

April 2016

PANDAS

Pediatric Neuropsychiatric disorder associated with strep: knowing when to screen in children who present with OCD and Tic disorders.

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Case: The PCP of a 6 year old boy, DM, called because of recent onset of tics and insomnia. On the phone, the PCP reported that he had no history of prior psychiatric or neurological issues. Two months before the call, he had presented with repetitive movements of neck, eyebrows, hips and feet. These movements were noted by family to begin suddenly and lasted throughout the day, interfering with sleep.

Continued on page 2



In this Issue:

Children's Mental
Health Awareness
Week 5

MCPAP Releases
RFI on Potential
Program Changes 6

Clinical
Conversations 8

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Despite being asymptomatic, DM was tested for streptococcus type A by throat culture which came back positive. No blood work was drawn at that time. He was given a 9 day course of azithromycin with some improvement noted in his tics. Because of the lack of improvement and uncertainty of his diagnosis, a face-to-face consultation to help with further workup and treatment.

At the time of his consultation, additional symptoms were elicited from the family. During the same time period as the tic disorder, DM began to complain to parents about “nightmares” and would wake in the middle of the night, go into his parents’ room and fall back to sleep. Parents noted having to engage in ritualistic reassurance to help DM fall asleep at night including leaving lights on and lying down with him. There were no issues with separation anxiety,

changes in eating, or food preferences or refusal, specific phobias or fears of contamination that family had noted. His parents had noted that DM was more hyperactive and restless since the tics began but denied any moodiness, lability, or sensory issues. There were no changes noted in concentration or focus at school and no history of any arthralgia or enuresis.

Following his MCPAP consultation, the diagnosis of PANDAS, or Pediatric Neuropsychiatric Disorder Associated with Strep, still seemed most likely. The following recommendations were suggested to the PCP:

- 1) Obtain labs including CBC, TSH, ASO, antiDNase, ANA, RF, Lyme and mycoplasma titers (lab work results are listed on page 3)
- 2) Place DM on a clonidine transdermal patch for his sleep and tic disorder.
- 3) Refer DM to both Massachusetts General Hospital’s PANDAS clinic as well as to an infectious disease specialist.

Continued discussion with the PCP over the next several months documented four separate and acute episodes of streptococcal infections each associated with worsening of tics, hyperactivity, poor frustration, moodiness and one episode of obsessional thinking and behavior.

Continued on page 3



In addition, several months after the first consultation, DM was noted to have some behavioral issues within the classroom. He was described as being uncharacteristically hyperactive, restless, and impulsive. Because of a history of a severe urticarial rash with penicillins, each episode was treated with azithromycin with modest improvement. He was seen by infectious disease specialists, and during the last episode was given a course of cefadroxil with notable improvements in tics and symptoms over the two-week course of treatment. He remained on maintenance cefadroxil, and at follow up several months later remained asymptomatic.

DM Bloodwork (Normal labs in parentheses):

WBC: 7.4 (4.5-11.0)

Hct: 32.9 (35.0-45.0)

Hgb: 11.4 (11.5-15.5)

Plt: 265(140-440)

ASO: 285 (0-640)

AntiDNase: 1550 (0-375)

