CYSTIC FIBROSIS-AN INTEGRATIVE/HOLISTIC APPROACH



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OBJECTIVES

- To better understand the integrative or holistic approach to cystic fibrosis care
- To discuss how a multidisciplinary team can work with patients and families to improve adherence and possibly outcomes
- To discuss strategies for "integrating" nonconventional therapies to better manage both chronic and acute symptoms in cystic fibrosis.
- Become comfortable in discussing all therapies with the cystic fibrosis care team.





WHAT IS CYSTIC FIBROSIS?

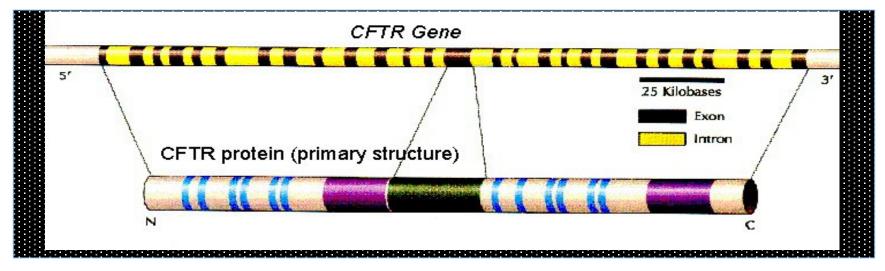
- Multisystem disease with a broad spectrum of severity
- Genetic disease with autosomal, recessive inheritance
- Progressive disease, especially chronic respiratory disease





GENETICS OF CF: CFTR

Chromosome 7:



The gene responsible for CF is located on chromosome 7, in band q31. This gene encodes a protein product called the cystic fibrosis transmembrane conductance regulator (CFTR).

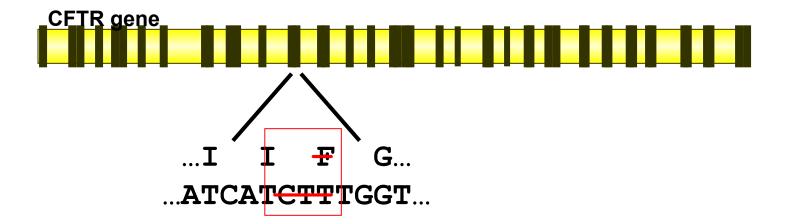
The predicted protein product *(bottom)* showed strong resemblance to known membrane-associated proteins and was likely involved in transmembrane ion transport, hence its designation, "cystic fibrosis transmembrane conductance regulator" (CFTR).





GENETICS OF CFTR

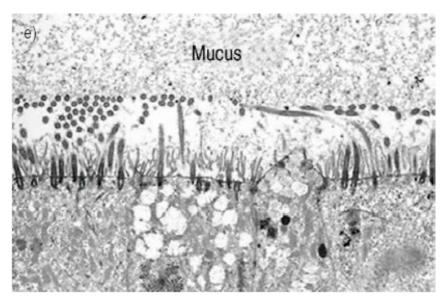
- Over 1600 mutations identified
- Most common mutation: deletion of 3 base-pairs in exon $10 \rightarrow loss$ of the phenylalanine (F) at amino acid position 508 in the protein (Δ F508)

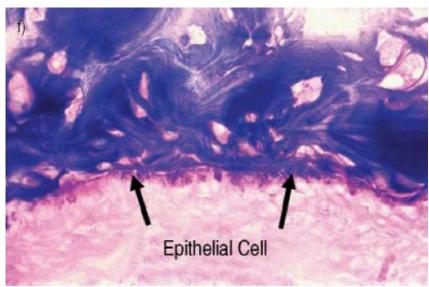






MUCUS IMPACTION IN CF









PATHOPHYSIOLOGY OF CF

Modifier Genes Abnormal CF Gene **Environment** CFTR dysfunction or absence Infection with

P aeruginosa

- Mucus plugging
- Inflammation





CASE STUDY PRESENTATION

- Cheri is a 25 yr old who is delta F508, homozygous. Has CFRD and some liver involvement
- She has done well, works full time, graduated from college, married and requires ~1-2 hosp /year for pulmonary "tune up".
- Currently has no increase pulmonary symptoms but feeling "run down". Would like "something" else to help maintain health, but no more "medications".
- Presents to the clinic with questions about using complementary and alternative medicine (CAM).
- Past history of good acherence, does have CFRD.





