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A Hidden Epidemic and What You Can Do About It

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Abstract

Introduction: In the United States ¼ of the children of a parent with a mood disorder will develop a major psychiatric diagnosis upon a 7 year follow up. Moreover, the earlier the onset of symptoms, the longer the delay to first treatment, and this is posing major short and long-term health threats for a sizable portion of the population.

Methods: We review data that childhood onset mood and behavioral disorders are more frequent in the US than in many European countries and suggest possible approaches to this problem.

Results: Despite the high incidence of psychiatric illness in the US, many children are not being evaluated and treated in a timely fashion. Multiple factors including those related to stigma around psychiatric diagnosis and treatment of very young children account for this deficit. There is also a shortage of child psychiatrists, and most children are being seen in primary care settings. We suggest that parents and older children themselves play a key role in screening and longitudinal assessment of mood and behavioral problems to assist physicians in decisions about diagnosis, need and effectiveness of treatment.

Conclusions: Childhood onsets of mood and externalizing disorders appear to be increasing in the US population in more recently born individuals reflecting a cohort effect. Greater attention to these problems by pediatricians and primary care providers by enlisting the help of parents and children themselves in screening and monitoring of symptoms may be one way to better address this ongoing and worsening health problem.

[1-3]. In the study of Axelson, et al. upon 6.7 years of follow up, offspring of a parent with bipolar disorder had received the following lifetime diagnoses: An anxiety disorder in 39.9%; depression in 32.0%, ADHD in 30.7%; disruptive behavioral disorder in 27.4%; oppositional defiant disorder in 25.3% and bipolar spectrum disorder in 19.2%. Even the children of the community controls (whose parents did not have a bipolar disorder) had a major childhood psychiatric disorder about half the time (in 48.4%) [1]. Upon 20 years follow up, 80% of the offspring of a parent with unipolar depression will have a major psychiatric illness [3].

In epidemiological studies, some 2 to 3 percent of adolescents (13 to 18 years of age) will screen positively for a bipolar spectrum disorder, yet only 20% of them are in any kind of treatment [4]. Treatment delay in the mood disorders is inversely related to the age of onset, such that the youngest children have the longest delays to first treatment for their mood disorder [5-7]. These youngsters are at double jeopardy because early onset mood disorder (unipolar or bipolar) and treatment delay are both risk factors for a poor outcome in adulthood [5,8].

In this report, report we review the magnitude of the problem of childhood onset psychiatric disorders with a focus on bipolar disorder, and suggest several types of screening instruments that involve parents and children in the evaluation of mood and behavioral difficulties that then might lead to earlier recognition and treatment, as necessary.

Hidden Obstacles to Recognition and Treatment

Parents and physicians are often reluctant to iden-

Introduction

There is a very high rate of psychiatric illness in children and adolescents in the general population of the United States and some ¼ of the offspring of a parent with bipolar disorder or unipolar depression will have a major psychiatric diagnosis upon long term follow up



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tify psychiatric illness in very young children because of a variety of factors, some of which involve uncertainty about illness trajectory, but many of which are linked to stigma. This includes both the idea of a psychiatric diagnosis and reluctance to consider drug treatment because of the child's age [9]. This contrasts markedly to other serious illnesses of childhood such as epilepsy, diabetes, rheumatoid arthritis, heart disease or cancer where diagnosis is sought, and treatment is cherished. "Of the 74.5 million children in the United States, an estimated 17.1 million have or have had a psychiatric disorder - more than the number of children with cancer, diabetes, and AIDS combined. Half of all psychiatric illness occurs before the age of 14 and 75 percent by the age of 24" [10].

While one may counter that these medical illnesses are life threatening and thus merit appropriate pharmacological treatment, it is increasingly clear that the mood disorders are potentially lethal by suicide, as well as later in life by a vast number of years of lost life expectancy (ranging from 1 to 3 decades depending upon the State where one resides) mostly because of cardiovascular disease [11,12]. "The suicide rate among young people 14 to 24 stays remarkably high. We're going to lose close to 5000 young people to suicide. More children will die from suicide than from asthma, cardiac disease, AIDS, diabetes, and peanut allergy combined. Every physician and, in particular, pediatricians should care about this". (Koplewicz, 2017, commenting on the Child Health Report, 2015).

There has also been the widely promulgated view that the increasing recognition of childhood onset bipolar illness is one of changing diagnostic criteria, over diagnosis, or a result manufactured by the pharmaceutical industry. The data speak otherwise. However, based on retrospective data in adults with a clear-cut diagnosis of bipolar disorder involved in research networks, more than ¼ of illness onsets (the occurrence of manic or depressive episodes) begins before age 13, and cumulatively 2/3 begins by adolescence (before age 19) [13-16].

Part of the controversy about childhood onset bipolar disorder stems from the fact that many other European countries and Canada do not see these same illnesses until early adulthood [13,14,17]. However, our data and those of Bellivier, et al. [18], Etain, et al. [19], and Holtzman, et al. [20] show that early onset bipolar disorder is much more prevalent in the US than in Germany, the Netherlands, many other European countries, and Argentina. Both genetic and environmental factors appear to account for this earlier onset of illness.

Compared to the Europeans, outpatients from the US have both greater genetic vulnerability (more mood and addictive illness in their parents and grandparents), and more psychosocial adversity in childhood in the form of verbal, physical or sexual abuse [13]. Our data also show

that the patients with bipolar disorder from the US are sicker than those from Europe with more anxiety disorder, alcohol and substance abuse, more with more than 20 prior episodes or rapid cycling (4 or more episodes/year), and more treatment refractoriness [13,14]. US patients' parents and grandparents also have more depression, bipolar disorder, alcohol and substance and "other" psychiatric illness than those from the Netherlands and Germany [13,21-24], and this family burden is related to earlier onset of bipolar disorder.

