Maine AIDS Care

AIDS Consultation Service • Maine Medical Center • Fall 1995

"Alternative" Treatments or "Complementary" Medicine? The Current Status in HIV Disease

Many persons with HIV avail themselves of "alternative" or "unconventional" therapies in addition to the medical regimen prescribed by their physicians. A recent survey in Maine by the Maine Community AIDS Partnership (MCAP) revealed 30% of HIV patients questioned had used "alternative" therapies.

These therapies may include physical treatments (ie. accupressure or massage) or herbal and other pharmacologically active treatments. While physical modalities may provide a sense of well being and reduction of stress without any associated risks, the picture is more complex for other remedies such as herbs. For example, the recent popularity of ingestion of Kombucha "mushrooms" which are actually a fermenting colony of yeasts and bacteria raises questions of potential toxicity in immunocompromised people. Most physicians don't know what herbal remedies their patients use and have little information available on them. In an effort to better understand these regimens, we have focused this issue of Maine AIDS Care on "alternative" therapies.

Background

"Alternative", "unconventional", "natural", or "complementary" therapies are terms used to describe a broad range of treatments and practices that are generally seen to be outside the norm of standard Western medical practice.

In recent years, unconventional therapies have begun to gain a foothold in American medicine. In 1992, the National Institute of Health established an office for the study of Unconventional Medical Practices to evaluate a wide range of treatments. Many medical schools now offer courses on unorthodox medicine in order to introduce American M.D.'s to the theory and practice of alternative treatments.

Since the beginning of the AIDS crisis, a number of alternative treatments have been proposed and used with unknown success. Some of these practices (ie. compound Q, etc) have been criticized as being unproven and potentially dangerous, and have been subject to warnings from the Food and Drug Administration. Other practices such as therapeutic massage have become commonly employed adjunctives to medical treatments. A comprehensive report on the current status of alternative medical systems and practices in the United States, Alternative Medicine: Expanding Medical Horizons was published in December 1994.

Philosophical Underpinnings of the Alternative Approach

Several key concepts underlie many of the alternative health practices. These include *holism, balance vs. imbalance, energy,* and *healing.*

Holism is the principle that all aspects of the person - physical, emotional, mental, social, and spiritual health, as well as diet, lifestyle, and environment - are interrelated, and that all of these factors must be considered in treatment of any disease.

Balance refers to harmony among the organs and systems of the body, in a person's diet, and in relationships with other individuals, society, and the environment. Balance or imbalance, in any system affects the others, according

HIV/AIDS Clinical News Briefs: Update from San Francisco ID Meetings (Sept 1995)

Role for Combination Antiviral Therapy Supported

The long awaited results of the ACTG 175, a large trial of combination antiviral therapy (ie. AZT-DDI and AZT-DDC) versus monotherapy (AZT or DDI alone) for asymptomatic persons with CD4 counts of 200-500 were presented. For the first time, standard antiviral regimens were shown to delay the onset of AIDS and to decrease mortality in this patient group. Both of the combination regimens or DDI alone were superior to AZT alone in both previously treated and AZT-naive patient groups. The benefits of DDI monotherapy were unexpected, and stand in contrast to another ACTG study that had documented the superiority of AZT over DDI for initial monotherapy. In patients previously treated with AZT, the DDI-containing regimens had more apparent benefit than the AZT-DDC combination.

A second report at the same conference, and based on the ACTG 175 results, demonstrated a more profound effect on lowering viral load with either combination regimen versus single agent therapies.Given the equivalent clinical outcomes with DDI alone and the combination regimens, the study does not unequivocally demonstrate superiority of combination therapy. However, preliminary results from another large clinical study, the European-Australian Delta trial, demonstrates a benefit of combination regimens that contains AZT

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"Alternative" Treatments... (cont from page 1)
to this concept.

Energy is defined as the vital force necessary to achieve balance. The part of the system that is deficient may need to acquire energy, and the portion that is in a state of excess may have to give up energy. Pathology is visualized as the natural flow from one to the other. Specific treatments, exercises, lifestyle changes, or diet alterations may be prescribed to balance the system or nourish the healing process within the alternative approach.