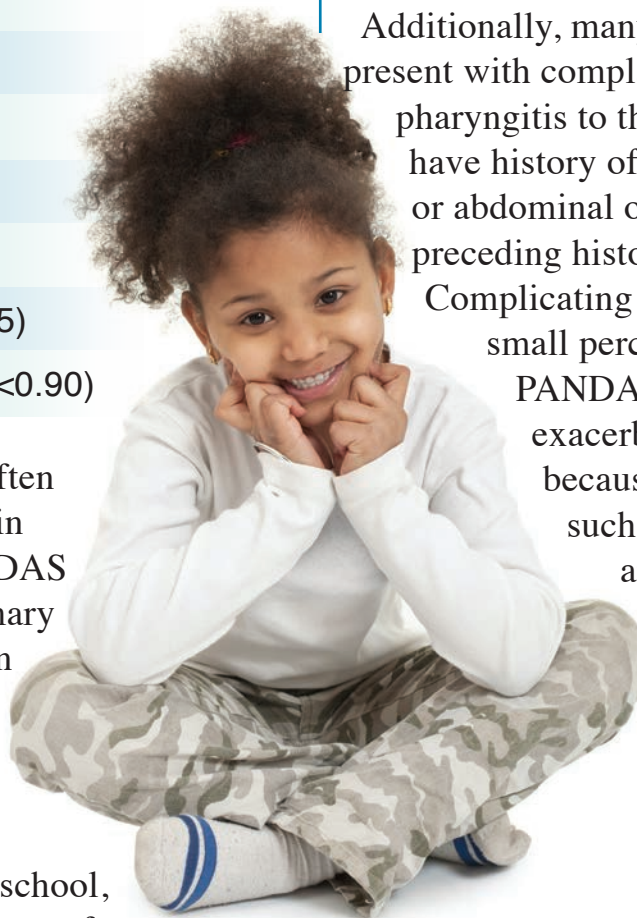
Mycoplasma IgM: 1.61 (<0.90)

This case highlights the often subtle but common ways in which children with PANDAS can present to a busy primary care office. PANDAS is an autoimmune disorder that typically occurs in children ages 5-10.

Because of its onset and timing with entrance into school, many of the initial symptoms of

obsessional fear of harm and resultant separation anxiety may confuse physicians as being issues related to transitions or external family stressors. This hypothesis is often confirmed for the clinician when after a few weeks or months the child appears to suddenly improve on his or her own, often without much intervention or treatment. Because parents may not return to their physician until the child is having an acute flare, it may appear as if the symptoms have been ongoing when in fact that is not the case. Unless clinicians are vigilant about obtaining careful timeline and histories, it can be easy to miss the characteristic “waxing and waning” course that occurs in children with PANDAS.

Additionally, many children may not present with complaints of sore throats or pharyngitis to their PCP but instead have history of headaches, vomiting, or abdominal or chest pain, making the preceding history of strep not evident. Complicating this is the fact that a small percentage of children with PANDAS may present or have exacerbations of their illness because of OTHER pathogens such as mycoplasma, Lyme, and coxsackie leading to some renaming PANDAS as “PANS” [Pediatric Neuropsychiatric Disorder Syndrome].



Continued on page 4

Not all children with Obsessive Compulsive Disorder [OCD] and tics have PANDAS and therefore differentiating children with PANDAS from “other” children with anxiety or tics requires careful history and data collection. It is estimated that up to 25 percent of childhood OCD may be related to PANDAS with boys developing PANDAS at rates twice that of girls. 40 percent of PANDAS cases will present with anxiety and OCD symptoms while in 20 percent of cases children will present with purely tics. In many cases however, there is a mixture of both OCD and tics and the presentation may change with each successive episode. Obtaining clear onset and timeline of symptoms and course, preceding illnesses or history of strep, sinusitis or URIs and course of illness is key to diagnosis and detection. Children with PANDAS and their families characteristically describe a sudden onset [sometimes with date and time] and will have accompanying features including

