inter-
view Survey and the National Health and Nutrition
Examination Survey, both of which are seeking ways to
incorporate more information about psychiatric disor-
ders into their surveillance of the national burden of dis-
ease. The National Health Interview Survey is using
a psychiatric screening questionnaire for children 4–
17 years old in its national household surveys of health
and service use. The Strengths and Difficulties Quest-
ionnaire (Goodman, 1999) is widely used in the United
Kingdom and many other countries. The full Strengths
and Difficulties Questionnaire was used in the National
Health Interview Survey in 2001, 2003, and 2004, and
CDC developed a brief (six-item) version for use in
2002 and in future years (Bourdon et al., 2005). Pre-
liminary results extrapolated from interviews of 9,878
families in 2002 show that 5.5% of U.S. children 4–
17 years old were reported by a parent to have definite
or severe difficulties with emotions, concentration, be-
havior, or being able to get along with other people.
Twice as many boys as girls (7.5% versus 3.5%) were
reported to have “mental health problems.” The per-
centage of children with mental health problems was
higher in families with incomes below the federal pov-
erty level (11%).

These estimates are much lower than those from de-
tailed psychiatric interview studies and need to be vali-
dated against full psychiatric assessments. Data should
be available soon from studies around the world using
both the Strengths and Difficulties Questionnaire and
detailed psychiatric interviews, including the latest round
of the National Comorbidity Study in the United States,
which includes a sample of some 3,000 adolescents (Ron
Kessler, personal communication), a study of 300 pre-
school children (Egger and Angold, 2004), and a sample
of 1500 9–17 year olds recruited from a primary care
pediatric setting (A. Erkanli, personal communication).

Other Surveys of Prevalence and Burden

There has never been a nationally representative sur-
vey of the prevalence and burden of child and adolescent
psychiatric disorder in the United States. The United
Kingdom has recently carried out a national prevalence
study (Ford et al., 2003; Meltzer et al., 2003b), and it
deserves attention as a first for child and adolescent
psychiatry.

The British survey was conducted by the Office for
National Statistics, with funding from the Department
of Education and other agencies. The primary purpose
was to produce prevalence estimates of conduct, emo-
tional, and hyperkinetic disorders as well as pervasive
developmental disorders, eating disorders, and tic dis-
orders, using both ICD-10 and DSM-IV criteria. The
second aim was “to determine the impact or burden
of children’s mental health. Impact covers the conse-
quences for the child; burden reflects the consequences
for others” (Meltzer et al., 1999). Third, the study mea-
sured service use. A stratified random sampling plan for
England, Scotland, and Wales produced a sample of
10,438 children ages 5–15 years. Parent and child were
interviewed using the DAWBA (Goodman et al.,
2000), a computer-assisted lay interview that uses
a “best-estimate” approach to diagnosis. The first inter-
view wave, conducted in 1999, was followed by a mailed
questionnaire 18 months later and a second interview
3 years after the first.

Nationally representative data on older adolescents can
also be extrapolated from the 479 15- to 17-year-olds in-
cluded in the first U.S. National Comorbidity Survey
(NCS; Kessler, 1994). Although publications from the
NCS have not focused much on the adolescents (Kessler
and Walters, 1998; Miller et al., 2000), the data set is
publicly available for analysis of this subgroup, and
the NCS replication study in progress will oversample
adolescents ages 13 and older. Other studies have carried
out similar single-wave surveys of child and adolescent
psychiatric disorders based on smaller geographic areas,
and some updates from longitudinal epidemiological
studies have also been published in the past decade (re-
viewed in Costello et al., 2004). Figure 1 presents a sum-
mary of data from these studies.

