



HHS Public Access

Author manuscript

Health Promot Pract. Author manuscript; available in PMC 2018 May 15.

Published in final edited form as:

Health Promot Pract. 2017 January ; 18(1): 5–7. doi:10.1177/1524839916677730.

Interpreting the Prevalence of Mental Disorders in Children: Tribulation and Triangulation

Joseph R. Holbrook, PhD, MPH¹, Rebecca H. Bitsko, PhD¹, Melissa L. Danielson, MSPH¹,
and Susanna N. Visser, DrPH¹

¹Centers for Disease Control and Prevention, Atlanta, GA, USA

Abstract

Knowledge on the prevalence of mental disorders among children informs the work of many health care providers, public health researchers, educators, and policy makers, and any single data source and study methodology can provide valuable insight. However, it is only after prevalence estimates from complementary studies are considered together that distinctions can be made to more deeply inform an assessment of community needs, including diagnosed prevalence versus underlying prevalence, differences between insured and uninsured populations, and how estimates change over time. National surveys, community-based studies, and administrative claims data each provide a different type of information that builds broad understanding. This article presents some of the overarching complexities of the issue, discusses strengths and weaknesses of some common data sources and methodologies used to generate epidemiological estimates, and describes ways in which these data sources complement one another and contribute to a better understanding of the prevalence of pediatric mental disorders.

Keywords

child/adolescent health; epidemiology; mental health

INTRODUCTION

Determining the prevalence of a condition is a fundamental epidemiological responsibility. Data on a condition's prevalence inform health care providers on how often they may expect to diagnose a specific condition and assist policy makers and administrators in assessing community needs and allocating prevention and treatment resources. However, characterizing the prevalence of mental disorders is particularly challenging for a variety of reasons. Rather than a definitive number, discussions on the prevalence of mental disorders often becomes a narrative on the broader characterization of these conditions, their diagnosis, and changes in diagnosis rates (Perou et al., 2013). This article provides an overview of different data sources and surveillance methods for pediatric mental disorders,

Address correspondence to Joseph R. Holbrook, Division of Human Development and Disability within the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, 4770 Buford Highway, MS E-88, Atlanta, GA 30341, USA; vzt4@cdc.gov.

The findings and conclusions of this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

describes their relative strengths and limitations, and suggests how they may be triangulated to describe disorder prevalence.

SYSTEMATIC COMPLEXITIES

In the United States, mental disorders are primarily diagnosed and classified according to criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013). Diagnostic criteria for each disorder include symptom presence and select specifiers including functional impairment, age of onset, and symptom duration. Over time, the *DSM* has been revised to reflect improved and expanded understanding of mental disorders, most recently in 2013 with the release of *DSM-5*. These changes have the potential to affect the number of children who meet disorder criteria. For example, a higher percentage of children meet criteria for attention deficit hyperactivity disorder (ADHD) using *DSM-5* criteria than would using *DSM-IV* (4th ed., American Psychiatric Association, 1994; McKeown et al., 2015), while a lower percentage of children meet criteria for an autism spectrum disorder under *DSM-5* than *DSM-IV* (Maenner et al., 2014). In addition to changes in diagnostic criteria, other sources of variation in prevalence estimates across studies and over time may be due to methodological differences in data collection, an actual change in the disorder's underlying prevalence, or a combination of these factors.

Variability in culture—a group's shared set of traditions, beliefs, norms, and values—is another issue with broad implications for estimating the prevalence of mental disorders. Cultural subgroups that are less likely to report symptoms and less likely to seek mental health treatment would also be less likely to meet diagnostic criteria or be diagnosed. This is complicated further when examining mental disorders among children, as the parent or caregiver is typically the primary informant and the person seeking help. Poor access to care—known to be more common among some demographic groups—will also affect prevalence estimates based on diagnosis (Council on Community Pediatrics, 2013).