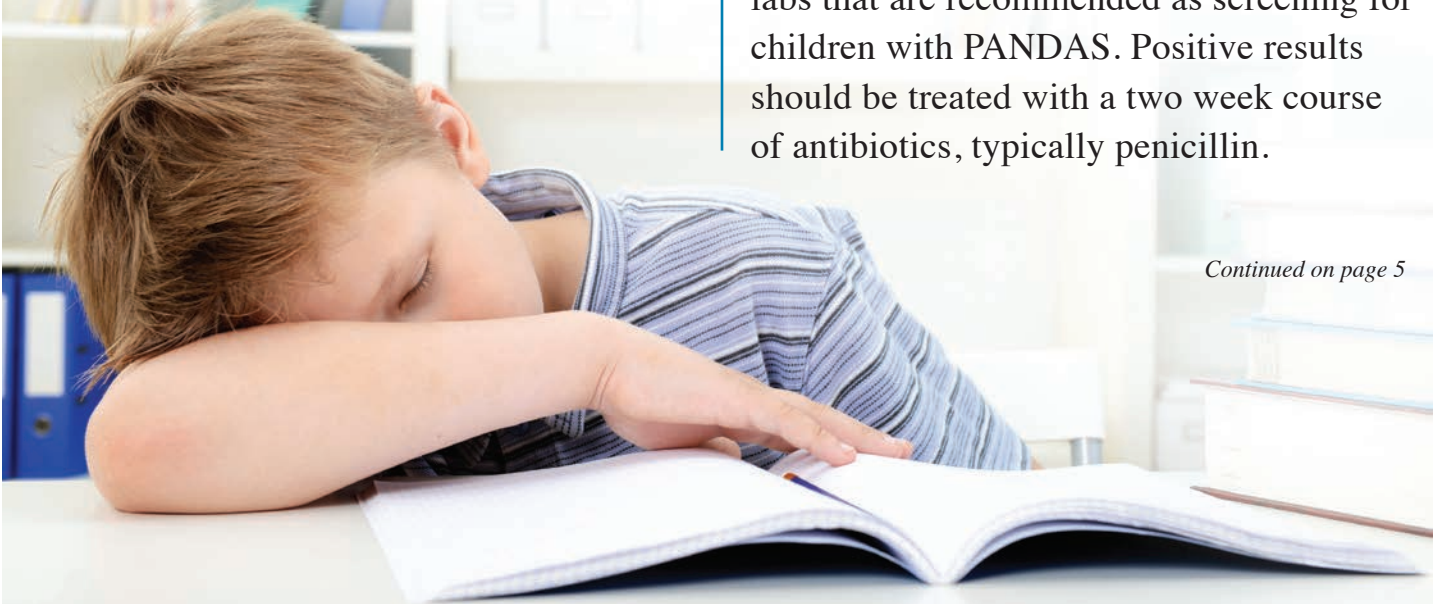
restlessness, hyperactivity, changes in concentration, worsening handwriting, sensory and mood issues and sleep disorders. Additionally, children may develop enuresis or encopresis during episodes and complain of joint pains. PANDAS occurs in children with family histories of autoimmune disorders with 70 percent or more of families reporting positive histories in extended families for illnesses such as rheumatoid arthritis, thyroid disease, inflammatory bowel disease, diabetes or psoriasis.

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The workup for children with PANDAS include obtaining throat cultures for the presence of strep and blood work to assess for immune response. CBC with differential, ANA, ASO, antiDNase, mycoplasma and Lyme titers, RF and TSH are among the labs that are recommended as screening for children with PANDAS. Positive results should be treated with a two week course of antibiotics, typically penicillin.

Continued on page 5



The cephalosporins or azithromycin can be used in children who cannot tolerate or have a history of an allergic reaction to penicillins. Treatment of PANDAS following initial infection requires vigilance going forward especially during school year when strep exposure is high and clinicians should have a low threshold for checking throat cultures or labs. The alpha adrenergic medications such as clonidine or guanfacine can be helpful in children during acute exacerbations to decrease anxiety and alleviate sleep issues. There have been some controversy regarding potential worsening of mood and behavior in children with PANDAS

with benzodiazepines and, therefore, they should be avoided or used with caution. Clinicians should consider prophylaxis with antibiotics or anti-inflammatory medications [ibuprofen] during the academic year for children with recurrent illness. In children who present with difficult to control symptoms and illness, consideration of addition of a low dose antidepressant or referral to an ENT specialist for consultation and tonsillectomy may be warranted. Finally, clinicians should consider referring to specialists in areas of infectious disease to help confirm diagnosis, guide treatment, and consideration of IVIG therapy.

In Recognition of Children's Mental Health Awareness Week

Wear a Green Ribbon... May 1-7, 2016

The message: Mental health is essential to overall health and well-being. Wear a green ribbon and start the conversation on May 7 with patients and families.

Why a green ribbon? To fight stigma! In the 1800s, the color green was used to brand people labelled "insane." The children's mental health community chose to continue with the color green to signify new growth, new life, and new beginnings. By wearing a green ribbon you can raise awareness about the importance of children's mental health.

