Chapter Two

National Utilization of Mental Health Services

National Estimates of U.S. Children with ADHD, LD, or Emotional/Behavioral Difficulties and Their Use of Mental Health Services

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Introduction

Approximately 2.6 million U.S. school aged children have mental health difficulties (Bourdon, Goodman, Rae, Simpson & Koretz, 2005; Simpson, Bloom, Cohen, Blumberg & Bourdon, 2005), but many are not receiving the mental health services they need (Burns et al., 1995; President's New Freedom Commission, 2003). In response to the need for national data on mental health services, the National Institute of Mental Health and the Center for Mental Health Statistics, Substance Abuse and Mental Health Services Administration collaborated with the National Center for Health Statistics (NCHS) to include new questions on mental health services for children 4 to 17 years of age in the 2005 National Health Interview Survey (NHIS). The purpose of this presentation is to use the new NHIS questions to provide national estimates of children with attention-deficit hyperactivity disorder (ADHD), learning disability (LD) or emotional and behavioral difficulties and their use of mental health services.

Methods

The NHIS collects health and demographic data on family members annually using a nationally representative sample of the noninstitutionalized civilian population. Data collection is done throughout the year by Bureau of the Census interviewers. In each family, one child under 18 years of age (the "sample child") is selected at random, and an informed adult, usually the parent, is asked for additional information about the child's health and use of health services. In 2005, Black and Hispanic Americans were over-sampled in order to provide increased sample sizes for analyses of these groups. There were 9,642 sample children 4 to 17 years of age in the 2005 NHIS. The final response rate was 86.1% for the sample child portion of the survey[1].

Estimates were calculated by using the NHIS survey weights, which are calibrated to the 2000 Census-based population. Point estimates and estimates of their variances were calculated using SUDAAN software to account for the complex sample design of the NHIS (Research Triangle Park, 2004).

Questions Used to Identify Children with ADHD, LD, or Emotional/Behavior Difficulties

- ADHD was identified by a positive response to, "*Has a doctor or health professional ever told you that (child's name) had Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)?*"
- LD was identified by a positive response to the question, "*Has a representative from a school or a health professional ever told you that (child's name) had a learning disability?*"
- For emotional/behavioral difficulties the adult was asked, "*Overall do you think that (child's name) has difficulties in any of the following areas: emotions, concentration, behavior, or being able to get along with other people?*" A child was considered to have emotional/behavioral difficulties, if the adult responded positively to the following answer categories, "*Yes, definite difficulties,*" or "*Yes, severe difficulties.*"

Mental health services presented here included a visit with a general doctor "*for an emotional or behavioral problem,*" contact with a mental health professional, receipt of special education services, contact with a health provider or school staff about an emotional or behavioral difficulty, having taken prescribed medication for an emotional or behavioral difficulty, having taken prescribed medication for ADHD symptoms, and having received treatment other than medication for emotional or behavioral difficulties. A child may have received more than one type of service. Unmet medical need is defined as the child getting delayed medical care because of worry about the cost, or the child not getting needed medical care, prescription medicine, mental health care or counseling, eyeglasses, or dental care.

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[1] *Additional information about the NHIS is available on the NHIS Web site: www.cdc.gov/nchs/nhis.htm.*

Results

Overall, 7% of U. S. children 4-17 years of age were reported to have ADHD (10% of all males and 4% of females), 7% LD (9% of males and 6% of females), and 5% definite or severe emotional/behavioral difficulties (5% of males and 4% of females). More than one-third of these children were reported to have more than one of these conditions. Older children aged 12 to 17 years had higher prevalences of these conditions than children aged 4 to 11 years (ADHD: 9% versus 5%, LD: 9% versus 6%, and emotional/behavioral difficulties: 6% versus 4%). There were no significant differences between non-Hispanic white and non-Hispanic Black children. However, Hispanic children had lower prevalences of these conditions than either non-Hispanic White or non-Hispanic Black children.

Family structure was significantly related to whether children were reported to have ADHD, LD or emotional/behavioral difficulties. Higher percentages of children living with their mother only had ADHD (9%), LD (9%), and emotional/behavioral difficulties (7%) compared with children living with both parents (ADHD 6%, LD 6%, and emotional/behavioral difficulties 4%) and children living with their father only (ADHD 7%, LD 7%, and emotional/behavioral difficulties 4%).

