

Treatment of Children with Developmental Disorders

Science, Non-science, and Nonsense

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"Every complex problem has a solution that is simple, direct, plausible, and wrong."

H.L. Mencken



Management of Children with Developmental Disorders

Educational and Behavioral Interventions

- Preschool and School Programs
- Specific Strategies
 - Intensive behavior therapy - ABA
 - Structured teaching
 - Speech and language therapy
 - Occupational therapy
 - Physical therapy
 - Social skills instruction

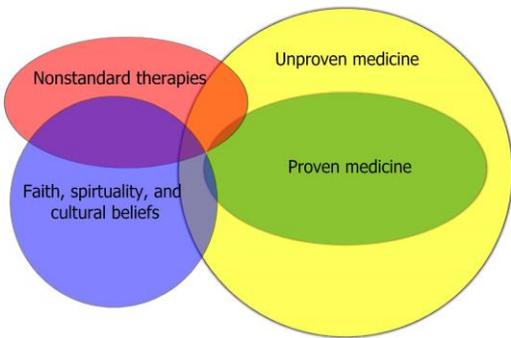


Management of Children with Developmental Disorders

Medical Management

- Medication for challenging behaviors
- Seizures
- Gastrointestinal Problems
- Sleep Disturbance

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Definition of Complementary and Alternative Medicine (CAM)

Cochrane Collaboration (1999):

“A broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health systems of a particular society or culture ...”



NCCAM classification of CAM

Mind-body medicine (meditation, biofeedback, hypnosis, yoga)

Manipulative and body-based practices (chiropractic, massage, reflexology)



NCCAM classification of CAM

Energy medicine (therapeutic touch, qi gong, Reiki, magnet therapy, acupuncture)

Biologically-based practices (herbs, diets, vitamins and other supplements)

Alternative medical systems (Homeopathy, Naturopathy, Traditional Chinese medicine, Ayurvedic medicine)



Prevalence of CAM Use

The use of therapies considered CAM is common among adults and children
NHIS (2002): 62% of adults used CAM in the previous year (including prayer)
A majority of patients in these surveys did not discuss their use of these interventions with their regular medical provider



Prevalence of CAM Use

In pediatric populations, there is considerable variation in estimates of CAM use
Selected pediatric outpatient and inpatient populations: 11-53%
Medical Expenditure Panel Survey (1996): 1.8-2.0%



Prevalence of CAM Use

CAM use is common among children with chronic health conditions
Cancer, arthritis, inflammatory bowel disease, asthma
Autism
CAM use is also increased in children with ADHD, CP, spina bifida, Down syndrome



Prevalence of CAM Use

CAM use in autism (Levy, et al. 2003):
284 children recently diagnosed with an autism spectrum disorder

- 30% were using some form of CAM
 - Vitamins, GI medications, melatonin
 - Gluten-free/casein-free diet, secretin
 - Cod liver oil, anti-infectives, chelation
 - Non-biological therapies



Prevalence of CAM Use

CAM use in autism (Levy, et al. 2003):
284 children recently diagnosed with an autism spectrum disorder

- 16.9% were using a "biological" therapy
- 9% were using a potentially harmful therapy



Prevalence of CAM Use

CAM use in autism (Green, et al. 2006):

- Internet survey of 552 caregivers
- Alternative diets: 26.8%
- Vitamin supplements: 42.6%
- Detoxification (including chelation): 8.9%
- Other alternative therapies: 25.9%
- Mean number of interventions per child (standard + nonstandard): 7



Prevalence of CAM Use

CAM use in autism (Hanson, et al. 2007):

- Survey of 112 families
- Biologically based practices: 54%
- Mind-body interventions: 30%
- Manipulation/body-based practices: 25%
- Energy therapies: 8%



Why Do People Use CAM?

Adults who use CAM are generally not dissatisfied with conventional medicine

- CAM therapies may be more congruent with their specific values and life philosophies (Astin, 1998; Eisenberg, et al., 2001)

Pediatrics:

- Higher parental education
- Higher rates of parental CAM use



Why Do People Use CAM?

Birdee GS, et al.: Factors Associated With Pediatric Use of Complementary and Alternative Medicine (Pediatrics Vol. 125 No. 2 February 1, 2010, pp. 249 - 256)

- Pediatric CAM users were more likely to take prescription medications, have a parent who used CAM, and have chronic conditions (anxiety or stress, musculoskeletal conditions, dermatologic conditions, or sinusitis)



Why Do People Use CAM?

