HOW ADHD SHAPES YOUR PERCEPTIONS, EMOTIONS & MOTIVATION

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What Are We Going To Talk About Today?

- •The field of ADHD has been stuck for the last 20 years. Try to name two new advances in the last two decades.
- •Emotional Dysregulation (Rejection Sensitivity)? And what else?
- •Have we been asking the wrong questions?

Why Don't Non-Medication Therapies Work?

The Need For a Totally Different Understanding of ADHD

The DSM-5 and ICD-10 Diagnostic Criteria

- Neither the DSM or ICD diagnostic criteria have ever been validated for older adolescents, adults, or the elderly.
- This was to have been corrected in the DSM 5 but any updating was completely ignored.
- Initially the childhood (ages 6 to 12) criteria continued to be used for adults to "establish syndromatic continuity" between the childhood condition and ADHD in adults.
- This failed completely because it requires an adult to be functioning on the level of an untreated elementary school-aged child in order to meet diagnostic criteria.
- This puts in doubt all of the research done on adults with ADHD.

Why Do Diagnostic Criteria Matter?

- It determines what gets researched and who is studied.
- It determines who gets the diagnosis and who does not.
- It determines who gets treatment and insurance coverage.
- It determines who gets accommodations and protections at school and work.
- It determines what clinicians are taught and how well they will understand their patients.

Multimodal Therapy is No Longer the Standard of Care

- > Multimodal really meant "you have to do more than medication."
- ➤ This was changed in the 2007 AACAP Practice Parameter on ADHD.
- Recommendation 10: "If a patient has a robust response to psychopharmacological treatment,...then psychopharmacological treatment alone is satisfactory." (AACAP Guideline; page 912)
- ➤ 52 studies in a row have failed to show that psychosocial interventions have "any detectable, lasting benefits" for the core features of ADHD. (Page 903)
- > Provide "non-specific benefits" that are situation bound.

Practice Parameter for the Assessment and Treatment of Children and Adolescents With Attention-Deficit/Hyperactivity Disorder. AACAP Official Action. (2007). Journal *of the American Academy of Child and Adolescent Psychiatry*. 46 (7):894-921.

Why weren't these therapies working?

- Moderately effective for peripheral issues and deficits but no benefits for the *Core Features* of ADHD. (This is going to be a vitally important distinction later.)
- All of these older approaches viewed ADHD as a person with a Neurotypical nervous system that was damaged in some way. The goal was to make them be "Normal" again.
- They all assumed that people with ADHD nervous systems as being broken and needing to be fixed. The proponents of these interventions were apparently unaware of how hostile, shaming, and incorrect this attitude was.

Let Us Be Very Clear About the Term "the Core Features of ADHD"

These are the 4 basic and constant features that make ADHD what it is.

- ➤ Inattention/ High Distractibility
- >External Hyperactivity/Internal Hyperarousal
- >Impulsivity
- > Emotional Dysregulation

The term CORE does not refer to common but non-specific features found in many other conditions such as poor working memory, slow processing speed, etc.

Core Features of ADHD – cont.

- •This lack of efficacy of non-pharmaceutical treatments for the core features of ADHD does NOT mean that these treatments are not needed or not effective.
- •BOTH are needed. Medications vs. therapy is a false dichotomy.

We Must Have Both Medications and "Therapies"

- The medications level the neurological playing field so that distractibility, impulsivity, hyperarousal, and emotional regulation are the same as Neurotypical people. No better but also no worse.
- But "Pills don't give skills."
- The various "talking therapies" are then needed to repair the damage that was done while waiting to get diagnosed and treated.
- >Academic and occupational remediation.
- > Work on self-esteem and Shame.
- Learning how to manage an interest-based nervous system and that you will never be Neurotypical.

New Diagnostic Criteria for Adults with ADHD Updated European Consensus Statement (2019)

Six Criteria for the Diagnosis of Adults with ADHD

- Inattention
- Hyperactivity if external; Hyperarousal if it is internal
- Impulsivity
- Excessive mind-wandering (multiple unrelated thoughts that are constantly changing)
- Behavioral self-regulation (executive function deficits but EF deficits correlate poorly with measures of impairment)
- Emotional Dysregulation

Kooij J.J.S., Bijlenga D, Salerno L, Jaeschke R, Bitter I, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. (2019) European Psychiatry 56: 14–34.

"Emotional Dysregulation"

(Still remains vague and non-specific to ADHD)

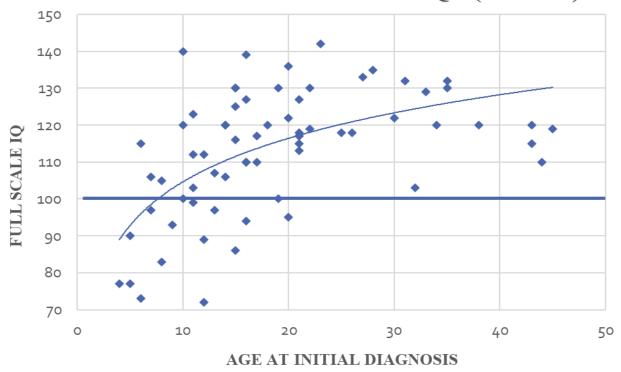
- Mood lability change unpredictably, instantaneously, but match the nature of the trigger.
- Low frustration tolerance
- Irritability
- Emotional impulsivity (expresses emotions without thought)
- Anger outbursts (Rarely have warning of the emotional release.)
- Premenstrual increase of symptoms

But...ADHD conveys a lot of positive traits

- High IQ (average FSIQ = 123)
- Out-of-the box problem solving.
- Cleverness
- "Cognitive dynamism" Inventive
- "Relentless determination." Hyperfocus.
- Quick zany sense of humor.
- Devoted, loyal to friends.
- Keen sense of fairness and justice.