CONVENTIONAL THERAPY

- Combivent nebulized 2/day
- Pulmozyme nebulizer daily.
- 7% hypertonic saline nebulized bid
- Vest bid with acapella
- Advair 250/50 2/day
- Rhinocort two puffs per nostril 2/day
- Sinus rinse daily
- Lantus, once a day

- Pancrecarb MT-8 capsules 2 per snacks, 6 with meals
- Actigal 300 mg 2/day
- A ciphex 20 mg 1/day.
- Multivitamin daily
- ADEK daily.
- Vitamin K 5 mg daily.
- Azithromycin 500 mg 3/wk
- Tobi 300 mg neb 2/day every other month



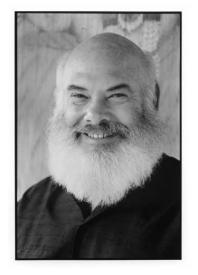
CASE CONTINUES



- Cheri is uncertain about the continual use of inhaled steroids, antibiotics and insulin
- She is interested in more "natural" approaches to CF therapy
- When asked which ones, she wasn't sure but asked for the help of the CF team.
- What does the "team" say?
 - http://www.drweil.com/drw/u/ART02973/Cystic-Fibrosis.html
 - http://www.greenmedinfo.com/blog/43-natural-alternatives-cystic-fibrosis1
 - >1 million hits on Google!
 - About 1,070,000 results (0.39 seconds)













Remember-Cystic fibrosis can look like anyone-so therapies can also vary!









HOLISTIC APPROACH TO CYSTIC FIBROSIS

- The current system of conventional health care can be enormously frustrating and lacking in answers in many areas of health for someone with the diagnosis of CF.
- Visits to the doctor may result in drug prescriptions with which one may not feel comfortable (steroids, inhaled meds).
- The medication(s) may keep the symptoms in check, but what the person may really want is to reclaim health and vitality.
- The holistic approach to health does not reject conventional medicine, but is a form of healing that considers the entire picture of health and uses the best and most appropriate options for healing.





WHERE IT ALL STARTED....



- The physician Hippocrates (460–377 BCE) "cured" his patients using holistic medicine, where he emphasized the whole person.
- His primary tool was rehabilitation of the "character". His medicine was the medicine of the west for more than 2 millenniums.
- Since 1950, biomedicine (using medications) has become more popular than holistic medicine, but patients unsatisfied with the results and the side effects of biomedicine have recently returned to the "old way" (with a new approach).
- Everyone would want a medicine that is fast, efficient, affordable, preventive, safe, and gives lasting results and, if possible, we would also like to improve not only health, but also the quality of life!





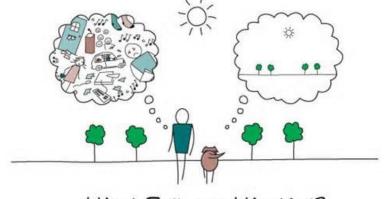
HOLISTIC APPROACH

- The underlying foundation and prerequisite for healing is compassion for the patient, and consideration of all aspects of the patient's nature, including the family, culture and community
- Complementary and Alternative Medicine (CAM) covers a broad range of healing philosophies, approaches, and therapies that can be used alone, in combination with other alternative therapies, or along with conventional medicine.
- Many CAM practitioners are holistic, considering all aspects of their patients and assisting them in achieving a vibrant state of health.
- But not all alternative practitioners can be considered holistic, nor is a conventional medical doctor necessarily not holistic
- Alternative practitioners who believe that all disease is caused by vitamin deficiencies or spinal misalignments are no more holistic than a medical doctor who believes that all illness is caused by germs





HOLISTIC APPROACH



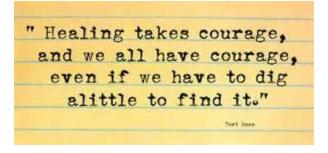
Mind Full, or Mindful?

