



# Erdheim-Chester Syndrome

An Integrative Medicine Perspective

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# This Presentation

- Discuss and Understand Erdheim-Chester Disease, or ECD
- Definition of Integrative Medicine
- Apply to a particular patient case, to better understand what integrative medicine has to offer patients with ECD

# What is ECD?

- Rare Disorder
- Polyostotic Sclerosing Histiocytosis
- Onset in middle age of life, mean age: 53

# A Pathology Lesson

- Histiocytes: a WBC
- Part of Phagocytosis (Reticuloendothelial System, or RES)
- A Tissue Macrophage (Greek: big eaters) that engulf and digest cellular debris, foreign substances, microbes, cancer cells

# A Pathology Lesson

- A Connective Tissue Disorder
- Connective Tissue: One of 4 types of biological tissue that supports, connects, or separates different types of tissues and organs in the body.
- The other 3 types:
  - Epithelial
  - Muscle
  - Nerves

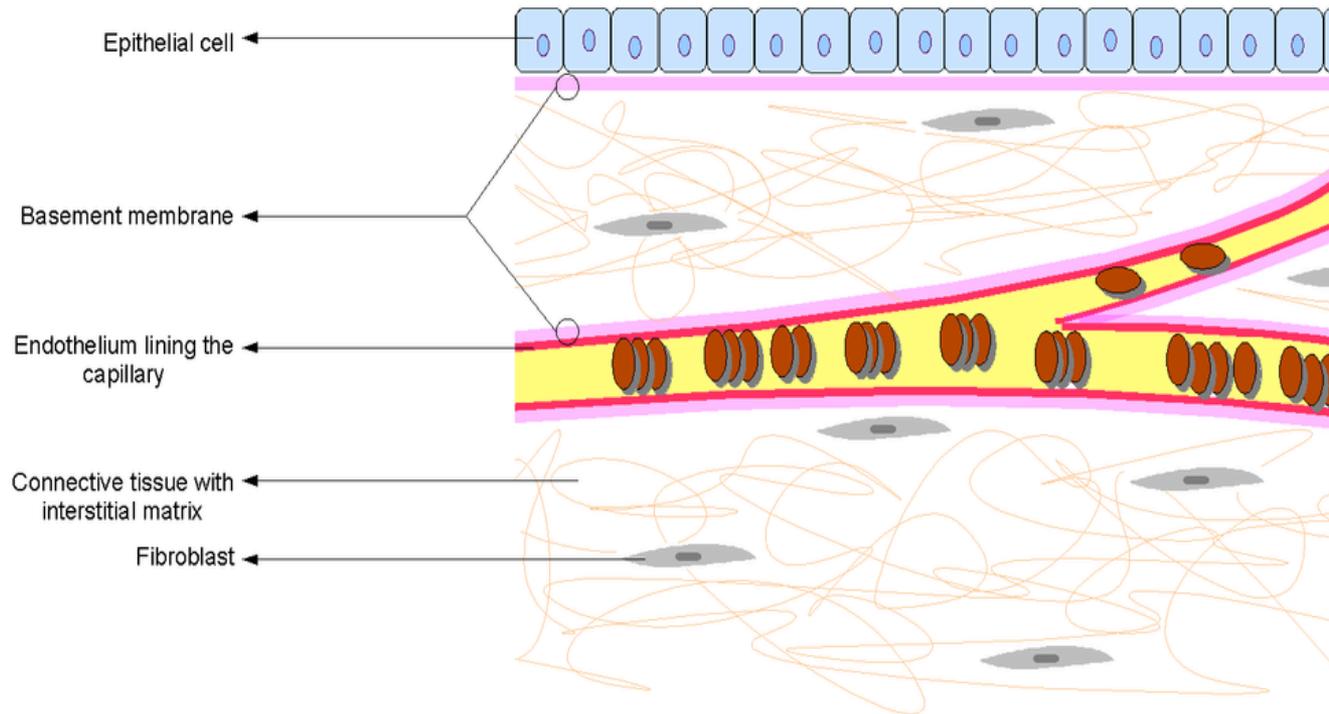
# Connective Tissue

- Found between other tissues everywhere in the body
- 3 main components: Fibers (elastic and collagen), ground substance, and cells
  - Ground Substance: Gel-like substance that surrounds cells. Surrounded by and supported by ECM or extracellular matrix
- Interconnected by fascia

# Cells in Connective Tissue

- Cells in Connective Tissue:
  - Fibroblasts
  - Adipocytes
  - Macrophages
  - Mast cells
  - Leukocytes