In developmental disorders, non-standard interventions are often pursued based unsupported theories regarding the cause(s) of the disorder

- Mercury → chelation
- "Leaky gut" → GF/CF diet
- Yeast "overgrowth" → antifungals



"It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts."

Sherlock Holmes, in Arthur Conan Doyle's *A Scandal in Bohemia*





"Cottingley Fairies"



Research into CAM

1999: creation of the National Center for Complementary and Alternative Medicine (NCCAM)
Total NIH expenditure on research into CAM therapies since 1999: >\$3 billion



What Does the Evidence Show?

Effectiveness of CAM in children

The evidence-base for complementary medicine in children: a critical overview of systematic reviews

Hunt K, Ernst E. *Arch Dis Child* 2011;**96**:769–776.

What Does the Evidence Show?

Overview of 17 systematic reviews

- Acupuncture, chiropractic, herbal medicine, homeopathy, hypnotherapy, massage and yoga
- **Results were unconvincing for most conditions**
- Acupuncture may be effective for postoperative nausea and vomiting
- Hypnotherapy may be effective in reducing procedure-related pain



111 published articles on CAM use in children in 2011

Modality	# of articles	Percentage
Herbal/dietary supplements	31	34%
Acupuncture	29	32%
Massage (bodywork)	10	11%
Chiropractic	6	7%
Homeopathy	5	5%

Snyder J, Brown P. Complementary and alternative medicine in children: an analysis of the recent literature. Current Opinion in Pediatrics, 24:4, August 2012.



Melatonin

Several studies have shown that average night sleep duration was longer on melatonin, and sleep-onset latency was shorter (by about 30 minutes)



Omega-3 Fatty Acids

ADHD:

13 trials with 1011 participants

“Overall, there is little evidence that PUFA supplementation provides any benefit for the symptoms of ADHD in children and adolescents.”

Gillies D, et al. Polyunsaturated fatty acids (PUFA) for attention deficit hyperactivity disorder (ADHD) in children and adolescents. Cochrane Database of Systematic Reviews. 7:CD007986, 2012.



Omega-3 Fatty Acids

Autism:

“...there is currently insufficient scientific evidence to determine if omega-3 fatty acids are safe or effective for ASD.”

Bent S, et al. *Journal of Autism and Developmental Disorders*. August 2009 v39 i8 p1145(10)



Omega-3 Fatty Acids

Autism:

Two controlled trials – 37 participants

“To date there is no high quality evidence that omega-3 fatty acids supplementation is effective for improving core and associated symptoms of ASD.”

James S, Montgomery P, Williams K. Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). Cochrane Database of Systematic Reviews. (11):CD007992, 2011.



Highly Implausible Therapies

“Energy” healing
Homeopathy

“Energy” Therapies

“Therapeutic touch”
Accupuncture



Remember:

There is no alternative physics.

Placebo/Expectancy Effects

Placebo effect: “a genuine psychological or physiological effect, which is attributable to receiving a substance or undergoing a procedure, but which is not due to the inherent powers of that substance or procedure” (Stewart-Williams & Podd, 2004)



Placebo/Expectancy Effects

In trials of medical treatment of depression, response rate to placebo is as high as 50%

Risperidone in ADHD (Armenteros, et al. *JAACAP*, 2007)
– 77% response rate in the placebo group



Placebo/Expectancy Effects

Placebo/expectancy effects have major implications for the interpretation of improvement observed in the use of nonstandard therapies in children with developmental disorders

Highlights the necessity of well-designed clinical trials to test specific interventions



Case #1

Two brothers with autism

Saw Doctor "X" in our region who recommended the following:

- Transdermal DMPS (dimercaptopropanesulfonate) drops, to remove 'toxic heavy metals' (\$160/ounce)
- A product called 'Advanced Cell Life'
- Avoiding all future vaccines





- "We have perhaps the greatest find in the whole earth at this time. It is located on Native American land in western America. It is loaded with minerals, amino acids, vitamins and DNA material."



"We have perhaps the greatest find in the whole earth at this time.

It is located on Native American land in western America. It is loaded with minerals, amino acids, vitamins and DNA material.

... all the particles ["Bions"] were perfectly aligned with the north and south and when they went for higher magnitude, light was being emitted from the particles."



“... anti-tumor, anti-viral, anti-bacterial and anti-parasitical. They both repair the DNA, Detox and rebuild the liver...”

Also contains latent solar energy hidden deep within its complex molecular structure ...

High quality Fulvic acid does an amazing job at repairing the DNA and re-connecting the DNA to all cells.”

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“Some testimonials show how within a month or two a child went from the worst player on their baseball team to the best using (X-1).”