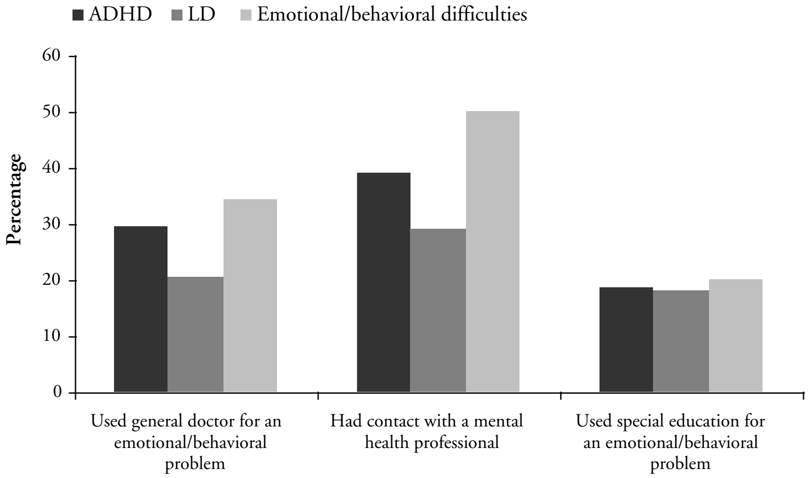
There were also significant differences by poverty and health insurance status. Children living in families with incomes less than 100% of the poverty level had higher reported prevalences of ADHD (8%), LD (11%), and emotional/behavioral difficulties (7%) compared with other children. Higher percentages of children with public health insurance coverage had ADHD (9%), LD (11%), and emotional/behavioral difficulties (7%) than children who had private health insurance (ADHD 6%, LD 6%, and emotional/behavioral difficulties 4%) and children who were uninsured (ADHD 5%, LD 6%, and emotional/behavioral difficulties 5%).

Use of mental health services is shown in Figures 1 and 2. Among children with ADHD, approximately 68% had contact with a health care provider or school staff about an emotional/behavioral difficulty, and over 50% took prescribed medicine for ADHD. Among children with emotional/behavioral difficulties, over 80% saw a health care provider or school staff about an emotional/behavioral difficulty, and 50% had contact with a mental health provider. Compared with children who did not have ADHD, LD or emotional or behavioral difficulties, children with these conditions had a higher percentage of unmet medical need. The percentages of children with unmet medical need were 17% for children with ADHD, 22% for children with LD, 25% for children with emotional or behavioral difficulties, and 11% for children who did not have these conditions.

Conclusion

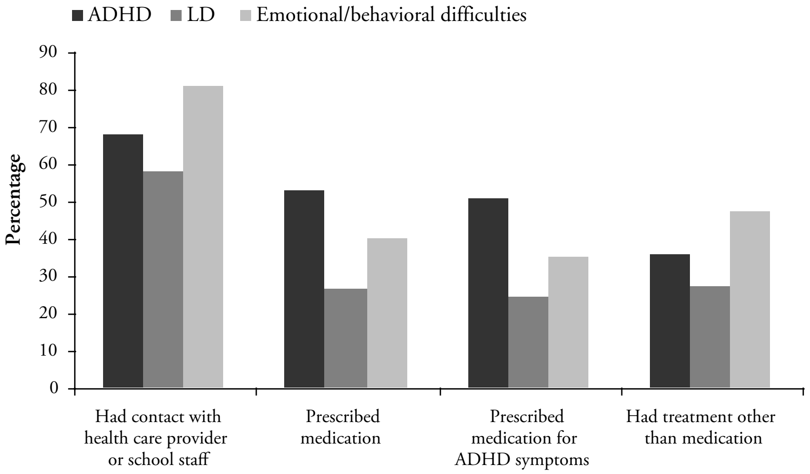
Children with ADHD, LD, or emotional or behavioral difficulties utilize a wide range of mental health services, including services from mental health professionals, general doctors, and schools. Many of these children (20-50%) also take prescription medication. However, 25% of children with emotional or behavioral difficulties have unmet medical needs. Future surveillance will indicate whether the goals set forth in the Freedom Commissions Report (New Freedom Commission, 2003) will become a reality.