IQ and ADHD

AGE AT INITIAL DIAGNOSIS VS FULL SCALE IQ (314.00)



- IQ can compensate for the impairments of ADHD
- Can forestall diagnosis of ADHD

Children With ADHD Grew Up To Be Adults With ADHD

- ADHD is no longer a childhood condition.
- By 2014 more adults with ADHD were being diagnosed and treated with medication than children (17 and under).
- The average age at diagnosis in the US was 31 years of age.
- Finally, patients could tell us what their experience of ADHD and the medications used to treat it were like.
- They could also tell us experiences of non-pharmacological treatments.

We Started Asking the Right Questions

- "If you have been able to get engaged and stay engaged with literally any task of your life, has there ever been anything you *couldn't* do?
- The vast majority of people with ADHD will answer "If I can get engaged, I can do anything."
- "Omnipotential."
- The whole orientation toward ADHD being a deficit of something that had dominated the thinking about ADHD for 25 years fell apart.

ADHD was not a deficit of:

- Effort
- Character
- Willpower
- Brain activity
- Brain size
- Brain integrity

- Structure
- Parenting skills
- Intelligence
- Self-control
- Neurotransmitters
- Executive functions

Deficit models have not produced therapies that have shown "detectable, lasting benefits."

Jadad AR, Boyle M, Cunningham C, Kim M, Schachar R. (1999),. Evid Rep Technological Assessment Summary. November: i-viii, 1-341.

MOST IMPORTANTLY, DEFICIT THEORIES WERE NOT PRODUCING THERAPIES THAT WERE BENEFICIAL

MTA Study Results

All treatments led to improvement in core ADHD symptoms

Medication management alone

Medication management + behavioral treatment

Equal in effectiveness and superior to both:

Behavioral treatment alone

Community-based treatment

NYU-McGill Study

In medication responsive children there was "no support for or advantage from adding:"

- Long-term (2 yrs.) psycho-social intervention
- Long-term O.D.D. prevention interventions.
- Academic remediation and tutoring.
- Organizational skills training.
- Social skills training.
- "Attention control training"
- Parental practices training.

Virtually No Interventions Were Effective.

- Neurofeedback (The Neurofeedback Collaborative Group. Double-Blind Placebo-Controlled Randomized Clinical Trial of Neurofeedback for Attention-Deficit/Hyperactivity Disorder With 13-Month Follow-up (2021) *J American Academy of Child & Adolescent Psychiatry* 60 (7) 841-855
- Diet and Nutrition (Rucklidge, JJ, Mairin R. Taylor MR, Johnstone, JM. Do Diet and Nutrition Affect ADHD? Facts and Clinical Considerations (2018) Psychiatric Times, 35 (9). If there are benefits, they are small (ES-0.29).
- Working Memory Training Monica Melby-Lervåg¹, Charles Hulme. Is working memory training effective? A meta-analytic review (2013) Developmental Psychology 49(2):270-91. "Current findings cast doubt on both the clinical relevance of working memory training programs."
- Cognitive Behavioral Therapy (CBT) Rajeh A, Amanullah S, Shivakumar K, Cole, J. Interventions in ADHD: A comparative review of stimulant medications and behavioral therapies, (2017) Asian Journal of Psychiatry, 25: 131-135. "Behavioral interventions play a key role for long-term improvement of executive functioning and organizational skills. There is a paucity of long-term RPC studies and current literature is inconclusive on what is the preferred intervention.

Galanter C. Limited Support for the Efficacy of Nonpharmacological Treatments for the Core Symptoms of ADHD (2013) Am J Psychiatry 170:3, 241-4.

One Treatment Modality Worked Well

Aerobic Exercise:

- Robustly effective (i.e. equal to medications) for about 10-12% of people with ADHD.
- The trade off is one hour of aerobic exercise for four hours of concentration and calmness that can be as good as a simulant medication.
- These people come in for more conventional treatments when they get an injury that prevents exercise.

Only four successful new initiatives have been added to the field of ADHD in the last 20 years

- 2000 "Understanding Girls (Women) with ADHD" from Nadeau, Littman, and Quinn.
- 2010 The ADHD Effect on Marriage Orlov
- 2019 Kooij, J. J. S.; et al. (2019). <u>"Updated European Consensus Statement on diagnosis and treatment of adult ADHD"</u>. *European Psychiatry*. **56**: 14–34.
- 2022 (in press) ADHD in the elderly from Nadeau and Littman

Why are non-pharmacologic therapies not working?

This answer requires that we start over again from the beginning with no preconceived ideas of what to look for or what we will find.

Attention "Deficit"

The most important feature is that attention is not deficit, it is inconsistent

but in a very consistent way.

- ➤ 3 or 4 times every day people with ADHD will "get in the Zone" or "get in the Flow" during which they have few if any impairments.
- This inconsistency of being able to function at a very high level *sometimes but not others* appears to others to be willful or defiant.

Back to the 1st Right Question

• "Look back over your entire life; if you have been able to get engaged and stay engaged with literally any task of your life, have you ever found something you couldn't do?"

Executive Function Deficit Theory

- This makes EFD Theory almost completely wrong.
- EFD Theory has dominated the field of ADHD for more than 20 years.
- EFD Theory assumed that people with ADHD were the same as Neurotypical people, just broken or lacking cognitive abilities.
- This theory assumed that executive dysfunction was the *cause* of ADHD as opposed to the *result* of an ADHD nervous system.
- "EF weaknesses are neither necessary nor sufficient to cause all cases of ADHD." (Willcutt 2005)

Willcutt EG, Doyle AE, Nigg JT, Faraone SV, Pennington BF. Validity of the Executive Function Theory of Attention-Deficit/Hyperactivity Disorder: A Meta-Analytic Review. Biological Psychiatry 2005;57:1336–1346.

A Totally New Definition of ADHD is Needed

Any new approach must give diagnostic certainty....