Thus, it is of no surprise that the offspring of the patients with bipolar illness from the US have more illness (including depression, bipolar disorder, suicide attempts, substance use, and "other" illness) compared to the Europeans [25]. Compounding this problem, there appears to be a cohort effect where more recent birth cohorts have an earlier age of onset of illness and greater burden of family illness compared to those in more distant birth cohorts [26-28].

Therefore, the problems are not only more profound and complex in the US than many other European countries, but they are not likely self-correcting, and, on the contrary, may be getting worse because of cohort and anticipation effects.

Another impediment to early treatment is a lack of a robust treatment literature about the best approaches to childhood onset bipolar disorder and many other childhood onset illnesses as well except for ADHD. For ADHD there are more than 20 FDA approved agents [29]. For bipolar disorder for children under 10 years of age there are no approved treatments. Thus, children with bipolar disorder (which is often comorbid with ADHD) tend to get treated for their ADHD with stimulants and antidepressants and not treated for their bipolar disorder which requires mood stabilizers (such as lithium), the anticonvulsants (such as valproate, carbamazepine/oxcarbazepine or lamotrigine), or an atypical antipsychotic (most of which have antimanic effects in adults, but none are approved for children under 10) [30,31]. The atypicals although they are approved for mania in adolescents have a range of side effects including weight gain and extrapyramidal side effect with some but not other agents [32].

Even when the diagnosis of bipolar disorder was made by experts in academia, some 37% of the children upon follow up of 8 years of treatment in the community never received any of the appropriate treatments for the disorder. Children remained ill some 2/3 of the time of follow up, although children who did receive lithium had the longest remissions [33].

Another problem is lack of available experts in psychosocial management of these syndromes or prodromes. Family focused treatment is highly effective in children at high risk because of a family history of bipolar who also have anxiety or depressive syndromes or other bipolar prodromes [34]. Yet, receiving this or

other related psychosocial treatment [35] is not routine and a shortage of well-trained clinicians exists in most communities.

Approaches to Improved Recognition and Treatment

Given these multiple impediments to early recognition and treatment what are some positive approaches? Increasing numbers of children with major psychiatric illness are being seen by pediatricians and primary care providers [36] who are less familiar with diagnosis and the sparse treatment literature that does exist for childhood bipolar disorder, depression, anxiety, oppositional defiant disorder, conduct disorder, and substance abuse disorders. Being alert to risk factors for early onset illness such as family history of mood and related psychiatric disorders and adversity in childhood may help direct attention to those at highest risk for difficulties [37,38].

Since these diagnoses are difficult and are time consuming for the primary care provider, we suggest placing the burden of screening and monitoring on the parents or, if old enough, the children themselves. Use of mood and behavioral checklists and other systematic monitoring strategies should be as common and accepted as vital signs, weight, and blood chemistries such as glucose. Some on line screening and ongoing assessment tools are available.

My mood monitor or WhatsMyM3 is a self-rated on-line instrument that screens for depression, anxiety disorder, PTSD, OCD, bipolar disorder, and alcohol and substance abuse. This 26-item instrument takes just minutes to fill out, and screens more broadly than the PHQ 9 which only assesses depression severity. The M3 has been validated in adults [39] but is appropriate for adolescents and can be performed repeatedly and printed out longitudinally to track symptoms and treatment effectiveness.

For children age 2 to 12 we suggest the utility of parents joining the Child Network which can be accessed on line at www.bipolarnews.org. (click on Child Network). In the Child Network, parents rate on a weekly basis the severity of their child's symptoms of depression, anxiety, ADHD, oppositional behavior, and mania on a secure website under a John Hopkins IRB-approved study. Parents can then print out these ratings longitudinally which should help them, and their clinicians visualize the trajectory of the symptoms, need for treatment, and effectiveness of any treatment given [40,41].

The Child Network also involves filling out a short one-time demographics form and a longer symptom check list on a yearly basis. The longitudinal ratings and listing of pharmacological and psychosocial treatments that are completed weekly by the parents will also allow us to begin to assess how very young children with a variety of mood and behavioral disorders are being

treated in the community. We urge that physicians, nurses, social workers, and other office personnel encourage parents with children (2 to 12) to join the Child Network and begin to more systematically track mood and behavior in a fashion similar to other monitoring in medicine.

When good treatment and careful monitoring on follow up is employed, even the most serious illnesses can have a more benign course than is seen with more casual treatment as usual. Kessing, et al. [42] randomized those with a first hospitalization for mania to either two years of specialty clinic treatment (involving psychotherapy, pharmacotherapy, systematic monitoring, and psychoeducation) or 2 years of Treatment as Usual (TAU). Those who had the specialty clinic treatment had many fewer relapses not only over the 2 years, but also over the next 6 years even though all had returned to TAU after 2 years. These patients apparently learned about the illness and developed self-management skills that continued to lead to fewer recurrences long into the future.

The Child Network does not offer such specialty treatment, but the longitudinal monitoring and careful assessment of how well treatments are working should be helpful to parents and clinicians in recognizing psychiatric symptoms in need of treatment and then monitoring treatment effectiveness and tolerability.

Shonkoff and Garner [43] wrote about how toxic stress in the form of childhood adversity has negative health consequences throughout childhood and into adulthood as it is associated with the development of multiple psychiatric as well as medical illnesses. Shonkoff and Garner [43] urge that pediatricians become guardians of childhood physical and mental health and play a key role in management of mood and behavioral problems in addition to more traditional medical illnesses. Parents providing the key information about their child's mental health will go a long way in assisting pediatricians and other primary health care workers better assess children's mood and behavioral problems, decide about treatment, and refer as necessary. Please encourage parents of children 2-12 to join the Child Network.

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