Figure 1
Use of Mental Health Services* Among U.S. Children 4-17 Years with ADHD, LD or Emotional/Behavioral Difficulties**



*Children may receive more than one service.
**Definite or severe difficulties with emotions, concentration, behavior, or being able to get along with others.
Source: *2005 National Health Interview Survey*

Figure 2
Use of Mental Health Services* Among U.S. Children 4-17 Years with ADHD, LD or Emotional/Behavioral Difficulties**



*Children may receive more than one service.
**Definite or severe difficulties with emotions, concentration, behavior, or being able to get along with others.
Source: *2005 National Health Interview Survey*

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Medication Use among Youth in Systems of Care Initiatives: A Longitudinal Analysis

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Introduction

Currently, more children and adolescents are receiving psychotropic medications than ever before (Gadow, 1997; Jensen, Bhatara, & Vitiello, 1999; Kelleher, Hohmann, & Larson, 1989). Since the 1980s, the amount of psychotropic drugs prescribed to children has increased dramatically (Rawal, Lyons, MacIntyre, & Hunter, 2004). According to Lyons (2000), 80% to 90% of children in hospitals and residential treatment settings are currently on at least one psychotropic medication, and nearly half of these children are on two or more medications. This study builds upon previous work which indicates that both clinical and non-clinical characteristics are related to child medication status (Pavkov & Walrath, 2006), and investigates the extent to which medication status of children after entering system-of-care service impacts six-month child and family outcomes. In addition, the predictors of medication use at six months into service, among children who entered systems of care medication free, are also explored.

Psychotropic Use in Community-Based System of Care Programs

Currently, community based system of care programs are responding to children's mental health needs by providing accessible, effective, and comprehensive multi-dimensional services. While the effectiveness of these programs is a result of agency and system coordination, an integration and array of interventions/services has also contributed to the program's success (Pumariega, DelMuno & Vance, 2002). Specifically, advancement in psychopharmacological treatment has been an important addition to community-based programming (Jensen, Hoagwood, & Petti, 1996). Because these systems of care approaches use collaborative techniques in creating positive change at the child and practice level, involving the child and family members in medication decisions—in addition to any and all other service planning decisions—is paramount. This includes informing caregivers of risks and benefits of medication use, side effects and what to do if they occur, dose adjustments, and important drug monitoring (Pumariega et al., 2002). Including caregivers in this process promotes empowerment in making the ultimate medication decision with their child, which may result in more adherences with treatment (Werry & Aman, 1993). Bussing, Leon, Mason, and Sinha (2003) also agree that caregivers need to be more involved in direct treatment, as they have proved to be valid reporters when asked to manage their child's medication regimens and doctor visits.

The Comprehensive Community Mental Health Services for Children and Their Families Program has funded 126 communities across the United States and its territories to develop community-based family-driven culturally appropriate systems of care for children with serious emotional disturbance and to develop individualized service plans to meet the unique needs of those children, which may or may not include the use of medication. Due to the need for and increase of psychiatric evaluation of disorders, a multisystemic model, such as community-based, family-driven systems of care, is essential for treatment of children and adolescents (Bassarath, 2003).

Beyond the scope of treatment, however, questions persist related to the role of community psychiatry in these settings. Key questions include the following: (a) What changes occur related to the use of medications as part of treatment in system of care initiatives? (b) What is the net effect of medication use upon children apart from other dimensions of community-based intervention such as therapy or non-traditional services?, and (c) What is the role of families in the decision making and medication management of medication use?

Current Psychotropic Use with Children and Adolescents

In reviewing other studies, it is evident that there are different trends in psychotropic medication use with children and adolescents. For instance, Rawal (2004) suggested that the most commonly used medications in the general pediatric population are stimulants and antidepressants. However, MacIntyre, Lee, Carpinello, Zuber, & Fazio (2004) found that stimulants and antidepressants are commonly used, but they are not over prescribed, while antipsychotic medications seem to be prescribed without evidence of psychosis. Also, residential treatment facilities show different trends in the types of medications used to treat children and adolescents. In a statewide study of residential treatment centers, 53% of cases that indicated a need for stimulants were not receiving this type of medication. The same was true for 51% of cases that suggested a need for antidepressants. In addition Connor, Ozbayrak, and Harrison (1998) found that residential treatment centers are common sites for the use of antipsychotics. Among the 75% of children receiving some type of psychotropic medication, 58% were prescribed antipsychotic medication.