A few general conclusions can be drawn from the
data. First, between 3% and 18% of children have a psy-
chiatric disorder causing significant functional impair-
ment (the federal definition of serious emotional
disturbance [Federal Register, 1993]). The median es-
timate of serious emotional disturbance is 12%, more
than twice that generated from the National Health In-
terview Survey screen. The implication for clinicians
and policymakers is that at any time one child in eight
has an impairing psychiatric disorder.
Research in the past decade has made it clear that prevalence rates are highly dependent on the extent to which the algorithms used to make the diagnosis include or ignore functional impairment. The DSM-IV itself is somewhat inconsistent on this topic: Some symptoms and diagnoses require impaired functioning to be present, and others do not. It is clear from two papers that present prevalence estimates with and without impairment (Canino et al., 2004; Shaffer et al., 1996) that rates can be dramatically affected by this; for example, in the Methods for the Epidemiology of Child and Adolescent Mental Disorders study, the prevalence of DSM-III-R simple phobias varied 30-fold, from 0.7% to 21.6%, depending on how impairment criteria were applied.

Additional studies in the past decade have only served to confirm this (Briggs-Gowan et al., 2000; Burns et al., 1995; Horwitz et al., 1998; Leaf et al., 1996; Sawyer et al., 2001; Wu et al., 1999). They have, however, added depth to our understanding of who receives services and why.

Evidence has accumulated for child mental health care disparities associated with age (Olfson et al., 1998), income (Witt et al., 2003), insurance status (Briggs-Gowan et al., 2000), geographical location (Sturm et al., 2003), and family characteristics (Angold et al., 1998b). The NCS and the Ontario Health Survey both showed that the likelihood of receiving treatment during the year of onset of a depressive disorder was 14 to 15 times higher for adults 30–54 years old than it was for children 0–12 years old (Olfson et al., 1998). A similar, though somewhat smaller, disparity in likelihood of prompt treatment was seen for many other disorders. Family income has a confused relationship with access to care. The National Health Interview Survey Disability Supplements showed family financial burden as a barrier to care (Witt et al., 2003), but the survey study of Horwitz et al. of public assistance in Connecticut showed no association with use of mental health care for children (Briggs-Gowan et al., 2000). Whereas health insurance would be expected to mediate access to care, there is growing evidence that children with private insurance are at a disadvantage as compared with
publicly insured children in obtaining access to needed care (Burns et al., 1997; Weller et al., 2003; Witt et al., 2003). The gap between need and use is seen not only in the United States but also in countries with more comprehensive healthcare systems (John et al., 1995; Meltzer et al., 2003a; Sawyer et al., 2001; Waddell et al., 2002). Within the United States, geographical disparities in access to services have also been documented (Sturm et al., 2003), often outweighing the effects of race/ethnicity or income. Thomas and Holzer (1999) have pointed out that in the United States, the distribution of child and adolescent psychiatrists is inversely proportional to that of children living in poverty.

An important consideration in children’s access to mental health care is their dependence on others, primarily parents, to negotiate the system, make appointments, physically transport them, and pay for treatment. Characteristics of the family such as the perceived burden of the child’s problems (Angold et al., 1998b; Teagle, 2002) and family history of mental illness (Johnson et al., 2001) have been shown to have a major impact on a child’s chance of receiving needed care in the specialty mental health system. Only when school-based services are available are children sometimes able to seek help for themselves (Farmer et al., 1999, 2003).

A worrisome finding from epidemiological studies of mental health service use is the race/ethnic disparities in access to needed care. A review of the literature (Elster et al., 2003) found that in six of nine studies, African American adolescents received fewer mental health services than did white youths, whereas the other three showed no differences. In three of six studies, Hispanic youths received fewer mental health services, whereas the other three studies showed no differences. Two studies of rural youths in North Carolina found that African American youths were as likely as white youths to receive mental health services through schools, juvenile justice, child welfare, or pediatric primary care providers, but were only half as likely to receive care from psychiatrists or psychologists in specialty mental health settings (Angold et al., 2002). Another study compared white with Native American youths (Costello et al., 1997). There was no overall difference in the likelihood of receiving mental health care, but Native American youths were more than twice as likely as white youths to have used inpatient services at some time.