For additional resources, you can access these websites:

Parent Professional Advocacy League (PPAL)

www.ppal.net

National Federation of Families for Children's Mental Health

www.ffcmh.org/awarenessweek

Substance Abuse and Mental Health Services Administration

www.samhsa.gov/children/national-events



MCPAP Releases a Request for Information (RFI) on Potential Program Changes

Recently, MCPAP engaged in a strategic assessment of the program. After more than a decade in existence, it was time to evaluate how well MCPAP is meeting its purpose: to help pediatric primary care providers manage the behavioral health needs of their patients.

This assessment was especially critical in the current rapidly changing healthcare environment with the emphasis on integrating behavioral health and primary care. MCPAP and the Department of Mental Health (DMH), the primary funder of MCPAP, selected DMA Health Strategies (DMA) to conduct this strategic assessment and to work collaboratively to evaluate MCPAP's strategic options for potential redesign.

DMA conducted more than 50 interviews with key stakeholders of MCPAP, analyzed 11 years of MCPAP utilization data, and reviewed the myriad articles that have been published about MCPAP and other psychiatric consultation programs. Stakeholders interviewed included the MCPAP PCP Advisory Committee and a sampling of enrolled pediatric primary care providers across the state, among many others. The assessment report is available on the MCPAP website at <http://www.mcpap.com/About/ReportsNPublications.aspx>.

The report provided a great deal of insight

and information regarding MCPAP's performance, the changing needs of pediatric primary care providers for managing behavioral health in their practices, and insight into some larger health system approaches to integrating behavioral health and primary care. The report also included numerous potential opportunities for MCPAP to modify and enhance our infrastructure and services; many more opportunities than can be implemented within current resources. Consequently we need additional input from our stakeholders.

On March 27, MCPAP released a Request for Information (RFI) to solicit additional information on potential changes to MCPAP. This RFI is available on our website at www.mcpap.com/RFI.aspx. This RFI was distributed electronically to all stakeholders who were interviewed as part of the Strategic Assessment as well as to our MCPAP Hub leadership. We welcome feedback from any of our enrolled primary care providers and their practices as well.

For further information about the strategic planning process or the RFI please contact Marcy Ravech at 617-350-1978 or marcy.ravech@beaconhealthoptions.com

What's Happening for you at MCPAP

Have you responded?

The MCPAP Annual Provider Experience Survey has been sent via email to all enrolled providers for whom we have an email address. A paper version will be sent via snail mail to providers for whom we do not have an email address. Your responses to this survey are critical to help us assess our services, identify areas for improvement, and gain a front-line perspective on the changing healthcare environment relative to the integration of behavioral health and primary care in pediatric and family practices. If you did not receive the survey, please email Andrew.scearce@beaconhealthoptions.com or call Andrew at 617-350-1990. MCPAP appreciates your time in completing the brief survey and greatly values your input.

Have you had your S2BI training yet?

The Screening to Brief Intervention Tool (SBIRT) has been developed specifically for substance use disorder screening and brief intervention with adolescents in the primary care setting. Your MCPAP team is available to bring the training to your practice. Please call or email your MCPAP Hub for more information.



The S2BI Toolkit is available at the DPH Clearinghouse! To order your free S2BI toolkit, follow this link – <https://massclearinghouse.ehs.state.ma.us/>. If you are having a training on-site, the MCPAP team will provide toolkits for your practice.

Clinical Conversations

Log in the on the fourth Tuesday of each month from 12:15-1:15 p.m. to learn more about managing pediatric behavioral health issues in your practice. Staff from our MCPAP teams will highlight topics as requested on last year's Provider Experience Survey:



April 26

Managing ADHD in Pediatric Primary Care: Beyond the Basics

May 24

Identifying and Managing Autism Spectrum Disorder in Pediatric Primary Care

June 28

Assessing Risk: Preventing Youth Suicide

You can register for these webinars by visiting <http://www.mcpap.com/About/NewsNEvents.aspx> and clicking on the webinar(s) that you would like to register for. For any questions regarding the clinical conversations, please contact Mary Houghton at mary.houghton@beaconhealthoptions.com.