- Mindfulness includes attention, intention and attitude
- Integrative medicine (another word for holistic medicine) is an emerging system of health care which respects all valid systems of healing, recognizing the value of each one.
- Alternative and conventional treatments are combined in order to meet the needs of the patient on all levels of healing.
- The treatments that are the most effective in helping the patient are the ones used. It is not a matter of what type of medicine is better. It is a matter of what works for each patient.





HOLISTIC APPROACH



- Practitioners establish healing partnerships with their patients and emphasize prevention and self-care. This involves the entire team of physicians, nurses, RT, SW, Dietician, PT/OT, and CAM providers.
- They consider the patient's thoughts, feelings and beliefs when prescribing treatment.
- They may incorporate one or several alternative therapies into their practices (teaching relaxation) and/or work in partnership with alternative practitioners (acupuncture) either through referrals or by working directly with them.
- Although health care team can help facilitate healing, the ability to heal ultimately comes from within.





HOLISTIC/INTEGRATIVE ASSESSMENT

- Several factors are important to consider in determining your entire picture of health.
- Many chronic illnesses can be alleviated or improved after making certain changes in these areas.
- Nutritional, environmental and structural problems may seem physical in nature, these factors can greatly affect your mental and emotional health.
- Likewise, mental and emotional nurturing can positively affect the physical body.
- More than just what medicine to take or treatments to do





HOLISTIC-CAM VS CONVENTIONAL

- Patients with chronic illness comfortably reconcile the potential benefits of remedies and practices whose foundations derive from radically different worldviews and understandings of human health and illness processes.
- CAM use in and of itself does not indicate irrational decision-making or unrealistic expectations of cure; in contrast, it maybe more usefully understood as one part of a complex process of self-care management.
- It is consistent with taking responsibility for one's own health to the extent that it is possible in the context of a chronic disease.
- Further, it is consistent with an orientation toward doing what one can to improve one's own quality of life despite a disease.
- Thus, health care systems that set CAM in opposition to conventional medicine create a problematic barrier to the optimal practice of self-care management for persons living with a chronic condition.





IM/HOLISTIC FACTORS



Nutrition:

- Nutrients are needed to provide energy and assist in the functioning of your children's many body processes. Food is a vital part of health, and diet can be important.
- Food is medicine.

Structural:

- Many forms of massage and bodywork can help correct imbalances and decrease symptoms of pain and tension.
 - Exercise and yoga can be helpful.
 - Deep breathing, relaxation techniques and meditation
 - A cupuncture or acupressure can be helpful.
 - Reiki, therapeutic touch, or energy work may positively affect physical health as well as mental, emotional, and spiritual well-being.





FACTORS



Environment:

Be aware of what you are breathing, touching, applying to your skin, and eating. Remember to take environmental factors into account when you are determining the cause of any problem.

Mental-Emotional:

- The field of psychoneuroimmunology is helping us to better understand how the nervous, immune and endocrine systems communicate.
- Neuropeptides and neurotransmitters are messengers released by the brain that influence the cellular activity in the body
- One's state of mind definitely influences the development of and the healing of illness.





FACTORS



Spirit

- Beyond the mind-body connection, there is a source of inspiration that you can access. This is your spiritual connection.
- Working with spirit means reaching beyond your understanding of your own limits to access a greater healing power.
- It can take the form of prayer, inspiration
- It is not necessary to subscribe to a particular religion in order to work with spirit.
- One can explore one's own beliefs about what spirit means. Intuition, gut feelings, hunches, meditation, and prayer are only a few of many spiritual processes.





MAJOR CLASSES OF CAM

Enhance the mind's capacity to affect bodily function and symptoms

Chiropractice

Osteopathy

❖Massage

Alternative medical systems

Mind-body interventions

Biologically
-based
therapies

Manipulative & body-based methods

Energy therapies

- **❖**Homeopathic
- **❖**Naturopathic
- ❖Traditional Chinese and Ayurvedic treatments

- ❖Dietary supp
- **∜**Herbs
- **∻**Foods
- **❖Vitamins**
- ❖Natural substances

Biofield therapyBioelectromagnetic therapy



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TIME TO INTEGRATE: BUILD THE TEAM

- Start with a knowledge of each modality both by the practitioner and the family
- Discuss ideas and any therapies that are being used or considered.
- Just like there is with conventional therapies, there needs to be adherence and follow-up.
- Often just having the discussion of CAM helps improve adherence to conventional therapies
- Develop a plan, which can easily change

Textbook of Integrative Pediatrics (2009) Oxford Publishing





WHERE TO START?