Not only are there diverse trends in the types of medications prescribed, but there also appears to be variation in populations targeted for medication treatment. Hallfors (1998) conducted a study to identify which type of children and adolescents were more likely to receive psychotropic medication in a residential treatment facility. It was discovered that children younger than 13 were twice as likely as older children to have a medication record. Also, boys were more likely to be targeted than girls due to a higher risk of restrictive placement. Children were also more likely to receive medication if they had a diagnosis of Attention Deficit Hyperactivity Disorder or a psychotic disorder, while children with a diagnosis of depression were least likely to receive medication. In order to explore additional trends in psychotropic medication use, further research is needed. Many past and current studies express concern about medication use, as there is still more to understand about medication use with children and adolescents (Hallfors, 1998).

Non-Clinical and Clinical Correlates of Medication Use

As evidenced through the literature review above, gender, age, and ethnic correlates of medication use are often mixed and confounded with diagnosis. Males are more likely to be treated with any psychotropic medication (Goodwin, Gould, Blanco & Olfson, 2001). Females are more likely to use antidepressant medication (Shireman, Olson, & Dewan, 2002) and are males more likely to be treated with stimulants (Guevera, Lozano, Wickizer, Mell & Gephart, 2002). While the relationship between medication use and age is not clear across studies (Warner, Pottick, & Bilder, 2005), recent analysis of data from systems of care indicate that younger children are more likely to use medications in these community-based systems (Pavkov & Walrath, 2006). Multiple studies indicate that children from minority populations are less likely to use medications than Whites (Pavkov & Walrath, 2006; Martin, Van Hoof, Stubbe, Sherwin & Scahill, 2003; Leslie et al., 2003; Goodwin et al. 2001). Generally, studies show that medication use increases for those having access to Medicaid or other payment source (Pavkov & Walrath, 2006; Warner et al., 2005; Zito et al., 2003) and also among those having private insurance (Hoagwood, Burns, Kiser, Ringeisen & Schoenwald, 2000). Research has also indicated that many youth involved in non-clinical youth-serving systems (i.e. child welfare or juvenile justice) may be less likely to use medications (Zima, Bussing, Crecelius, Kaufman & Berlin, 1999) than those who have extensive service histories in the mental health services system.

Clinical correlates associated with medication use include the characteristics of diagnosis, impairment, and family and service history. Recent analysis of national data indicates that youths with two or more diagnoses are more likely to use psychotropic medication (Warner et al. 2005). Similarly, youths with elevated levels of impairment were more likely to be using medication (Leslie, et al. 2003). Analysis of system of care data also indicates that families with histories of mental health treatment are two to four times more likely to use medications (Pavkov & Walrath, 2006).

Methods

Participants

The current study uses a subset of baseline data collected as part of Longitudinal Outcome Study of the national evaluation between 1997 and 2004 from up to 45 communities across the United States. Children enrolled in the Outcome Study with valid data on medication use at both baseline and six-month follow-up were eligible for inclusion in the analyses (*N* = 2,645). Children in the current study sample were 11.8 years of age on average, slightly more than two-thirds of the study sample was male, and approximately 71% of the children were Medicaid eligible. Nearly two-thirds (63%) of the sample were non-Hispanic White, 26% non-Hispanic African-American, 6% Hispanic, and 5% Native American. Over one-third (38%) of the children were referred into their respective systems of care from mental health, 28% from the school system, 15% from juvenile justice, 9.5% by caregiver or self referral, 8.5% from child welfare, and the remaining 9% from other sources. Over one-half (54.6%) had reported use of medication for behavior and emotional problems during the six months prior to entering their respective systems of care and during the six months after entry as compared to 26.5% of the sample that had not medication use reported in the six months prior or subsequent to system entry and 18.9% who had a changed medication status after entering the system of care.

Indicators

The majority of data used in the current study were collected via caregiver interview at the child's intake into system-of-care services and at a six-month follow-up interview. Specifically, caregiver report of child and family demographic and psychosocial information; child medication and service history; child Medicaid eligibility; child and family behavior and functioning were provided via structured interview. Referral source information was obtained from record review. The Child Behavior Checklist total problem score (CBCL; Achenbach 1991), the Child and Adolescent Functional Assessment Scale total score (CAFAS; Hodges, 2000) and the Caregiver Strain Questionnaire global strain score (CGSQ, Brannan, Heflinger, & Bickman, 1997) were used as indicators of child and family outcomes.