Another index of access to care is the distribution of spending on mental health treatment across different age groups. We know enough from prevalence studies to be able to say with some confidence that the proportion of children having a psychiatric disorder, with or without impairment, is remarkably similar to that estimated for adults (Costello et al., 1998; Kessler et al., 1994, 1996; U.S. Public Health Service, 1999). A recent study of national spending for mental health and substance abuse (MH/SA) treatment (Harwood et al., 2003) shows the following distribution of expenditures: 11% on those younger than age 18 and 89% on the rest of the population. Another way to look at the picture is to estimate spending on MH/SA treatment as a proportion of all healthcare spending. Harwood and colleagues estimate that 9% of the healthcare spending on children and adolescents went to MH/SA treatment ($9.6 billion), compared with 11% of the healthcare spending on adults ($65.2 billion). It should be noted, however, that these figures do not include counseling and psychological treatment provided through the educational system, which provides mental health care to more children (although not necessarily more treatment sessions) than do medical or specialty mental health services (Burns et al., 1995; Farmer et al., 1999; Wu et al., 1999). The fact remains that one ninth of the money devoted to MH/SA treatment in the United States is being devoted to the youngest one fourth of the population.

There have been major changes during the past decade in the conditions under which mental health services are being provided and the settings in which they are provided. The dramatic move from inpatient to outpatient treatment of young people was already under way in the late 1980s (Kiesler and Simpkins, 1991), whereas a move to managed behavioral health is more recent, and an increase in pharmacologic treatments occurred in the 1990s for two of the most common disorders, attention-deficit/hyperactivity disorder and depression. Probably as a result of this, the extent to which mental health conditions are diagnosed and treated in pediatric primary care settings has risen dramatically: from 1.1 million visits in the mid-1980s to 4.5 million visits in the late 1990s (Glied and Cuellar, 2003).

Effectiveness of Interventions to Prevent and Treat Child Psychiatric Disorder

It may be argued that the reason for the gap between need for and use of mental health services is the lack of effective MH/SA treatments for children and
adolescents. The topic of how effective child mental health treatments are, how far they have improved in the past decade, and how the perception that treatment is appropriate and effective influences service use, is too unwieldy for this review (Kazdin, 1996). There is no doubt, as recent surveys have shown (Burns et al., 1999), that treatments that work are available for a wide range of child and adolescent disorders. The question for epidemiology is whether interventions of known effect are really having an impact at the community level.

Since the 1980s, John Weisz’s meta-analytic reviews of the effectiveness of psychotherapy have shown that even treatments that worked well in the controlled environment of a research clinic had minimal effects in the real world (Weisz and Jensen, 1999). In the past decade, controlled trials in real-world settings, such as the Fort Bragg experiment (Bickman et al., 1995) have shown disappointing outcomes using traditional data analytic methods (Salzer et al., 1999).

A major methodological problem with observational studies of real-world treatment settings is that children who receive needed care may be different in many ways from those who do not receive treatment. The usual method for dealing with this problem—random allocation to treatment and control status—is often impossible in the real world. Two recent studies have found ways to overcome the problem to some extent. Foster (2003) reanalyzed the Fort Bragg data using propensity score modeling (Rosenbaum and Rubin, 1983), a method that matches cases and controls using a composite score of potential confounders of the treatment-outcome relationship. Foster found a dose-response relationship between number of treatment sessions and children’s level of functioning, but no dose-response effect on symptoms (measured using the Child Behavior Checklist). Taking a different approach, Angold et al. (2000a) suggested that treated and untreated children with psychiatric symptoms may differ in the trajectory of their symptoms before entering treatment. They found that treated individuals were more severely disturbed and showed deterioration in their clinical status, even before they received treatment, indicating that comparisons with untreated individuals required controls not only for pretreatment clinical status but also for pretreatment clinical trajectory. A significant dose-response relationship was found between the number of specialty mental health treatment sessions received and improvement in symptomatology at follow-up.