- 50-70% of patients with cystic fibrosis use complementary and alternative therapies, the most common being herbal remedies/dietary supplements.
- For the patient who has mild to moderate disease, a step-wise approach in addition to conventional care might be considered.
- May include: Lifestyle, Nutrition, Supplements, Mind-Body therapies, Manipulative therapies and Alternative Health Care approaches (Traditional Chinese Medicine and Homeopathy)





LIFESTYLE AND CYSTIC FIBROSIS

- CF is best treated early in an attempt to delay or decrease the progression of the disease.
- At times, is difficult, especially with CF since there are so many regular treatments daily
- A voidance of allergens, tobacco smoke, and air irritants can help
- Sleep and good sleep hygiene can be important
- Exercise is a great activity-improves lung function, helps maintina weight and is an "anti-inflammatory" therapy.







EXERCISE AND CF- GOOD!

- Exercise used to be considered dangerous for CF patients
- Exercise is now considered a valuable tool for CF patients
- Natural form of chest physiotherapy-could use exercise as a substitute for "poundings" since the movements with exercise will help loosen mucus in the lungs.
- Exercise will often stimulate coughing, helping with the removal of secretions and better airway clearance
- Exercise also improves cardiovascular health
- Exercise can help with self esteem





EXERCISE AND CF- HOW?

- Help and direction should come from the health care (CF Center) team.
- The regimen needs to take into account the patient's interests and limitations- so called "prescription for exercise"
- The program should be organized if possible to allow slow increases and some monitoring of the progress
- A reas such as nutrition, fluid status and lung function should be watched closely and suggestions for maintaining good health should be available.





NUTRITION AND CYSTIC FIBROSIS

- Because diet is the major source of antioxidants, suboptimal intake during airway growth may lead to airway damage and reduced airway compliance.
- In chronic lung disease has been shown a beneficial association between fruits, vegetables, and other antioxidant-rich foods including fish.
- Along with a high calorie, high protein diet, patients with cystic fibrosis should increase their consumption of fruits and vegetables.
- Also, foods rich in omega-3 fatty acids while decreasing omega-6 fatty acid containing ones (vegetable oils) may decrease the inflammatory cascade in CF.

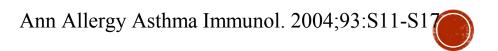




MIND-BODY THERAPIES AND CF

- Mind-body therapies or cognitive behavioral therapies encompass several approaches.
- These include relaxation therapy, breathing exercises, biofeedback, and hypnosis and guided imagery.
- The theory is based on decreasing the inflammatory process that can be triggered by the autonomic nervous system through strong emotions.
- Stress has been associated with higher morbidity and cytokine levels attributed to airway inflammation.
- In addition to anxiety, stress is shown to influence the immune response and may promote increased sympathetic activity, and promote airway inflammation without overt symptoms





MIND-BODY THERAPIES AND CF

- Self hypnosis, Breathing exercises including yoga, Relaxation with or without guided imagery have all been studied in CF
- Recent study (Anbar) on imagery and sputum production without using any "devices"!
- Guided imagery and/or self-hypnosis has been shown to decrease shortness of breath or dyspnoea.
- May also help decrease chronic symptoms such as cough and decrease the use of certain medications such as albuterol
- Breathing exercises may also help with lung expansion especially breathing used in Yoga and martial arts











DIETARY SUPPLEMENTS



- Herbal medications are classified as dietary supplements and are derived from plants.
- They be taken orally as pills, freeze dried capsules, or powders; used as tinctures or syrups; brewed in teas or decoction; or "applied" as salves, ointments, or poultices to the skin or mucous membranes.
- In survey studies, herbal supplements are often the most common CAM therapy reportedly used for the treatment of cystic fibrosis.
- A study of pediatric CF pts and families found 19% of patients were currently using supplements and 10% reported past use. 40% had not informed their physicians.