- 1) We needed pathognomonic features: What few things does everyone with ADHD share in common and no one has who doesn't have ADHD?
- 2) It must tell us why every non-medication-based therapy has thus far failed to benefit the core symptoms of ADHD and ...
- 3) What might work instead?

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Importance of Engagement



https://www.youtube.com/watch?v=6RuPH8asOOo

Orban, S.A., Rapport, M.D., Friedman, L.M. *et al.* Inattentive Behavior in Boys with ADHD during Classroom Instruction: the Mediating Role of Working Memory Processes. (2018) *J Abnorm Child Psychol* **46,** 713–727

This Requires That We Look at ADHD in a Totally Different Way

- The impairments of ADHD depend on the situation.
- The Executive Functions can often be there but the person does not have access quickly enough.
- ADHD is a problem of consistent Access on Demand.

Therefore, ADHD is NOT a DISORDER.

• It is a 2nd nervous system that functions perfectly well but by its own set of rules, principals, and methods.

Functional/Experiential Definition of ADHD ADHD is a:

- Genetic, neurological / brain-based...
- Difficulty with engagement as the situation demands...
- In which not just 1) performance, but also
- 2) mood, and 3) energy level...
- Are solely determined by the momentary sense of...
- Interest, (Fascination)
- Challenge or competitiveness,
- Novelty (Creativity),
- Urgency (Usually a deadline).

INTEREST-BASED NERVOUS SYSTEM (the COGNITIVE COMPONENT OF ADHD)

Each element of the functional definition has many implications

Genetic and Neurological

- ADHD is biological, neurological, and brain-based.
- Runs in families. Up to 50% of 1st degree relatives.
- At least one parent will have ADHD.
- It is not a factor of poor parenting.
- It does not go away with age. People outgrow the childhood criteria, not the disorder itself.
- Its core features are BIOLOGICAL and NEUROLOGICAL and can not be treated with behavioral techniques any more than you can lower a fever with behavioral techniques.

Difficulty with Engagement on Demand

- ➤ If a person with ADHD can engage and stay engaged, they can do almost anything.
- This inconsistency is mystifying and frustrating to everyone. If you've done it before, the inability to do it now is seen as willful and defiant.
- ➤ Jobs, schools, and relationships demand that we be able to stand and deliver consistently and on demand...not when we "feel like it."
- ➤ On the positive side, persons with ADHD have extended periods when they see how capable they are when "in the Zone / in the Flow" or "Hyperfocus."

Another Right Question

- •"What are you like when you are good and thoroughly bored?"
- The nervous system controls every aspect of our lives.
- Performance is usually the only aspect that most people consider.
- Boredom and lack of engagement is almost physically painful for people with an ADHD nervous system.
- When bored, people with ADHD are irritable, negativistic, tense, argumentative, and have no energy to do anything.

Performance, Mood, and Energy

- •People with ADHD will do almost anything to relieve this **dysphoria**. Self-medication. Stimulus seeking. "Pick a fight."
- When engaged, people with ADHD are instantly energetic, positive, and social.
- This seemingly untriggered shifting of mood and energy is often misinterpreted as Bipolar Disorder.

What are you like when you are Bored?

Bored (Not Interested)

- No Energy
- Irritable
- Don't want to do anything
- The world is bleak.
- The future holds nothing you want,
- Almost physically painful.

Engaged "In the ZONE."

- Energetic
- Enthusiastic
- Gregarious
- Optimistic
- "Let's go do something new and fun and interesting!

Interest, Challenge, Novelty, and Urgency (and perhaps Passion)

•These are very personal and subjective features. Life requires that we engage the most important activities **as the situation demands.**

Things that are interesting today may not be interesting next week.

A person with an interest-based nervous system must be personally interested, challenged, find it novel, or urgent **right now** or nothing happens.

Contrasted to *Importance*-Based Neurotypical Nervous Systems

Neurotypical people are able to get engaged because:

- The task is important and of great significance or value,
- There is a reward for doing the task, or
- There is a punishment or consequence if the task is not done.

Tasks don't have to be important to the individual; Can be important to boss, teacher, spouse, parent, etc.

"2nd Hand Importance"

Importance Based – cont.

- Tasks don't have to be important right now.
- Can prioritize, that is, arrange things in order of importance.
- It is the *importance* of the task that helps the individual...
- 1) Engage on demand
- •2) Get access to intellect and abilities every time they are needed.
- 3) Stay engaged all the way to the payoff.

ADHD is a hard way to live.

- You get very little useful help and guidance. So far, all of the non-pharmacologic interventions are designed to work for an Importance/Reward style of nervous system.
- As a result, they are set up to fail and then the ADHD person gets blamed for failing because they didn't try hard enough.
- Children with ADHD get more than 20,000 negative or corrective messages by the time they are 10 years old.¹

¹Jellinek M. Don't Let ADHD Crush Children's Self-Esteem Clinical Psychiatry News. (May 2010) pg 12.

Weaknesses of an Interest-Based System

- > Solutions do not last.
- Things that were challenging today are not helpful once the challenge is met and mastered.
- Newness is time-limited. Everything becomes old hat after a while.
- ➤ Urgency substitutes for importance. The person with ADHD cannot get engaged with a task (procrastinates) merely because it is important.

Sometimes the person creates crises and chaos because they have found that it helps them get engaged and get things done. This can be mistaken for Borderline Personality Disorder.

Implications

- Planning and organization are very difficult. Most planning systems are built for neurotypicals who can use Importance/priority and time..... Two things which the ADHD nervous system does not do well.
- Since it is hard to make use of the concepts of importance, priorities, and rewards, it is hard for people with an ADHD nervous system to figure out what is the best place to start projects. People with ADHD work best if they go backwards from the end to the beginning.

An Interest-Based Nervous System Defines ADHD

- •One of the few times in life we can say Always and Never.
- A person with an ADHD style nervous system has **ALWAYS** been able to do anything they want IF they can get engaged through ICNU and they have **NEVER** been able to make use of the Importance, rewards, and consequences that organize and motivate the other 90% of Neurotypical people in their lives.