DATA SOURCES AND SURVEILLANCE METHODS

National Surveys

Surveys of parents reporting on their children have long been used to gather health-related information, including the National Health Interview Survey (NHIS), which has been conducted since 1957 (Centers for Disease Control and Prevention [CDC], 2016). Other national surveys that periodically collect information on mental disorders include the National Survey of Children's Health (NSCH; CDC, 2016), the National Health and Nutrition Examination Survey (CDC, 2016), and the National Survey on Drug Use and Health (Substance Abuse and Mental Health Services Administration, 2016). Some of these recurrent surveys offer opportunities for follow-back surveys to gather additional information on children with selected diagnoses (CDC, 2016). The large sample sizes and sampling approach of national surveys allow for estimates that are representative at the national level (and some at the state level), allow for inspection of temporal trends, and provide the opportunity to make comparisons to other health indicators among children with and without mental disorders. However, parent surveys are subject to recall and reporting

biases, and response rates of telephone-based surveys (e.g. NSCH) have decreased over time (CDC, 2016). Also, both the NHIS and NSCH rely on parent report of diagnoses, which assumes accurate diagnosis by clinicians and reporting by parents. Additionally, methodological changes made between periods of data collection may affect the resulting prevalence estimates; one example is the effect of adding cell phone samples in telephone-based surveys (Blumberg & Luke, 2015). These factors present limitations when using national parent surveys for examining trends: Changes in parent-reported prevalence over time may be due to changes in survey methodology, changes in reporting by parents, changing diagnosis patterns by providers, or true changes in the underlying prevalence of the condition.

Administrative Databases

The availability and use of administrative data (i.e., health care claims) for research have increased in recent years, including in prevalence estimation of childhood mental disorders. Analysts are now equipped with the computing power to make use of these large data sets, while owners of these databases continue to invest in cleaning and preparing these data for external use. Administrative records representing both public and private insurance have been used to track diagnosed mental disorders and service use (Getahun et al., 2013; Visser et al., 2016). However, because administrative records' primary purpose is billing, they have limitations for research. For example, providers may use diagnosis or procedure codes on a claim only if they link to reimbursement. Also, researchers using administrative data may use different case definitions or analytic choices (e.g., number of claims, time span between claims) to identify the same disorder, making direct comparisons across studies difficult. Finally, administrative data usually include only insured populations, and data sets offered for analysis may represent only a convenience sample of an insured population. These limitations of administrative data must be considered alongside their strengths when used as a data source to investigate diagnosis of, and service use for, mental disorders and to estimate the related economic burden.

Community-Based Studies

Community-based studies offer the opportunity to gather information via direct observation or report, with the potential to engage multiple reporters. With this approach, information about specific symptoms and community diagnoses has greater depth and breadth than from most other data sources. In addition, this approach allows for the assessment of the impact of case definition on prevalence estimates, as a stricter case definition may result in a lower prevalence estimate (McKeown et al., 2015). The National Comorbidity Survey–Adolescent Supplement (Kessler et al., 2009) stands out as a community-based study that was also nationally representative, though it was conducted only once.

In addition to generating greater detail about specific population characteristics, community-based studies can provide information on undiagnosed and untreated children who meet criteria, along with children who receive treatment but do not meet criteria. These children may be receiving appropriate treatment and as a result no longer meet diagnostic criteria, or they may have been misdiagnosed. Children who are effectively treated for a mental disorder may exhibit subthreshold symptoms and therefore no longer meet criteria. In this case, the

community prevalence based on direct assessment would underestimate the disorder's true prevalence. Alternatively, including all treated children as cases may overestimate true prevalence if some children are being unnecessarily treated. Other limitations of community-based studies include issues of generalizability, noncoverage bias, sample size, response rates, and capacity of research personnel to conduct diagnostic assessments.

An Application

A recent publication illustrated the importance of careful interpretation when comparing prevalence estimates from studies of differing methodologies (Visser, Danielson, Bitsko, Perou, & Blumberg, 2013). The prevalence of diagnosed ADHD in a database of southern California medical records was considerably lower than national parent-reported estimates from NSCH (4.9% vs. 9.5%; Getahun et al., 2013). However, NSCH data limited to insured children in California with the same age range of the medical record comparison group provided an estimated diagnosed prevalence of 4.6% (Visser et al., 2013). After accounting for some of the extenuating factors that made these two groups demographically quite different, this study provided convergent validity between parent report and medical record indication of ADHD diagnoses in children.