DIETARY SUPPLEMENTS AND CF

- Common use has caused concern, because herbs may have interactions with conventional medications and even other herbal supplements.
- The FDA regulate dietary supplements as foods so they do not need to meet the same standards as pharmaceutical medications for proof of safety and effectiveness. (changed in June 2007)
- Also, in many herbal supplements, the plant itself may not be characterized, active ingredients and standardization may not be known
- This makes the conventional scientific understanding of how herbal supplements might affect the body in conditions, such as asthma, difficult.
- Also reports of some supplements being contaminated with metals, unlabeled prescription drugs, microorganisms, and other substances





STUDIED SUPPLEMENTS

- In cystic fibrosis, asthma and other chronic lung diseases, antioxidants such as Vitamin C, selenium, and fish oil/omega 3 fatty acids have been studies with variable results
- Taurine, an essential amino acid may improve fat absorption and weight gain in CF (studies-80's)
- N-acetyl cysteine (NAC) may soon be standard of care for the anti-oxidant properties it provides.
- Creatine has been studied in CF and shown to improve muscle strength, at least short term.
- There are so many one might think about taking......



DIETARY SUPPLEMENTS FOR CYSTIC FIBROSIS

- Probiotics
- B complex
- Extra Vitamin C, E, A
- Calcium, Vitamin D
- Magnesium
- Ginger, ginko, garlic
- Echincacea (not routinely)
- Essential oils for inhalation (eucalyptus, oregano)
- Lipoic acid (esp for CFRD)
- Milk thistle

- Grapefruit seed extract
- Baker's yeast, Green tea
- Airborne: 18 ingredients
- Coenzyme Q-10
- Blue green algae
- Spirulina, alfalfa
- Pine bark (Pycnogenol)
- Gingseng
- Licorice
- Boswellia, bromelain
- Cayenne, mullein, horehound





SUPPLEMENTS AND SIDE EFFECTS?

- Case: 11 yr old CF patient noted bluish skin color after ingesting a colloidal silver solution to facilitate mucus clearance.
- Serum silver level was elevated to more than twice the upper limit of normal suggesting argyria, typically permanent discoloration of the skin due to dermal silver deposits.
- Devices that create silver solution for ingestion and
- Colloidal silver is commercially available- over 800 000 colloidal silver websites. ~10 000 cystic fibrosis listed as giving benefit (>650 diseases). 19th and early 20th century: used for gonorrhea, tetanus and rheumatism
- Silver ingestion is associated with toxicity, including argyria, seizures, and altered mental status













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MANIPULATIVE THERAPIES IN CF

- Manipulative therapies include osteopathic manipulation, chiropractic manipulation and massage
- Children with CF and their parents have reported a positive response to massage therapy with reduction in anxiety, improved mood and increase in peak flow measurements have been shown in small studies.
- Therapeutic massage can help drain mucus from the lungs
- Osteopathic manipulation- 5 main categories with over 100 different individual maneuvers





TRADITIONAL CHINESE MEDICINE (TCM)

- TCM uses the belief in an unseen vital energy that affects patients' health and how this energy, or qi (chi), flows through the appropriate channels is monitored
- Practitioners can affect this flow or intensity by manipulating its balance using acupuncture, Asian herbs, diet, and physical therapy.
- Cystic fibrosis has not been recognized in Asian medicine but there are traditional herbal formulas used for all of the symptoms and possible deficiencies or excesses seen in CF





ACUPUNCTURE?