No effect of treatment on secondary psychosocial impairment or parental impact was identified, however.

Psychotropic Medication. Monitoring the use of mental health care also requires monitoring the use of psychotropic medications, and this has been an area of growing concern. A review of two Medicaid databases and a large health maintenance organization, published in 2003 but referring to 1987–1996, found that the 1-year period prevalence of psychotropic medication use grew to 6% of youths younger than 20 years old, a two-to almost a threefold increase over 10 years. Most of the temporal change occurred between 1991 and 1996 (Zito et al., 2003). Medication rates for children are approaching those of adults. For example, the 1996 federal Medical Expenditure Panel Survey showed a 4.1% psychotropic medication rate for 6–17 year olds and a 5.0% rate for 18–44 year olds (Zuvekas and Taliaferro, 2003), and Stein et al. (2001) found that in a population with private insurance in 1998, there was a 4.3% psychotropic medication rate for 1–17 year olds as compared with 4.7% for adults. There is no evidence that the use of psychotropic medications for children and adolescents is falling since these papers were published.

Recent research has begun to document a worrisome aspect of the treatment of psychiatric disorders in children and adolescents—its lack of consistency with treatment guidelines. Olfson (2003) used the Medical Expenditure Panel Survey data to show that whereas many children with depression (especially uninsured and African American youths) did not receive treatment, “antidepressant medications were used far more commonly than would be expected on the basis of published treatment recommendations.” In a study of the use of stimulant medication in the general population, Angold et al. (2000b) found that “stimulant treatment was being used in ways substantially inconsistent with current diagnostic guidelines.” Whereas three fourths of children with attention-deficit/hyperactivity disorder received stimulants, the majority of children receiving stimulants was never, during a 3-year period, reported by parents to have any impairing attention-deficit/hyperactivity disorder symptoms.

There is no question that many psychiatric disorders impose a huge social burden in terms of disability and public and private expenditures (e.g., Cohen et al., 1994; Glied and Neufeld, 2001; Harwood et al., 1998; Kind and Sorensen, 1993; Scott et al., 2001). There is also evidence that improved treatment and/or case management
can reduce these costs (Dubowitz, 1990; Lave et al., 1998). For example, Foster et al. (2004) used data from two evaluation studies to show that better mental health services reduced the risk of involvement with the juvenile justice system by around 30%. Furthermore, effects were more pronounced for the more serious offenses. One of the tasks of epidemiology in the next decade will be to monitor trends in treatment and prevention and the impact on the prevalence and burden of child and adolescent mental illness.

CONCLUSIONS: WHAT HAVE WE LEARNED IN THE PAST DECADE ABOUT THE BURDEN OF CHILD AND ADOLESCENT PSYCHIATRIC DISORDERS?

From the public health viewpoint, child and adolescent psychiatric epidemiology in the past decade can be said to have come to terms with reality. It has stopped agonizing over how many children have this or that disorder as if there were a "true" answer to the question. It is now clear that measures of psychopathology, whether they take the form of interviews, questionnaires, or so-called objective tests, can be set to generate a wide range of prevalence estimates, depending on the severity of the scoring criteria used. Also, they can only be as good as the taxonomy that they are designed to operationalize. Given the status of our taxonomies (currently DSM-IV and ICD-10), the highly structured psychiatric interviews developed by epidemiologists are the closest that we are going to get to a gold standard for diagnosis. As was established decades ago for adults, structured interviews are infinitely more reliable than clinical judgment and have high validity vis-à-vis clinicians (Robins et al., 1982). There is little difference in psychometric properties among the various styles of interview, whether they are respondent based, such as the DISC, or interviewer based, such as the CAPA, or use a best-estimate approach, such as the DAWBA. Choice should be dictated by the task at hand. If screening questionnaires are needed, then there is a large range available, most of which work reasonably well at the population level. However, screens cannot be used to replace detailed psychiatric assessments, and even if used to identify high-risk children for more detailed assessment, they will identify large numbers of false positives and false negatives.