## Illustration depicting extracellular matrix in relation to epithelium, endothelium and connective tissue



# Significance of ECM in ECD

- Extracellular molecules secreted by cells provides structural and biochemical support to cells
- Key: Toxin storage place: chemicals, heavy metals, other... Contribution to cancer! Biotoxins, GMO's
- Regulatory function in cell behavior and intercellular communication, via ANS

# More on ECM in ECD

- Important role in fibrosis, wound healing, tumor invasion, and metastasis ( ECM destruction by enzymes related to cancer)
- Plays a role in gene expression
- Components: many, a few named here
  - Heparin sulfate (coagulation and angiogenesis)
  - Chondroitin sulfates: cartilage, ligaments
  - Collagen proteins: structural support to ECM



# ECM and Cancer

- Storage and release of environmental toxins, and for cancer and other cells that are dying (apoptosis)
- Biofilms of microorganisms embedded here
- Leads to disruption of cell to cell communications
- \* Tumor microenvironment and gene expression

# ECM and Cancer

- ECM becomes dysregulated, influences cancer progression, tumor angiogenesis and inflammation
- Influence of Autonomic Nervous System here
- Role of ECM Hypoxia in Metastasis and Death
- Oxygen Utilization and Hypoxia, Role of Ozone Therapy (discussed later)

# Histiocytosis

## Erdheim-Chester Disease

- Excessive production of histiocytes, a WBC that fights infections and injury, then collect in different organs and tissues
- Can lead to organ failure
- Not categorized as a cancer, immune disorder, or infection
- A proliferation of histiocytes. But why?
- Onset in middle age



# Integrative Medicine

- “The best of both worlds”: Cliché
- Combines mainstream medical therapies with CAM therapies that have high-quality “scientific” evidence of both safety and effectiveness
- Dr. Andrew Weil: “Integrative medicine is a healing-oriented medicine that takes into account all aspects of lifestyle, emphasizes the therapeutic relationship, and makes use of all appropriate therapies, both conventional and alternative.”

# Integrative Medicine: A Rare Bird in Today's Medicine

- Dr Andrew Weil, M.D. (U of A Department of Integrative Medicine; author of many books: biggest proponent of Integrative Medicine
- Today's world: 2 ships passing in the night, one ship almost completely omitted from economics and thinking in modern medicine.

# 2 Ships Passing In the Night Living in Two Worlds

Modern Medicine and CAM



# Alternative/Complementary Medicine: CAM (re: Dr. Weil)

- Closer to Nature
- Cheaper
- Less invasive
- Some are more “scientifically” validated than others: what is science?
- Complementary: used in conjunction with a conventional medicine therapy:
  - Example: ginger syrup to prevent nausea during chemotherapy

# Principles of Integrative Medicine

- A partnership between patient and practitioner in the healing process
- Appropriate use of conventional and alternative methods to facilitate the body's innate healing response by effectively up-regulating inherent biological systems
  - Do we trust this?
  - Is our faith in mechanistic medicine?
- Does not reject conventional medicine or accept all alternative therapies uncritically

# Principles of Integrative Medicine

## *(Continued)*

- Good medicine should be based in good science, be inquiry driven, and be open to new paradigms
- Use of natural, effective, and less invasive interventions whenever possible
- Promotion of health and well-being, and the prevention of illness: Is this possible today?
- Why? mechanistic materialistic model prevails

# Principles of Integrative Medicine (Continued)

- The need of today: include this in the economics of health care, where it is largely excluded, except in out of pocket payments by patient, regardless of the research
- Include integrative medicine, and biological systems thinking and practice...in the economics and practice of health care...

# Integrative Medicine Diagnostic Lab Evaluations: Terrain

- CBC, Ferritin, CMP all normal parameters
- Pro time, PTT good parameters
- C-Reactive Protein: 18.2 = inflammation
- Gliadin antibodies normal range( accurate?)
- Fibrinogen, D-Dimer
- Vitamin D levels
- Other required labs: Galectin-3, ...

# What Problems Can Arise in Interface with Modern Medicine?

- Does patient have insurance that can pay for tests if ordered by a licensed MD?
- If Medicare, find a Medicare based physician as ally
- If no insurance, or high deductible, take this into account in ordering tests and prescribing treatments

# What Problems Can Arise in Interface with Modern Medicine?

- Integrative and Naturopathic Medicine have much to offer and may be the future of health care.
- Intolerance by Patient Physicians: Be delicate

# Integrative Medicine: A Rare Bird in Today's Medicine

- Conventional Medicine and Alternative “Complementary” Medicine
- Alternative Medicine: any therapy that is typically excluded by conventional medicine, regardless of the science



# How Therapies are Chosen Today

- Allopathic Medicine: Mechanistic Therapies that do the work for us: surgery, chemotherapy, radiation, pharmaceuticals
  - Does not address the underlying causes (stressors) of illness
- Question: Do antibiotics really kill microorganisms?
  - Or do they kill enough microorganisms so that our inborn biological systems ramp up?