CONCLUSIONS

Any single data source and study methodology can provide valuable insight into the prevalence of pediatric mental disorders. However, results from complementary studies considered together can be more deeply informative with regard to diagnosed prevalence versus true prevalence, differences between insured and uninsured families, and how these numbers change over time. National surveys, community-based studies, and administrative claims data each provide different types of information that build understanding of disorder prevalence, community needs, and associated changes over time. Additional research is needed to better understand results attained from multiple data sources and surveillance methods. Until then, it is important for health care providers, public health researchers, and policy makers to carefully interpret similarities and differences in reported prevalence estimates derived from different surveillance methods.

References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th. Washington, DC: Author; 1994.
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th. Washington, DC: Author; 2013.
- Blumberg SJ, Luke JV. Wireless substitution: Early release of estimates from the National Health Interview Survey, January–June 2015. 2015. Retrieved from <http://www.cdc.gov/nchs/nhis/releases.htm#wireless>
- Centers for Disease Control and Prevention. National Center for Health Statistics. 2016. Feb 19, Retrieved from <https://www.cdc.gov/nchs/>
- Council on Community Pediatrics. Community pediatrics: Navigating the intersection of medicine, public health, and social determinants of children's health. *Pediatrics*. 2013; 131:623–628.
- Getahun D, Jacobsen SJ, Fassett MJ, Chen W, Demissie K, Rhoads GG. Recent trends in childhood attention-deficit/hyperactivity disorder. *JAMA Pediatrics*. 2013; 167:282–288. DOI: 10.1001/2013.jamapediatrics.401 [PubMed: 23338799]

- Kessler RC, Avenevoli S, Costello JE, Green JG, Gruber MJ, Heeringa S, Zaslavsky AM. Design and field procedures in the US National Comorbidity Survey Replication Adolescent Supplement (NCS-A). *International Journal of Methods in Psychiatric Research*. 2009; 18(2):69–83. [PubMed: 19507169]
- Maenner MJ, Rice CE, Arneson CL, Cunniff C, Schieve LA, Carpenter LA, Durkin MS. Potential impact of DSM-5 criteria on autism spectrum disorder prevalence estimates. *JAMA Psychiatry*. 2014; 71:292–300. [PubMed: 24452504]
- McKeown RE, Holbrook JR, Danielson ML, Cuffe SP, Wolraich ML, Visser SN. The impact of case definition on attention-deficit/hyperactivity disorder prevalence estimates in community-based samples of school-aged children. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2015; 54:53–61. DOI: 10.1016/j.jaac.2014.10.014 [PubMed: 25524790]
- Perou R, Bitsko RH, Blumberg SJ, Pastor P, Ghandour RM, Gfroerer JC, Huang LN. Mental health surveillance among children—United States, 2005–2011. *MMWR Surveillance Summaries*. 2013; 62(Suppl 2):1–35.
- Substance Abuse and Mental Health Services Administration. National Survey on Drug Use and Health frequently asked questions. 2016. Retrieved from <https://nsduhweb.rti.org/respweb/faq.html>
- Visser SN, Danielson ML, Bitsko RH, Perou R, Blumberg SJ. Convergent validity of parent-reported attention-deficit/hyperactivity disorder diagnosis: A cross-study comparison. *JAMA Pediatrics*. 2013; 167:674–675. DOI: 10.1001/jamapediatrics.2013.2364 [PubMed: 23700143]
- Visser SN, Danielson ML, Wolraich ML, Fox MH, Grosse SD, Valle LA, Peacock G. Vital signs: National and state-specific patterns of attention deficit/hyperactivity disorder treatment among insured children aged 2–5 years—United States, 2008–2014. *Morbidity and Mortality Weekly Report*. 2016; 65(17):443–450. [PubMed: 27149047]