Substantively, we can say with certainty that only a small proportion of children with clear evidence of functionally impairing psychiatric disorder receive treatment. Once upon a time, when effective treatments for child and adolescent psychiatric disorders were rare, this was regrettable but not a major public health issue. Now it is. The tragedy is compounded by powerful evidence that most psychiatric disorders have their origins early in life: risk even for adult-onset disorders is often increased by childhood adversities, and disorders manifesting themselves in the early years often recur in adulthood. So the public health directive to intervene early is clear (Insel and Fenton, 2005), but the reality is different. The youngest one fourth of the population receives one ninth of the treatment dollars. A review of NIMH research funding shows that research on children is seriously underfunded. The role of primary and secondary prevention in child and adolescent mental health has never been the focus of serious planning at the federal level. The WHO has made it inescapably clear that psychiatric disorders with their origins in childhood are a major contributor to the "global burden of disease." The task of the next decade is to develop national and international policies to move research, prevention, and treatment resources to where they are most needed. The task of child and adolescent psychiatric epidemiology, in its public health role, is to monitor that process.

Disclosure: Dr. Egger holds a Pfizer Foundation Faculty Scholar Award in Clinical Epidemiology. The other authors have no financial relationships to disclose.

REFERENCES

Alcohol and Drug Defense Program (1991), Alcohol and Other Drug Use Patterns Among Students in North Carolina Public Schools Grades 7–12: Results of a 1991 Student Survey. Raleigh: North Carolina Department of Public Instruction


Angold A, Cox A, Prendergast M et al. (1999), The Young Adult Psychiatric Assessment (YAPA). Durham, NC: Duke University Medical Center


Angold A, Erkanli A, Farmer EMZ et al. (2002), Psychiatric disorder, impairment, and service use in rural African American and white youth. Arch Gen Psychiatry 59:893–901


58 Fed Reg 29425 (1993)


Foley DL, Eaves LJ, Wormley B et al. (2004), Childhood adversity, monoamine oxidase A genotype, and risk for conduct disorder. *Arch Gen Psychiatry* 61:738–744


Foster EM, Qaseem A, Connor T (2004), Can better mental health services reduce the risk of juvenile justice system involvement? *Am J Public Health* 94:859–865

Freedman DX (1984), Psychiatric epidemiology counts. *Arch Gen Psychiatry* 41:931–933


Insel TR, Fenton WS (2005), Psychiatric epidemiology: it’s not just about counting anymore. *Arch Gen Psychiatry* 62:590–592


Johnson SD, Stiffman A, Hadley-Ives E, Elze D (2001), An analysis of stresseors and co-morbid mental health problems that contribute to youth’s paths to substance-specific services. *J Behav Health Serv Res* 28:412–426


Kessler RC, McGonagle KA, Zhao S et al. (1994), Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: results from the National Comorbidity Study. *Arch Gen Psychiatry* 51:6–19

Kessler RC, Walters EE (1998), Epidemiology of DSM-III-R major depression and minor depression among adolescents and young adults in the National Comorbidity Survey. *Depress Anxiety* 7:3–14


Kohler L, Rigby M (2003), Indicators of children’s development: considerations when constructing a set of national Child Health Indicators for the European Union. *Child Care Health Dev* 29:551–558


Leaf PJ, Horwitz SM, Leventhal JM et al. (1990), Primary care pediatrics: what is required, what is done. Presented at the Annual Meeting of the Academy of Child and Adolescent Psychiatry, Chicago, October.


U.S. Public Health Service (1999), Mental Health: A Report of the Surgeon General, Rockville, MD: Department of Health and Human Services