# How Effective Therapies Need To Be Chosen

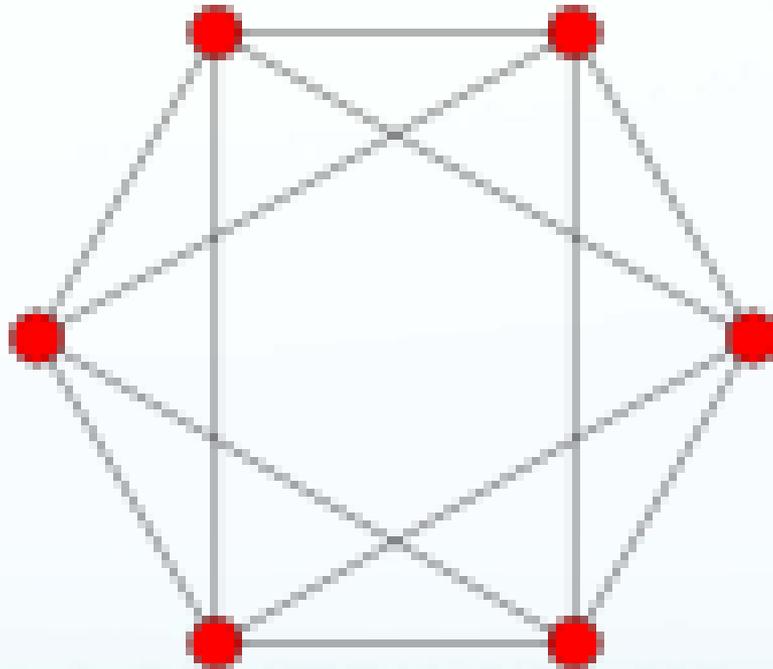
- Biological Medicine: The body was designed by God, and has systems that know how to repair, get better, and heal
  - Idea: Therapy that trusts this and enables the body to do the work by ramping up biological systems.

# Integrative Medicine Addresses the Stressors that Precipitate Chronic Conditions

- Infections, often chronic
- Emotional/Hidden Unresolved Conflicts: Often ignored or pharma medicated and suppressed
- Diet and nutritional deficiencies
- Toxins: Hg, Pb, chemical
- Electromagnetic
- Radiation (environmental and medical)
- Previous surgeries and their scars

# Biological Medicine: Systems Thinking

- Adrenal
- Liver
- Kidneys
- Neuroendocrine
- Immune system
- Digestive/Bowels
- Blood



# Why Do We Become Ill? And How Can We Heal?

- We become ill when stressors overwhelm our biological systems
- We can improve and possibly heal in 2 ways:
  - Remove or lower our stressor loads, or
  - Ramp up our biological systems

# PART 3

A PATIENT WITH ECD

# Practical Application in a Patient

- Female
- Age: 53
- Diagnosis: Connective Tissue Proliferative Disorder
- Prior to seeing me, saw oncologists at Mayo Clinic who recommended Cladribine (chemotherapy)
- Saw me for second opinion and for support if goes through chemotherapy

# Reasons for Integrative Medicine Consultation

- Reasons for consultation:
  - abdominal bloating, lower ext. edema in spite of diuretics, progressive fatigue, DOE
  - CXR: enlarged cardiac silhouette
  - Doppler US lower legs WNL
  - Bone Scan: many areas of uptake
  - Infiltrations in eyes, bones, and pericardium
  - Biopsies: histiocytes in pericardium, other nodes, with fibrosis, chronic inflammation

# Mayo Clinic Treatments

- Pericardial drain for effusion
- Cladribine
- Steroids

# Integrative Medicine Approach

- Support patient on her decision to do Cladribine, which is usually well tolerated
- Our Goals:
  - Enhance QOL
    - Support patient through treatment to help prevent side effects
    - Enhance general health and well-being by focusing on biochemistry, physiology, and mind-body approaches

# ECD Patient Case: Integrative Medicine and Biological Systems Thinking

- Can a contributing causes be identified?
- Secondary metabolic issues to discern/treat?
- Tests to look deeper into metabolic and immune function, and potential toxins
- How to support CT microenvironment
- What is the interrelationship of biological systems, and how can we design therapies that better support the synergies?

