UPIQ Conference Call

Early Autism Detection and Referral in the Medical Home

Tuesday, November 19, 2009

1:30 – 2:00pm

Call #4: Part 2: Management of Associated Conditions and Symptoms

Presenter: Paul Carbone, MD, University of Utah Division of General Pediatrics

Case

An 8-year-old boy with autism, fairly high functioning. Mainstreamed in school for some classes, in special ed for academic core classes. Difficult behaviors include impulsivity, hyperactivity, very poor sleep, difficulty staying on task, socially inappropriate behaviors, and aggression. Parents reward self-control and good behaviors by allowing him to play with his Etch-A-a-Sketch, on which he tirelessly narrates and illustrates a story to himself. A previous doctor had successfully curbed some of his aggression with 0.5 mg of Risperdal at night, but that effect seemed to be wearing off prior to our first visit. His ADHD was treated with short-acting methylphenidate, but mom discontinued that almost immediately due to the resultant emotional lability and intolerable "ups and downs."

During our first visit, we decided to increase the Risperdal to 1 mg at night (to help with maladaptive behaviors and also to hopefully help with sleep) and try Vyvanse 30 mg in the morning. Family did not follow up for two months; recently received a message from Mom that the medications aren't helping at all and that he is "out of control" at school. Also, Vyvanse seemed to help during the day, but they are seeing a huge rebound in the afternoon with self destructive behavior, which they haven't seen since he was 2 years old. Child has a hard time sleeping, calls out "Mom, are you okay?" during the night.

Discussion

Looking at the whole picture can be so overwhelming, so be sure to use the 5 tenants discussed during the last call to consider what your next steps should be:

1. Rule out medical diagnosis
2. Think about sleep
3. Think about caregiver stress and family-centered activities
4. Analyze the behavior
5. Identify a psychiatric disorder.

In this case, let's start by considering a medical problem. Any time you find that medications aren't working as you expected, step back and consider other possibilities. Am I missing something that meds aren't targeting? Constipation, reflux? If nothing comes up, consider the next step – sleep.

Always consider sleep up front, since sleep must be in as good of control as you can get it before you can deal with daytime maladaptive behaviors. Make an office appointment solely to address sleep issues. Send a pediatric sleep questionnaire to the parent to complete before the visit. (I like the Children's Sleep Habits Questionnaire – it isn't ASD specific, so it can be used with other children who present with sleep difficulties: http://www.kidzzzsleep.org/researchinstruments.htm.) Take a good sleep history, physical exam to determine problem. Discuss bed time, wake time, usual routine. Is the problem getting to sleep, night awakenings, or both? This is important to know since they are treated differently. Is there obstructive sleep apnea, snoring, complains of leg pain, or restless leg syndrome? Is there rhythmic leg movement? All of this is important to address since each symptom can mean something different and will tell me if I should refer for sleep studies, to an ENT, or other. For example, Risperdal is initially good for sleep but NOT long term; it causes sedation at first but wears off after 2 weeks. In this case, we have clues – the Risperdal effect wore off, which makes me think that we are temporarily suppressing a functional behavior that's working for the child; the sedation wore off, the behavior came back. If the trouble is getting to sleep, try 1-3 mg of Melatonin an hour before bedtime -- there are good

studies that show children with autism don't produce enough Melatonin. From there, we move into interventions that are less evidence-based: Clonidine has been shown to help with both getting to sleep and night awakenings; Trazodone can be used if kids are verbal (priapism is a one of Trazodone's side effects).

It sounds like this child has issues with both night awakenings and going to sleep. Separation might be an issue as well, since the child is calling out. We might need to target anxiety, which is amenable to behavior modification. If he is high functioning cognitively, one behavior intervention that can be tried is the use of a token system at night. He goes to bed with a token on the nightstand, and that will buy one curtain call from Mom, but once he uses the token, he's done – there's no more mom coming in. A good resource is the book, Sleep Better!: A Guide to Improving Sleep for Children With Special Needs by Vincent Mark Durand. It goes through graduated extinction procedures such as this one.

Next, consider caregiver stress and the family in general. Be sure to bring up or highlight the positives so everything's not always negative. It's good to plug families into resources such as The National Ability Center in Park City, which offers aquatics, equestrian activities, and wall climbing. An added benefit -- late afternoon activities will often help the child sleep.

Consider the function of the behavior. Try to understand what purpose the behavior serves for the child. If a behavior is rewarded, even inadvertently, it has a payoff for the child. Take a very good history (clues will show up). It's great if you have the ability to get someone else on the team to help you determine the function of the behavior -- ask for a functional behavioral analysis (FBA) through the school district. This is mandated through IDEA, but you may have to push a bit to get it done. Consider the child -- when he hits the wall, why does he hit it? Is it attention seeking? Is it an escape? Consulting with smart behavioralists can help so we don't inadvertently reward the bad behavior. Though not usually covered by insurance, there are a number of private groups who will work with families on a 1-1 basis (e.g., ASD Connections, Redwood Learning Center, Hope Interventions). Several can be found on www.medicalhomeportal.org.