- A nother modality often used is acupuncture for chronic lung problems including CF
- However, most studies have not shown improvement in such diseases as asthma or COPD.
- Some practitioners feel that acupuncture alone may not be beneficial since it is just one part of TCM, and TCM is a holistic approach to a chronic problem
- One study at Boston's Children's showed acupuncture to be effective in decreasing pain complaints in patients with cystic fibrosis

Am J Chin Med 2005;33:151-6





HOMEOPATHIC MEDICINE

- Homeopathic medicine is a belief that "like cures like"
- This **Law of Similars** means that small, highly diluted quantities of medicinal substances are given to cure symptoms, when the same substances given at higher or more concentrated doses would actually cause those symptoms.
- The most dilute remedies are the strongest (Law of Dilution)
- Before prescribing a remedy, homeopaths take into account a person's constitutional type: physical, emotional, and psychological makeup (dassical vs dinical)
- The remedies can be mineral, plant or animal





HOMEOPATHIC NOTATIONS



- The notation 6X means that the active substance is diluted 1:10 in a wateralcohol mixture and succussed.
 - This procedure (diluting and succussing) is repeated sequentially six times.
 - The concentration of the active substance is one part in ten raised to the sixth power, or one part per million.
- The notation 30X means the 1:10 dilution, followed by succession thirty times.
- Homeopathic physicians agree that not a single molecule of the active substance could remain in many of their remedies. The process of succussion is presumed to charge the entire volume of the liquid with the same memory.





HOMEOPATHY



- There are no studies with homeopathy and CF but there are such problems as for atopic disease
- Homeopaths feels there is a tendency or predisposition for a disease to first manifests in the less vital organs like the skin
- Often in children, the disease may often 'move-out' of one thing and 'move-into' another, like eczema to asthma
- Suppression of illness using such things as steroids or antibiotics may not cure the disease, and in fact, could drives it inwards
- It is often observed that when a right remedy is given, the symptoms increase before finally disappearing





INTEGRATIVE MEDICAL PLAN FOR CF

- Medications- what are the most important and how to improve adherence, discuss concerns about side effects and cost
- Lifestyle changes including exercise
- Nutrition and dietary changes
- Supplements including herbal remedies
- Possible use of TCM, Manipulative therapies and homeopathy
- Most important: education and teamwork in regard to all aspects of the health care plan
- Remember: Mindfulness includes attention, intention and attitude





PUTTING IT ALL TOGETHER



- Conventional therapies including airway clearance, nutritional support and anti-inflammatories
- May use some supplements in place of conventional meds after discussing with your health care team (bromelain, pine bark, grapefruit seed extract, garlic) along with anti-oxidants (Vitamins, selenium, NAC) and alpha lipoic acid (CFRD)
- Consider yoga, martial arts (Tai Chi), meditation
- Exercise!
- If interested, then TCM, homeopathy or naturopathic medicine but need to be able to communicate with all the providers so care is "transparent".





THAT'S ENOUGH-THANKS!













http://www.cflf.org/



http://runsickboyrun.blogspot.com/

http://www.cfww.org/about/





A GUIDE FOR USING CAM

Government sites

National Center for CAM:

http://nccam.nih.gov/

Office of Dietary Supplements:

http://ods.od.nih.gov/Research/CARDS_Database.aspx

MedWatch:

http://www.fda.gov/medwatch

CAM on PubMed:

http://www.nih.gov/news/pr/feb2001/nccam-05a.html





A GUIDE FOR USING CAM

A cademic sites

Boston-Longwood Herbal Task Force:

http://www.longwoodherbal.org/

University of Pittsburgh:

http://www.pitt.edu/~cbw/database.html

Beth Israel Medical Center NYC:

http://www.healthandhealingny.org/

Columbia University:

http://www.rosenthal.hs.columbia.edu/Botanicals.html

University of California, Berkeley Newsletter:

http://www.wellnessletter.com/html/ds/dsSupplements.php





COURSES AND WEBSITES

- Herbs and Dietary Supplements-Wake Forest
 - http://www.wfubmc.edu/Research/Center-for-Integrative-Medicine-Research.htm
- Botanicals and Health series-University of Arizona http://integrativemedicine.arizona.edu/education/index.html
- Botanical Medicine in Modern Clinical Practice (NYC) http://cait.cpmc.columbia.edu:88/dept/rosenthal/Botanicals_CME.html
- Consumer Labs http://www.consumerlab.com
- Natural Medicines Comprehensive Database http://www.therapeuticresearch.net/(ctt54155qny2vs55ryiv2d32)/home.aspx?li=0&st=08
- Quackwatch http://www.quackwatch.com.