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Case #2

2 year-old boy with autism

Saw a pediatrician (Doctor “Y”) in Virginia, who prescribed:

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A multivitamin	Colostrum
A multiminerall preparation	Transfer factor
A supplement to provide "liver support"	Grapefruit seed extract
Vitamin C	Grape seed extract
Vitamin B6/magnesium	A preparation purported to cleanse the body of yeast
Methyl B-12 injections	Nystatin oral suspension
Coenzyme Q10	Probiotics
Dimethylglycine	Two different "intestinal mending" medications
L-glutamine	Two different oral chelating agents
N-acetyl cysteine	Bentonite (clay) baths
Lutein	A homeopathic remedy for inattention
Lithium cream	Gluten-free, casein-free diet
Zinc cream	Hyperbaric oxygen therapy
Cod liver oil	

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Placebo/Expectancy Effects

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Does Evidence Matter?

Sandler, et al. (1999): Trial of secretin in autism

- Nearly 70% percent of the parents of the children in secretin study wanted to continue secretin treatment for their children, even after they knew the study showed that the secretin was ineffective



Bronislaw Malinowski: *Magic, Science, and Religion: and other essays* (1954)

- Anthropological study of Trobriand Islanders





Environmental conditions that result in increased danger or uncertainty lead to an increase in magical thinking

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In developmental disorders, causes can be obscure and outcomes uncertain

Caregiver stress is often high

This contributes to an environment in which caregivers are susceptible to the development of idiosyncratic beliefs concerning etiologies and treatments

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Attention should therefore be directed toward interventions that reduce caregiver anxiety and uncertainty

Appropriate psychosocial supports

Education about what is truly known regarding the etiology, potential outcomes, and best treatments



Twelve questions that can help identify questionable therapies (adapted from Nickel, 1996, and Lilienfeld, Lynn, and Lohr, 2003):



Questions related to the underlying theoretical basis for the therapy

1. Is the treatment based on a theory that is overly simplistic?
2. Is the treatment based on proposed forces or principles that are inconsistent with accumulated knowledge from other scientific disciplines?
3. Has the treatment changed little over a very long period of time?



Questions related to the scientific evaluation of the therapy

- 4. Is it possible to test the treatment claim?
- 5. Have well-designed studies of the treatment been published in the peer-reviewed medical literature?
- 6. Do proponents of the treatment "cherry pick" data that supports the value of the treatment, while ignoring contradictory evidence?

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Questions related to the scientific evaluation of the therapy

- 7. Do proponents of the treatment assume a treatment is effective until there is sufficient evidence to the contrary?
- 8. Do proponents claim that a particular treatment cannot be studied in isolation, but only in combination with a package of other interventions or practices?

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Questions

- 9. Is the treatment associated with any adverse effects?
- 10. Is the treatment based on anecdotal evidence?
- 11. Is scientific evidence available to prove the treatment is effective?
- 12. Is the treatment associated with any conditions?

	YES	NO	Score
1. Have you taken repeated or prolonged courses of antibacterial drugs?	<input type="checkbox"/>	<input type="checkbox"/>	4
2. Have you been bothered by recurrent vaginal, prostate or urinary tract infections?	<input type="checkbox"/>	<input type="checkbox"/>	3
3. Do you feel "sack all over," yet the cause hasn't been found?	<input type="checkbox"/>	<input type="checkbox"/>	2
4. Are you bothered by hormone disturbances, including PMS, menstrual irregularities, sexual dysfunction, sugar craving, low body temperature or fatigue?	<input type="checkbox"/>	<input type="checkbox"/>	2
5. Are you unusually sensitive to tobacco smoke, perfumes, colognes and other chemical odors?	<input type="checkbox"/>	<input type="checkbox"/>	2
6. Are you bothered by memory or concentration problems? Do you sometimes feel "spaced out"?	<input type="checkbox"/>	<input type="checkbox"/>	2
7. Have you taken prolonged courses of prednisone or other steroids; or have you taken "the pill" for more than 3 years?	<input type="checkbox"/>	<input type="checkbox"/>	2
8. Do some foods disagree with you or trigger your symptoms?	<input type="checkbox"/>	<input type="checkbox"/>	1
9. Do you suffer with constipation, diarrhea, bloating or abdominal pain?	<input type="checkbox"/>	<input type="checkbox"/>	1
10. Does your skin itch, tingle or burn; or is it unusually dry; or are you bothered by rashes?	<input type="checkbox"/>	<input type="checkbox"/>	1

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“Uncritically accepting every proffered notion, idea, and hypothesis is tantamount to knowing nothing.... Some ideas really are better than others.”

Carl Sagan