Identifying a psychiatric disorder that you're going to treat can be difficult but there are usually good clues if you know what to look for. Try to figure out what target symptom you're addressing. In this case, sleep problems and ADHD symptoms were present. Knowing the stimulant helped during the day changes things a bit. Since he didn't tolerate the short-acting medication, we know that a longer-acting medication might cause more problems in that the lowest dose of these medications exceeds the dose of short acting medicine he was on. Decide if the stimulant is worth the emotional lability the family was seeing. Usually the answer is no – it often causes too much emotional lability and problems within the family. If the answer is yes, add a short-acting stimulant (methylphenidate has the most evidence base) once he gets home from school to see if that helps. If you want to target ADHD but stimulants cause too much emotional lability, go to second line agents such as clonidine or guanfacine (http://www.medicalhomeportal.org/issue/alpha-2-agonist-use-in-children-with-autism). If you're going to use Risperdal, use a dose in the morning and at night. Add a small dose and keep them equal during the day. Usually start at .25 mg for a week, add .25 mg every week or so starting with the dose at the night. Once it's tolerated, add a dose during the day. If you keep him on a stimulant and Risperdal, you run the risk of side effects, such as QTc prolongation. Get an EKG to evaluate the QTc interval for any child who is on this combination of medications and watch it closely. Risperdal lowers the thresholds for seizures, can cause significant weight gain, hyperlipidemia, hyperprolactinemia, diabetes, and tardive dyskinesia. Monitor weight closely – an average gain of 10 pounds is not uncommon over a 6 month period, so you'll want to check labs at least yearly -- lipids, prolactin levels, and glucose. Be aware of these and other issues around monitoring risperidone and make sure families understand these. I often download the handout on his medication from the Medical Home Portal so that the family has full awareness of the potential side effects: http://www.medicalhomeportal.org/issue/risperidone-use-in-children-and-adolescents-with-autism. The last page contains a table of medications that I give to parents as we talk about medications so that they have something written to refer back to; it seems to make the talk go a bit more efficiently.

Questions & Answers

Question: To evaluate the QTc interval, would you get an EKG prior to starting meds?

> Answer -- Opinions differ. For stimulants current recommendations are to do so if there's a family history of cardiac problems. I would also get an EKG before any combination of alpha 2 agonists, stimulants and antipsychotics as they can all affect the QTc. If the first EKG is okay I try to get another one a couple of weeks after starting the medications, and any time I make a big change.

Question: What about using Clonidine?

> Answer – Clonidine has a side effect of sedation. It can help at night for those who don't sleep well and even the next day with ADHD symptoms. It can be added to the morning as well but watch out for sedation. In children with developmental disability one side effect that seems common with daytime use of alpha-2 agonists is irritability. Guanfacine (tenex and the new intuniv) is in the same family and is longer acting and less sedating than clonidine.

Question: Can you use tenex in the morning and clonidine at night?

> Answer – Yes, a small dose at night. Go to www.medicalhomeportal.org to see how to start medications. Click on ASD module then treatments, and you'll find all of these medicines.

You will be presented with some very challenging cases, so when you get involved, commit yourself to the family for the long term. This is a very nice thing to do. When we start a medication, we know we'll be going down a road that's full of bumps, especially with the change in seasons, holidays, etc. There are a lot of changes that will need to occur.

Question: Is it reasonable to refer a 3-year-old to the Child Development Clinic for ADHD?

> Answer – Yes, we see kids with a variety of other disabilities. 801-584-8510 is the number of the Child Development Clinic. In addition, don't hesitate to contact Paul with questions or to have him be the conduit to the child psychiatrist, page 801 339-3146 or paul.carbone@hsc.utah.edu.

List of Practice Attendees:	**Names:**
Greenwood	Ellie Brownstein
Memorial	Christi Poll (parent partner)
Mountain View	Kim Gehle
Sandy	Lisa Palmieri
Southwest	Renee Olesen
Summit	Monica Schaffer and Liz Wall (parent partner)
Terashima	Bridgett Hullinger

List of Other Attendees:

Paul Carbone, University of Utah
Rebecca Giles, UDOH
Barbara Ward, UDOH
Duane Yamashiro, PCMC
Sandra DeBry, UPIQ

Medications frequently used for children with autism spectrum disorders

Overdose of these medications may be life-threatening. Keep these and other medications out of reach from the patient and other children in the household.
Adapted from the Medical Home Portal, www.medicalhomeportal.org

Class of Medication	Examples	Target Symptom	Side Effects	Other Information
Stimulants	-Ritalin -Concerta -Metadate CD	-Hyperactivity -Inattentiveness -Impulsivity	-Appetite suppression/ Weight loss -Tics -Insomnia -Anxiety -Cardiovascular effects	-Regular checks of weight and blood pressure are needed -No refills and no call in prescriptions allowed
Alpha 2 agonists	-Tenex -Clonidine	-Hyperarousibility -Anxiety	-Decrease in blood pressure -Irritability -Sedation	-Avoid abrupt discontinuation as this may result in high blood pressure
Selective Serotonin Reuptake Inhibitors (SSRIs)	-Prozac -Zoloft -Celexa	-Anxiety -Depression -Repetitive Behaviors -Aggressive behavior	-"Activation syndrome" with hyperactivity, disinhibition, and agitation -Sleep disturbance -Headaches -Gastrointestinal symptoms -FDA WARNING ABOUT SUICIDAL THOUGHTS	-Avoid abrupt discontinuation
Atypical Antipsychotics	-Risperdal -Abilify	-Irritability -Agitation -Anxiety -Self-injurious behavior	-Weight gain -Increased cholesterol -Increased prolactin -Abnormal movements -Neuroleptic Malignant Syndrome (rare, but life-threatening, idiosyncratic reaction, characterized by fever, muscular rigidity, and altered mental status	-Regular monitoring of weight is advised -At least yearly blood tests (blood sugar, prolactin, lipids) -avoid abrupt discontinuation
Norepinephrine Reuptake Inhibitor	-Strattera	-Hyperactivity -Inattentiveness	-Fatigue -Sleep disturbance -irritability -Gastrointestinal disturbance -Cardiovascular effects -Gastrointestinal symptoms -FDA WARNING ABOUT SUICIDAL THOUGHTS	-Regular checks of blood pressure are needed