Medication status was based on a caregiver question that asked at intake, and then again at six-month follow-up, whether the child had taken medication for behavioral or emotional symptoms in the prior six months. This information was used to create three medication status categories: medication continuation [medication use six months prior and subsequent to entry into the system of care], medication status change after entry into the system of care, and medication free [no medication in the six months prior or subsequent to entry into the system of care].

Design and Analysis

Three General Linear Model repeated measures with a between-subjects factor were conducted. Specifically, the relationship between medication status and change in CBCL, CAFAS, and CGSQ total scores (covarying factors previously found to be related to medication status) was independently analyzed. Second, a logistic regression analysis was performed for a smaller sample of children (those who were medication free when they entered the system of care and for whom service experience data after entering the system of care was available) to identify predictors of medication use during the first six months of service, among children who enter the system medication free.

Results

The six-month outcome trajectories of children in systems of care appear related to their medication status, even after controlling for the clinical and non-clinical characteristics previously demonstrated to be related to medication status. Specifically, children who experience medication status changes (i.e., move either on or off of medication after entering the system of care) demonstrate the greatest reductions in behavioral and functional problems between entry into service and six months, followed by those who are medication free. Children with a continued medication status, while they demonstrate improvement, do less so relative to those in the other medication status categories. Interestingly, the rate of improvement on caregiver strain is lowest for those children in the medication free category.

Results of the logistic regression analysis, which included only those children who entered the system of care medication free, indicated that the non-clinical characteristics of children and the number of services they received, were more important predictors of medication usage than the clinical characteristics. Specifically, while CBCL total problem score at entry into services was indeed predictive of reported medication use at six month follow-up, CAFAS and CGSQ scores were not. Native American children were less likely to be using medications at six months than were White children. Children referred from mental health sources, from schools, and from child welfare were at least two times more likely to use medications than children referred from juvenile justice. Furthermore, the more types of services a child received during their first six months of services was predictive of medication use as was a child having a history of family mental illness. In contrast to previous analysis conducted on this population (Pavkov & Walrath, 2006), past service use, history of suicide ideation, family income, and caregiver strain scores were not predictive of children beginning to use medications between the period of baseline interview and six month follow-up.

Discussion

Based on this large sample investigation of children with serious mental health challenges entering system-of-care services, significant and important unique relationships were identified between the medication status of children (i.e., medication free, continued, or changed) and child and family outcomes. Furthermore, the findings suggest that non-clinical characteristics of medication free children may be more important predictors of later medication use than behavior and functioning problems. While it may be argued that some of the characteristics investigated may indeed have third-variable relationships with child presenting problems and symptoms (e.g., prior psychiatric hospitalizations, service history, etc.) these findings provide important information for consideration and discussion.

Prior to considering the implications of this analysis for practice and further research, it is very important to note that for each of the three groups compared in this analysis, the analysis indicates that involvement in systems of care is associated with improved functional status, lowered levels of psychiatric symptoms and lowered levels of caregiver strain. While the trajectories for each of the three groups differs across the outcome variables, the trajectories consistently indicate that youth and families involved in the system of care initiatives improve from baseline to six months.

It would appear that these findings are consistent with previous research indicating that youth having more impairment are more likely to receive medication. It is highly probable that without the use of medications, many of these youth would not be able to remain in the community and would require more expensive forms of restrictive placement.

This analysis also identifies intensity of service as a covariate predicting medication use. Again, it is likely that the role of medication and intensive community-based services contributes to the success of community placement. More analysis is needed, however, to understand the nexus between medication use, intensive community service, and the role of community psychiatry. Well coordinated community psychiatry may play a critical role in the success of youth in the community.

While this analysis does not indicate a broad set of non-clinical covariates associated with medication use as previous research (Pavkov & Walrath, 2006), the findings do indicate that a family history of mental illness is a powerful predictor of medication use among children and youth served by system of care initiatives. As such, community-based approaches must look beyond the immediate needs that children may have for medication. System-of-care practice must consider the broader context of treatment that may include both the needs of caregivers with a history of mental illness and also the broader context of family functioning.

In a broader context, the analysis also suggests that access issues may persist related to the use of medications. System of care involvement may provide better access to psychotropic medication for some groups but not others. With respect to access for native American youth, the analysis points to the need for practitioners to better understand the role that culture may play in medication use and also the challenges that systems of care have in allowing access for youth from underserved groups. Similarly, the analysis suggests access issues related to youth referred from juvenile justice; it is likely that medication use would assist in addressing many of the underlying mental health needs of youth involved in the juvenile justice system.

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