ADHD is a Second Type of Nervous System

- ADHD "therapies" incorrectly assumed that people with ADHD were actually neurotypical people who had deficits of executive functioning.
- Instead, "Therapy" should be teaching them the rules and techniques that work in their ADHD nervous system so that they can "get in the Zone" as the situation demands.

Can People Succeed in Life Using Neurotypical Techniques and Methods?

- Of course they can!
- But it quickly becomes a "Singing Pig."
- "Never try to teach a pig to sing. It annoys the pig and the results are never worth the effort."
- People with ADHD are extremely smart, world class problem solvers, and have relentless determination.
- But the results are rarely worth the tremendous effort it took.

We should now talk in terms of *managing* ADHD rather than *treating* it

Management has two pieces:

- 1. Level the neurological playing field with medication.
- 2. Help the person start the lifelong process of writing their personal owner's manual for their ADHD nervous system.

You need to have both pieces

The person with an ADHD system gets engaged through being interested, challenged, finding the task novel or urgent, or caring passionately

AND THEN...

The stimulant medications then keep them from being distracted. Up until recently we have only been doing the 2nd medication portion and getting poor results.

Take Home Messages So Far

- Neurology is destiny. ADHD does not go away with age.
- You are going to have to personally manage your ADHD nervous system forever. You are the only ones who can help your children, half of whom will have ADHD as well.
- No one can do it for you.
- You are going to have to master not one, but two nervous systems.
- Be reasonable and practical... find a good <u>ADHD</u> coach to help you.
- Be careful. Not just any coach will do. It must be someone who "gets it" and understands that techniques that work for Neurotypicals won't for people with ADHD.

Questions and Discussions

PART 2:

THE ADHD OWNER'S MANUAL

Picking up from Part 1

- The ADHD Nervous System works well but it works by totally different principles that the Neurotypical Nervous System.
- •People with ADHD Nervous Systems are not damaged or broken.
- Trying to lead life according to Neurotypical rules and techniques has been shown to be a set up to Fail.

The World Doesn't Support People with ADHD

- All schools are based on 2nd hand importance ... what does someone else (the teacher) think is important enough to teach and put on the test because it is going to be important to know it 10 years from now?
- 90% of jobs are based on 2nd hand importance as well. What does someone else (the Boss) think is important enough to them that they are willing to pay someone to do it for them?
- People with ADHD need to start thinking in terms of ADHD-friendly occupations by the time they are 14.

How Big of a Problem Is This?

Ask the right question:

Look back over your entire life. Where and how did you learn what you know about your life?

- Your occupation / skills
- How to behave with other people / life skills.
- How to establish intimate relationships.
- What you value in yourself and in others?

Most Common Responses

- In school 1%
- On the job − 1%
- In church/religion 1%
- From someone in my family 3%
- •"I have learned what I know on my own/ by myself/ observation of others." 94%
- People with ADHD nervous systems have to be self-made individuals because most other people do not know there is a problem much less how to be helpful.

This is a Failure Of Parenting and Schools

- Some people with ADHD can learn what they needed to know on their own.
- Most cannot.
- Everyone with ADHD needs as much assistance as they can get as early as possible...
- Before they internalize a negative view of Self and ...
- Before they fall hopelessly behind academically and socially.

The ADHD Owner's Manual

- Focuses on how and when the ADHD person does well.
- Highly personal and individualized.
- The manual is a written record of when things go spectacularly well so that you can do them again.
- Changes over time. Techniques work for about a month and then you have to use another technique until the original technique seems fresh again. Most people need 60-100 techniques in their manual.
- It does not demand that ADHD people do things in a neurotypical way that neurologically can't be done and then blame them for failure as we have in the past.

Owner's Manual: Examples of What Works

- > Implementer-finisher partner.
- Body doubling.
- > "You can't do that!"
- ➤ Loathing.
- > Planning for dead lines.
- > Injecting interest.
- > Distinguishing progress from outcome.
- > Trading interest for importance.
- Organize in ADHD friendly ways.

Implementer-finisher partner

- People with an ADHD nervous system are idea people.
- They are world class, intuitive problem solvers.
- "Cognitive dynamism"
- But once the problems are solved the project has no more interest, challenge, or novelty and the person loses interest. Lots of half-finished projects.
- Solution: Find someone who may not ever have great ideas and inventions but who will take the projects to completion. As partners they are unbeatable.

Body Doubling

- A variation on the partner idea.
- Using another person's ability to get engaged to get involved yourself.
- •"A Study Buddy."
- Probably the most successful academic technique.

Challenges: "Ah, You can't do that!"

- Competition usually brings forth our best efforts.
- Proving a detractor wrong brings extra and longer engagement and effort.

Loathing

- A variation on competition but adding passion.
- Passion and antipathy can bring out special sustained effort that simple competitiveness is not able to give.
- "I hate that guy. I am never going to let him do better than me!"

Planning for Deadlines

- Accept your ADHD patterns and habits.
- Accept that despite your good intentions, you almost always wait until the last possible moment to start a major project.
- If you know it's going to happen, plan for it.
- Make sure there is nothing else competing for that time.
- Tell other people you are going far away where they will not try to find you.
- You are still procrastinating but worry and guilt are not bothering you and you know nothing else will interfere in your hyperfocus.

Injecting Interest

- Most of what we do is repetitive and unchallenging. Even neurotypicals struggle to get engaged and stay engaged.
- Accept that it is your lifelong job to manage your engagement with the tasks of your life. Schools and jobs are built for neurotypicals and not for you.
- Know your personal passions and motivators that you can use to get yourself engaged.
- Use your imagination to create situations of interest, challenge, novelty, and urgency.