# Integrative Medicine Testing for this Patient

- Thyroid panel, including reverse T3
- CRP
- Galectin-3
- Serum iron and ferritin levels, soluble transferrin receptor
- Serum ceruloplasmin, zinc, copper, fibrinogen, D- dimer, 25 OH Vitamin D, DHEA sulfate, hidden infections? 1,25 OH Vitamin D levels

# Integrative Medicine Testing for this Patient

- Hair Mineral Analysis: ECM evaluation
- Thyroid Autoantibody testing: hers was high
- Possible External Lab evaluation of biopsy

# External Pathology Lab Testing

- Specific national labs:
  - Caris
  - Response Genetics
- My preference:
  - live tissue testing by Weisenthal Cancer Group in LA  
or
  - Rational Therapeutics in LA

# Why Do This Testing?

- Topoisomerase II: Etoposide (another option in ECD, along with Cladribine, Cytosine, Methotrexate. If Cladribine would not work.
- Cladribine ( 2-CDA) effective in systemic histiocytosis, but can suppress immune system
- A fine balance with this patient, with immune dysfunction with Hashimoto's thyroiditis antibodies and histiocytosis threatening her heart

# Hashimoto's Thyroiditis: An Autoimmune Disorder

- Most autoimmune conditions have infectious or inflammatory origins that lead to immune dysregulation

# Lab Results

- CRP high = chronic inflammation( behind many chronic conditions today)
- DHEA sulfate very low, came back normal later
- 25 OH Vitamin D low at 38
- 1,25 OH Vitamin D high at 77. From inflammation, causing Vitamin D conversion
  - Be careful with Vitamin D if inflammation is causing Vit D conversion: risk of kidney stones
- Clotting studies impaired, advised lumbrokinase, and not to fly on a trip re risk of DVT

# Lab Results

- Reverse T3 high = chronic stress, not making T3 for thyroid function and energy
- TSH low at .03, = thyroid med dose too high
- BNP high (124): B-type natriuretic peptide
  - Meaning: secreted in heart ventricles in CHF.  
Normal: below 100
    - CHF:100-300
  - Inexpensive test

# Integrative Medicine

## SUPPORTIVE Treatment

- Foundational Oral Program that includes
  - Appropriate low inflammatory diet (her history of abdominal bloating: possible gluten sensitivity can lead to chronic inflammation and autoimmune)
  - Adaptogenic herbs
    - Hawthorn to support heart
    - Minerals, including zinc (anti-angiogenic), magnesium, selenium

# Integrative Medicine

## SUPPORTIVE Treatment

- Fish oils w good EPA
- Anti-inflammatory botanicals
- Chlorella to support mercury detox (ECM)
- Immune supporting smoothie with good whey, colostrum

# Where is the Proof for Integrative Medicine? Outcomes are the Key

- Question: Did she improve because of chemotherapy, or because of the integrative medicine Rx?

# Where is the Proof for Integrative Medicine? Outcomes are the Key!!

- **Answer:** We will never know. No money in this. But we do not experiment on people, we use what works, is non-toxic and supports the body/mind in doing what it knows how to do, in what is divinely given to us. And we use integrative therapies that have well-published evidence-based research.



# What I Would Do Now for This Patient

- Celebrex if CRP too high and not coming down with treatment. Use Aloe with this.
- Support improved thyroid function.
  - A normal TSH does not mean normal thyroid function
  - Patient may need T3 to support metabolic function.

# What I Would Do Now for This Patient

- Mistletoe therapy, subcutaneous, for immune function
- IPT (low dose chemotherapy potentiated by insulin) or metronomic chemotherapy
- Ozone therapy
  - Major autohemotherapy with ozone

# Ozone Therapy to Ramp Up Our Biological Systems

- Major autohemotherapy with Ozone, and other ozone therapies ( saunas, rectally, oils,...
- ([www.aaot.us](http://www.aaot.us)):
  - 2300 articles on ozone therapies

# Ozone Therapies to Ramp Up Our Biological Systems

- 1920' s-30' s: medical grade ozone used in therapies throughout U.S. hospitals, as enemas and treating infections
- Ozone therapies ramp up our biological systems and improve Oxygen Utilization

# Ozone: Using the Power of Oxygen to Heal

- Ozone generates peroxides that enhance mitochondrial function by generating cytokines to improve response to infections
- Supports cellular immunity (TH1) so that we do not generate tissue destructive antibodies (TH2)
- Less expensive and often more effective than allopathic therapies
- Includes: rectal sufflation, limb bags, ozonated oils, major autohemotherapy with ozone