Distinguishing Wanting the Process From Wanting the Outcome

- "What most people really want is to have written a book."
 - Norman Mailer
- Be honest with yourself.
- If this task is not interesting, challenging, creative, or urgent, delegate it to someone else if possible...
- Or trade the task for something else.

Trading Importance For That Which is Interesting

- It may be important to get a task done but not necessarily by you.
- Many ways to do this:
- ✓ Find other ways to attain the end goal.
- ✓ Trade that which is important for that which is interesting.
- ✓ Each member of the team is selected for their talents in completing the work.

Organize In ADHD Friendly Ways

- Most organization systems are designed for neurotypicals and are designed to focus on priorities and time management.
- These are two things the ADHD nervous system does not do well for sustained periods of time.
- Example of something that has a chance of being successful:

5 folders: Red= must be done today; Orange= must be submitted by Friday; Yellow= ready to go on Monday; Blue= Need to start preliminary steps; Green=Ideas for future

Works on color and deadline not importance and time.

REGULATION OF MOOD

EMOTIONAL MANAGEMENT AND REJECTION SENSITIVITY

Two Type of ADHD Emotional Problems

#1 Intense, passionate emotions that are normal in every way except their intensity. Consistent with the popular concept of Emotional Dysregulation.

#2 Intense vulnerability to rejection and criticism that is probably unique to people who have an ADHD nervous system.

What is a Mood Disorder?

- 1. It is a disorder of the level or intensity of moods (not the quality of mood)....
- 2. That have taken on a life of their own.... Comes on gradually without a triggering event.
- 3. Separate from the events of the person's life and....
- 4. Outside of their conscious will and control.
- 5. Lasts without interruption for more than 2 weeks.

Type #1 Mood Dysregulation in ADHD

- People with an ADHD nervous system lead intense, passionate emotional lives.
- Their highs are higher and their lows are lower.
- They moods are almost always triggered by events and perceptions.
- Their moods match their perception of the trigger (i.e. congruent).
- The shift happens instantaneously.
- "Get over it" quickly; not sustained for weeks at a time.
- In other words, these are normal moods in every way except their intensity.

Clinicians are trained to recognize Mood Disorders but not ADHD

- Most people with ADHD are first misdiagnosed with "Mixed" anxiety and depression or Bipolar Mood Disorder.
- On average, an adult with ADHD in the U.S. will see 3.2 clinicians and go through 6.6 antidepressant trials wasting on average 7 years before the diagnosis of ADHD is made (if they don't give up).
- The irony is that about 20% will have both Depression and ADHD; about 7% of people with ADHD will also have Bipolar. (This is bidirectional...25-40% Of people with Bipolar will also have ADHD.)

Emotional Dysregulation

- The emotional component of ADHD was intentionally ignored by researchers in favor of the DSM and ICD sets of diagnostic criteria that are based on behavioral impairments that can be seen and counted.
- This made sense 50 years ago when the ADHD syndrome was struggling for research validation. Those days were over 25 years ago but researchers in the US never noticed.

Research Intentionally Ignored...

- The Cognitive Component ADHD as a 2nd type of nervous system that works by interest instead of importance.
- The Neurological Arousal Component insomnia, impulsivity, can't sit through a movie, mind always doing something. Never experience mental or physical peace.
- The Emotional Component Emotions that are too Intense with too little control.

Emotional Dysregulation

- This was to be corrected and updated with DSM 5 in 2013.
- Two minor changes that actually made the diagnosis less rigorous.
- Finally in 2010 scientists in the EU issued adult ADHD guidelines and in 2019 an update that put forth the 1st diagnostic criteria for adults with ADHD.

Kooij J.J.S., Bijlenga D, Salerno L, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. (2019) European Psychiatry 56: 14–34. http://dx.doi.org/10.1016/j.eurpsy.2018.11.001

REJECTION SENSITIVITY DYSPHORIA (THE EMOTIONAL COMPONENT SPECIFIC TO ADHD)

Asking the Right Questions: Rejection Sensitive Dysphoria

- "For your entire life have you always been much more sensitive than other people you know to...
- 1.Rejection
- 2. Teasing
- 3. Criticism, or
- 4. Your own perception that you have failed or fallen short?"

• In my practice 98% answered a strong "YES!" and 33% said that it was the most impairing aspect of their adult ADHD.

Features of RSD

- No one likes to be rejected or criticized. But for people with ADHD, it is "Unbearable".
- Triggered by a perception or possibility that someone has or might withdraw their love, approval, or respect.
- Or the ADHD person has done this to themselves when they do not meet their own high standards for performance.
- Physically painful "like a sudden punch in the chest."
- The ADHD person ceases to be able to function for hours or days. The episode "has to run its course."
- Most people lack the words to describe the experience; they can describe only the intensity. (It's terrible, awful, catastrophic.)

Features of RSD

- If internalized, it looks and feels like an instantaneous Major Depression
- If externalized, it is expressed as a rage at the person or situation that "wounded" them so badly.
- Physically painful as well as emotionally devastating... "like a physical wound."
- As if physically cut off from the world.... "profound loneliness," "as if cast out", "outside the realm of other people," "isolated."
- Episode is followed by profound Shame and humiliation for "being a head case" and not being able to control their emotions.

What Does RSD Feel Like?

- "Like a hard punch in the chest." "Like knives."
- "It turns from frustration into white hot rage so quickly."
- "Feelings of self-doubt and unworthiness." I'm a failure."
- "I'm shattered and I'm left feeling empty."
- "I'm a helpless child. I'm afraid it is never going to end."
- "Nothing helps me get out of feeling that way. Nothing derails the power of RSD."

RSD and Personality Development

• The avoidance of the unbearable pain of RSD appears powerful enough to have a major contribution to personality development...

Perfectionist/over-achiever, - to be the best and above reproach. The trap is that they must constantly perform. "Today's audience does not applaud yesterday's performance."

People pleaser – anticipates what each person would like and approve of... so much that they lose track of their own goals and desires.

Risk avoider/Slacker – will not try anything unless assured of quick, easy, and complete success. Looks like Social Anxiety Disorder

RSD is still in the early phases of inquiry.

- It is not an official condition and there is virtually nothing written on it in the scientific literature.
- Many clinicians discount it because they know nothing about it.
- But many people with ADHD identify with it <u>very</u> strongly. More "hits" on the topic on HowToADHD, Reddit, ADDitude, and Facebook than any other ADHD topic <u>ever</u> in only 6 months. Over 150 YouTube channels or videos in 6 months.
- You may think it is crap but your patients don't. When they tell you how vulnerable they are to criticism and shame, treat them with respect or you will do irreparable harm to the therapy.

Participation in the 1st validation research

- This is a new and unvalidated concept but one with which the majority of adults with ADHD identify.
- If you or your patients would like to participate in the 1st validation study of RSD, and ...
 - Are over 18 years of age
 - Clinician-diagnosed with ADHD to be a subject
 - Anyone who does not think they have ADHD can volunteer to be a control subject.
 - Time commitment is approximately 20 minutes.
- Please contact me at:

billdodson19@gmail.com

Why should I care about RSD?

- Scientific curiosity.
- •RSD is unique among the emotional dysregulations in that it robustly responds to medications in more than half of cases.
- About 60% can get almost complete, sustained prevention of these episode with the already FDA-approved alpha _{2a} agonists.
- Usually hidden due to shame over their lack of self-control and vulnerability. If you do not ask about it, they will not tell you about the most impairing aspect of their ADHD.

What medications help?

Alpha 2a Agonists

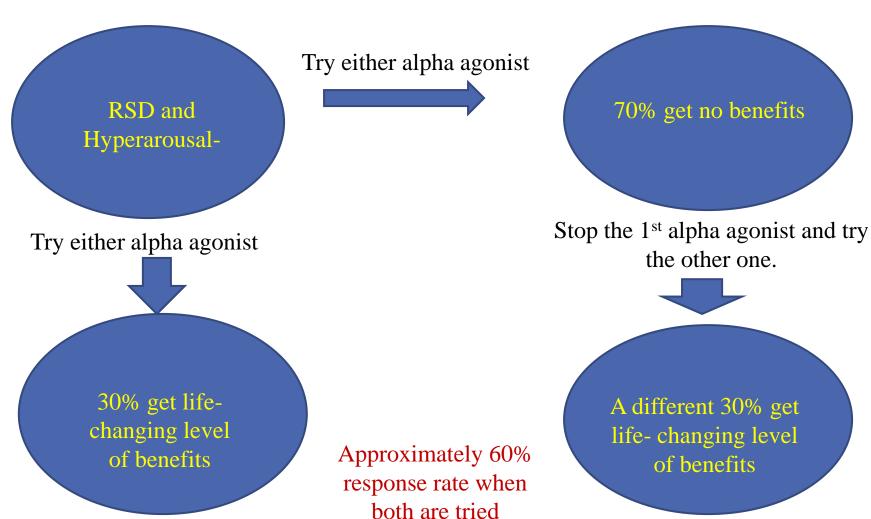
- Guanfacine (Intuniv) or Clonidine (Kapvay or Catapres)
- Originally failed blood pressure medications (1983)
- Most common use of an alpha agonist is as a sleep aide for children usually without any recognition that the cause of the insomnia is ADHD hyperactivity.
- Outcome goals: "At peace." "One thought at a time." "Emotional armor."
- Side effects: mild sedation, dry mouth, dizziness when standing up suddenly.
- Benefits take 5 days to develop so the dose is increased every 5th day. This means that alpha agonists can only be used as preventatives. Must be taken once a day every day.
- The optimal dose for 80% of robust responders is 0.3 mg of clonidine or 3 mg of guanfacine.

When Should an Alpha_{2a} Agonists Be Considered?

Asking the right questions:

- Do you have Extreme sensitivity to rejection, teasing, and criticism.
 (RSD)
- Have you ever been mentally and physically at Peace?
- How many simultaneous lines of thought do you usually have in your mind?
- Does it usually take more than an hour to settle down your mind and body to fall asleep every night? Do you take something almost every night to fall asleep? (Marijuana, alcohol, sleeping pill)

Disappointing 30% response rate to each alpha_{2a} agonist but...



Take Home Messages So Far

- ADHD is not a defective nervous system.
- •ADHD is a 2nd fully functional nervous system that works by its own set of rules and techniques.
- The importance based techniques of a Neurotypical Nervous System will never work well for ADHD.
- The person with ADHD must learn to manage their unique nervous system based on what they know works for them.

Questions and Discussions

OTHER FEATURES UNIQUE TO THE ADHD NERVOUS SYSTEM

PART 3

Poor Sense of Time

- "People with ADHD have only 2 times; Now and Not Now." They are usually stuck in the present moment. "If it feels good Now, go ahead and do it."
- They cannot look into the past and remember what happened in similar situations. Implication: It is much harder to learn from experience.
- The cannot look even a few moments into the future to predict the obvious outcomes of current behavior. Implication: Repeatedly surprised by well-known reactions and outcomes.
- This is the origin of what we see as "poor judgment" and "not learning from experience."

Lying, RSD, and living only in the Now

• Many parents and spouses are repetitively astonished when their ADHD loved one lies to them about a mistake or failure with a lie that is obviously not true. The lie is immediately detected. What is going on here? How do we get out of this cycle?

1st – The RSD pain of failure is so intense that the person says the first thing that comes to their mind in a desperate attempt to void the pain.

2nd –The lie is immediately seen to be false. The pain of humiliation and RSD gets even worse and the situation spirals out of control.

3rd – The relationship is damaged again and the self-worth of the ADHD individual gets worse and worse.