# Cytokines

- Small proteins
- Produced by many immune system cells like B and T lymphocytes, macrophages, fibroblasts
- Modulates or alters immune system response to infections and inflammation
- Important regulators of immune response
- Examples: Interferon alpha and gamma, interleukin 1, 2, 6, 8 and TNF alpha
- Not hormones

# How Do Ozone Therapies Work?

- Stimulate synthesis of more enzymes that squelch free radicals
- Ramps up our biological systems - Critical for healing
- Anti-aging; by enhancing fat metabolism (which most of us need). The process of aging means a shift from fat metabolism to glucose metabolism. It is this shift in our metabolism that underlies much chronic disease today.

# What I Would Do Now for This Patient

- UVLRX IV color and light therapy to lower inflammation and overcome hidden chronic infections

# UVLRX



# UVLRx

- An Innovative Treatment Device that is now under an FDA IRB study, with non-significant risk exemption from an IRB
- Principle: Apply ultraviolet A and visible light frequencies by IV route
- Goal of this treatment:
  - Reduction of pathogens in the blood
  - Reduction of Inflammation (*Red*)
  - Improved wound healing
  - Improved blood and oxygen flow
  - Reduction of Pain
  - Improved Energy (*Green*)

# What I Would Do Now for This Patient

- IV Artesunate (compounding pharmacy) for hidden infections, induce apoptosis
  - Anti-angiogenic
  - Prevents tumor resistance to effective chemotherapy
  - Directs cytotoxic activity against cancer cells
- IV Curcumin (poor oral absorption)
- Bone marrow soup and oral herbs to protect bone marrow during IV Cladribine chemotherapy

# Oral Botanicals and Nutrients

- Gotu Kola ( Centella Asiatica): strengthens connective tissue
- Boswellia high doses as anti-inflammatory
- Pectasol-C : Modified Citrus Pectin, to support healthy CT function from fibrosis.
  - Dose is 1.5 tsp bid between meals
- Artemisinin

# Post Treatment Protocol When Pt. is in NED or Remission

- Serum ceruloplasmin: keep low at 12-15 to prevent angiogenesis of histiocytes
- CRP keep under 2 with appropriate Rx
- Heavy Metal Challenge test to evaluate and possibly treat heavy metal toxicity
- Far Infrared Sauna to address chemical toxicities likely

# Post Treatment Protocol When Pt. is in NED or Remission

- General detoxification therapies (start early in case) ( Include colon hydrotherapy), MLD
- Address autoimmune thyroid condition: food (gluten free diet), low dose naltrexone (*lowdosenaltrexone.org*)

# Importance of Clinical Observation: Looking Back

- This woman had a breast lesion 2 years prior to ECD clinical syndrome. Lesion was not biopsied. Would it have shown ECD histiocytes?

# Importance of Clinical Observation: Looking Back

- History of abdominal bloating: could have been gluten sensitivity, which is not the same as celiac disease and not detectable by celiac lab tests. But could be behind her Hashimoto thyroid disorder and ECD.
  - Rx: Avoid gluten foods and see if symptoms improve.
  - Also could be SIBO
    - Diagnosis: breath test



# IN SUM

- THINK INTEGRATIVELY
- SYSTEMS THINKING
- BE OPEN MINDED AND INCLUSIVE
- BE GUIDED BY WHAT IS NEEDED
- AVOID BEING TOO MECHANISTIC

# IN SUM *(continued)*

ECD is not a cancer,  
but can have far reaching clinical  
effects and impairment of health  
and well-being due to its effects  
upon often toxic connective tissue.

# IN SUM *(continued)*

Integrative Medicine or Systems-Based Medicine takes the wide view and looks at the whole picture, especially what can impair ECM today, and what can be done to help the body heal, through foods and other appropriate therapies

# IN SUM

Eat an anti-inflammatory diet,  
and eat less food per meal

Michael Pollan

# Glancing Into the Future of Cancer Care

- The Social Lesson of Cancer: All life is interconnected
- The Systems-Based Biological Medicine Approach works best, because it embodies this principle of interconnectedness.
- We can become a network of healthy cells, and the body becomes stronger and healthier, with cells, organs and tissues held together in collaboration by the Principle of Love, through the eyes of God, the Divine Guiding Intelligence behind all Creation.
- Systems Thinking: The Community Self is the true antidote to Cancer mechanism (grow grow grow)



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