Lack of Self-Appraisal Abilities

- This was proposed as a criterion for adults with ADHD for the DSM-5.
- Also known as "Observing Ego."
- Also highly related to "Mindfulness."
- It is the relative inability or difficulty to assess how you are doing Right Now.
- This is more than not paying attention or not being engaged. It is being engaged but still not understanding the situation.

Components of Situational Awareness

- What am I thinking? What emotional responses am I having? RIGHT NOW.
- What is the other person thinking and feeling RIGHT NOW?
- What effect am I having on the people around me and is it the effect I want to have?
- Many people with ADHD are "self blind." They can assess other people but not have a clue about what they themselves think and feel.

Implications of Self-Blindness

- The social learning feedback loop is distorted or broken entirely. People with ADHD often are lost in groups and have to "Fake it." Imposter Syndrome.
- They develop fewer and less effective social skills no matter how hard they try.
- Interferes with closeness and intimacy.
- 70% of 3rd graders report that they do not have a single friend.
- Close family, partners, spouses, and friends may need to be patient when their ADHD loved one tells them that "I don't know what I feel."

What Do People Do About Lack of Self Awareness?

- Be aware that it is an almost universal part of ADHD and everyone needs to cut them some slack.
- Analyze situations with a coach or trusted ADHD friend after the episode is over to develop analytic skills (We do not yet know whether this works or not). ADHD therapy groups have been shown to be very helpful in learning social understanding.
- Try watching yourself on TV to literally see yourself. (research on use of video recordings began last year.)
- Both stimulant and alpha agonist medications seem to help so take them as much as possible. (Not yet looked at in research).

If the ADHD Medications Are So Great,

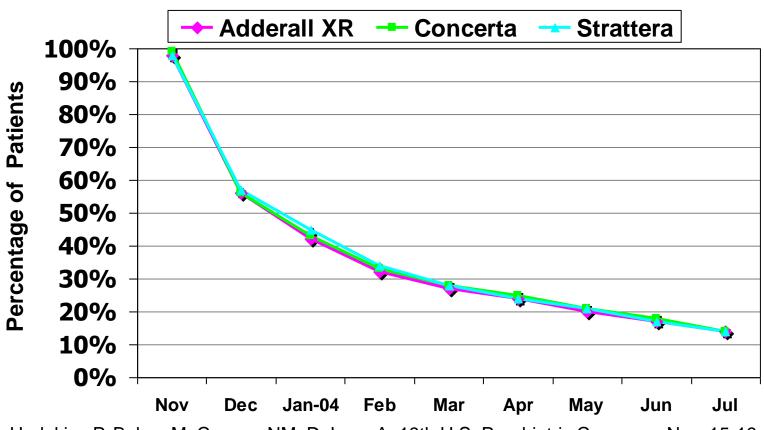
Why Do So Many People Stop Taking Them?



"I'm writing a prescription that will give you a new freedom and a new happiness. You will not regret the past nor wish to shut the door on it. You will comprehend the word serenity and you will know peace."

Persistence with ADHD Therapy is Poor Across Brands

Persistence with ADHD Treatment by Month



Hodgkins P, Boken M, Capone NM, DeLeon A. 19th U.S. Psychiatric Congress; Nov. 15-19, 2006; New Orleans, LA. Abstracts 123 and 124.

Optimize the 1st Line Agents

All 11 International Standards of Care agree:

- The stimulant class of medications is the Treatment of Choice, NOT the treatment of last resort when everything else has failed.
- 70% get a great response to Amphetamine;
- a different 70% get a robust response to Methylphenidate.
- 85% get a robust response if both molecules are tried.
- 15% do not respond to or tolerate either stimulant medication
- Both AMPH and MPH should be tried before trying anything else.

Only trying one molecule is the most common cause of treatment "failure."

Greenhill LL, et al. Medication treatment strategies in the MTA.(1996) JAACAP 35; 1304-1313.

What Are Reasonable Expectations?

- We measure how well any treatment in medicine is working with a statistical calculation called "Effect Size."
- •Effect size tries to estimate "How well does this treatment work as compared to all the other treatments we could have tried?"
- •It is a crude estimate but it is the best available.
- •E. S. compares the responses of groups, not individuals. Your personal response may vary.

Effect Sizes of ADHD Medications

• 1st Line Stimulants 1 (MPH and AMPH)

Research studies - force dosed	0.95
Fine-tuned/dose optimized	>1.80
• Either alpha agonist (guanfacine/clonidine) =	1.1 - 1.3
 Atomoxetine (children < 12 y/o) 	0.62
• Atomoxetine ² (2 adult studies)	0.44
• SSRI's for Major Depression	0.50
• SSRI's for anxiety disorders	0.39

¹ Michaelson et al. *Biol Psychiatry* 2003.

² Faraone SV. Using a meta-analysis to draw conclusions about ADHD medication effects. 156th Annual Meeting of APA; May 21, 2003;

Causes of Treatment Dropout

- The medications for ADHD work dramatically well.
- However, only 15% of patients are still taking medication 9 months later. Why?

- #5 Meds produce intolerable side effects (dose too high) or when mixed with other stimulant medications.
- #6 Meds don't adequately control symptoms (dose too low).

Causes of Treatment Dropout

- 1. Patient did not understand why they were taking the medication and the role of medications in the prevention of future impairment.
- 2. Both patient and clinician believe that a Rx will magically cure everything forever. "Antibiotic fantasy"
- 3. Clinician was perceived as being unsupportive of consistent medication through the entire day for life.
- 4. Patient or parent was not organized enough to take the medications as directed or get new refill each month. Treat the entire family.
- 5. Cost was 50th out of 51 reasons people stopped taking medications (listed as a factor by only 11%).

Successful Clinicians...

- Psycho-education about ADHD and lifelong impairment.
- Choose the best molecule and delivery.
- Determine the optimal dose.
- Never assume the patient is compliant...
- 1. Write down everything.
- 2. Vigilance effect (ask; count pills; call backs)
- 3. Pillbox timers, ticklers on PDA's
- 4. Assess the entire family

Plan For Common Times of Non-Adherence

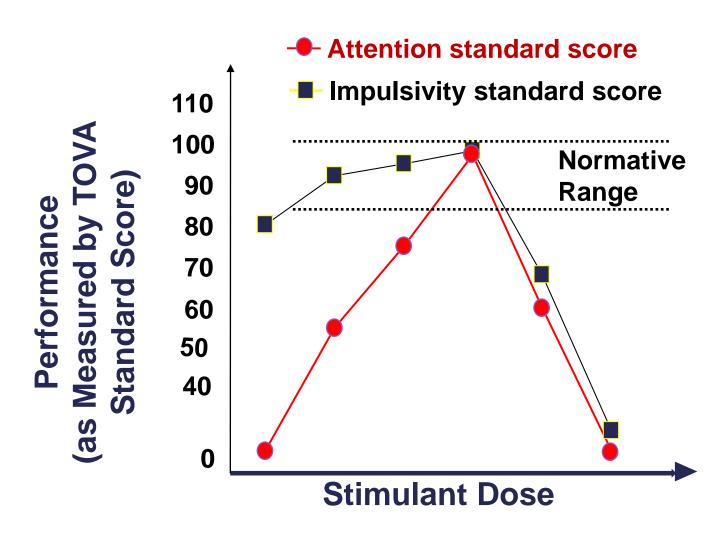
- Virtually every adolescent stops taking ADHD medications when they leave home for the first time.
- In the USA this is most commonly their first year of college. Typically, they crash and burn wasting \$30,000 to \$45,000.
- If possible, plan a semester of high school without medication to demonstrate the need for medication.
- Start the acquisition of independent skills 3 years before leaving home... do own laundry, manage own money, time management, make their own meals. If they are going to fail, do it before it costs \$40,000.

What is the Stimulant's Mechanism of Action?

Virtually no reason to think it is stimulation or neurotransmitter-based:

- □ Tolerance develops to the stimulation side effects in a matter of days.
- □But tolerance rarely if ever develops to the benefits.
- □ Just having stimulant (dopaminergic or adrenergic) neurotransmitter effects means nothing. 47 currently used medications in the US stimulate by the same mechanism but only 3 have benefit for ADHD.

Dose-Response of Stimulant Class Medications



This is a Replacement Model Graph

- •Dose response to ADHD first-line medications is curvilinear.
- •If the mechanism of action were stimulation, the dose response graph would be a straight line. The more you take, the more effect you see.
- •Curvilinear dose response is associated with replacement models (ex. Diabetes and insulin)

Ask the right question: What is the right dose for the individual?

- High dose vs. low dose makes no sense.
- The right molecule at the right dose for the individual is not an artificial state.
- It is a return to normal function without side effects.
- The "stimulant" medications have very little abuse potential for people with an ADHD nervous system.

Drugs of Abuse vs Meds for ADHD

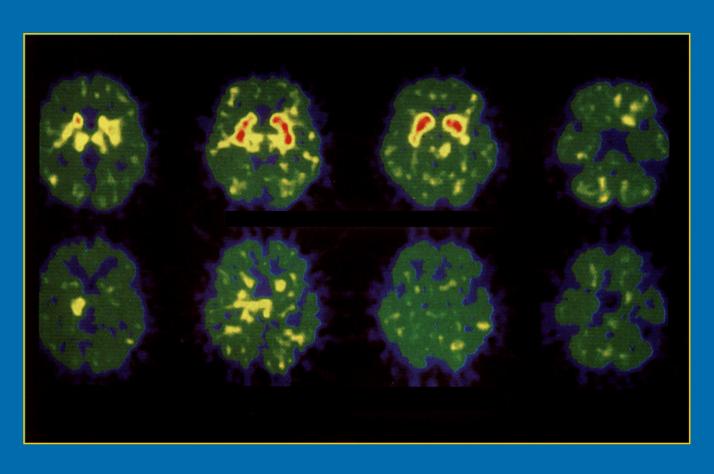
Drugs of Abuse

- Are taken to "feel good"
- Create craving in users
- Appeal to a large and ready market
- Involve a "struggle" to get people to stop taking them

ADHD Medications

- Dysphoric if over-dosed
- Are commonly forgotten by patients
- Are readily available, but long-term abuse is rare
- Involve a "struggle" to get people to take them

Rapid and Selective Distribution of <u>d-MPH to the Striatum</u>



d-threo-methylphenidate

I-threo-methylphenidate

*Transaxial PET images from one healthy volunteer after IV administration. Ding YS, et al. *Psychopharmacol Berl.* 1997;131:71-78.

What Does the Corpus Striatum Do?

- A novelty detector that also instantaneously assigns relative importance to every thought, emotion, and sensory experience.
- About 100,000 items a second.
- Sends the most important thing at that moment to the cortex to think about.
- The rest are handled but out of awareness.
- Failure leads to having 5 things in awareness for no particular reason.

Beware of What You Find on The Internet

• Dr Barkley's survey of the two largest ADHD chat rooms found that 92% of the postings were wrong.

Who can you rely upon?

ADDitudemag.com – great magazine and FREE website.

HowTO ADHD channel on YouTube by Jessica McCabe – short, fast moving, scientifically accurate topics on living an ADHD life.

Final Take Home Messages

- Recognition that non-pharmacologic therapies have to be of a very special type that work through getting engaged through interest, challenge, novelty, and urgency.
- Personal owner's manuals are desperately needed in conjunction with medications.
- Innovations from the European Union are finally bringing about change in how ADHD is defined and diagnosed especially in adults in regards to:
 - ✓ Unique ways of engagement with tasks,
 - ✓ Emotional regulation is a major source of impairment that was ignored until recently.
 - ✓ Rejection Sensitivity is possibly a unique feature of ADHD.
 - ✓ More reality-based attitudes toward misuse and abuse of stimulants.

Questions and Discussions