Pitfalls & Rational for Use

The chief difficulty in being able to use or recommend these "alternative" therapies is in the lack of empirical data. Herbal regimens promote the greatest concern because toxicity studies on most herbal therapies have not been conducted, and dosages in available products are rarely standardized. There has been no regulation to require disclosure of negative side effects. Thus persons with HIV and their health care providers are forced to make decisions about most alternative treatments in an information vacuum. Although most herbal remedies are considered to be innocuous, data is scarce. Kessler et al reported that 20% of persons attending the AIDS Clinic at UCSF were taking herbal remedies, and the average number of tablets taken per day was 4.5. Although no patients reported any toxicity from these regimens, 1/4 complained of symptoms that could have been caused or exacerbated by the herbs they were taking. These symptoms include nausea, diarrhea, dermatitis, and allergic reactions.

Therefore, physicians caring for patients with HIV must often balance the possibility that herbal regimens may be having an adverse impact on symptoms with the potential benefit the patient obtains from the use of an alternative regimen. This benefit often includes positive psychological effects of trying something new and taking some control of their own health. One simple strategy for symptomatic patients is to encourage a trial time off of herbal regimens to assess their impact on the symptoms. Additionally, physicians can focus on avoidance of the most questionable practices, and encourage use of safer regimens. Particular clinical situations may make use of some herbs more problematic (see insert). However, we can encourage patient's responsibility for his/her own decision-making process. People with HIV need to know that doctors do not have all the answers; they also need to be able to communicate openly about what they are taking so that any known side effects or interactions can be assessed. The provider's role should be to encourage thorough assessment of what is known about specific alternative or complementary approaches and open communication with our HIV patients about what they are taking and what the risks/benefits may be.

It is our general feeling that mind-body interventions, manual healing methods, acupuncture, and normal nutritional or vitamin supplements (as outlined in our issue of Nutrition-Summer 1994), are usually helpful if the patient considers them so. They may improve the sense of well-being and allow for the development of an increased sense of control over their illness. However, as standard medical care continues to improve for HIV, it is likely that many of the potentially harmful remedies will be less frequently pursued, and that beneficial therapies may become regular adjuncts to care.

References:

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Empowerment Through Dialogue

Cindy Luce, LCSW

Alternative therapies, when presented as optional additions to traditional medical treatment for HIV/AIDS, offer people some choices in their treatment and thus an opportunity to become active participants in their care. By presenting opportunities for choice we encourage empowerment in people whose bodies have been invaded by a disease which has limited their sense of control over their lives.

People with HIV/AIDS are often frightened. They are looking for help in coping with the physical as well as the emotional impact of living with the disease, and are often eager to try new therapies in hope of extending the length or quality of their lives. They are seeking to find ways out of an uncomfortably passive and vulnerable position. They need to believe there is something they can do other than simply doing what they are told, taking the medications, following the advice of experts, and hoping for the best. They need to discover concrete things that they can do for themselves and believe that there are still some aspects of their life experience, although compromised, that are still theirs to create. We can encourage patients to trust our medical expertise and cooperate in their treatment by acknowledging that we respect them as the true experts on how they experience and manage their lives. Exchanging information in a context of mutuality increases trust in the process. By sending the message we trust them as the experts on themselves it becomes more of a reciprocal response for them to trust us as the medical experts.

The sense of social isolation often experienced in the lives of people with HIV/AIDS creates an overwhelming sense of loneliness. Anyone who experiences isolation

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Common Alternative Therapies Used in HIV

Therapy	Possible Benefits	Possible Side Effects
Blue Green Algae	Extracts from 2 specific types (L.lager-heimmi and P. tenae) contain sulfolipids which inhibit cytotoxic the cytotoxic effects of HIV and reduced HIV replication in the test tube. These 2 specific types are not available, and it is unknown whether the common variety, Spiralina, contains such sulfolipids. It has not been shown to possess any direct benefit against HIV, though it is rich in amino acids and minerals.	GI: catharic
Compound Q An extract of Tricosanthin, a type of cucumber native to China.	Early test tube results seemed to indicate its ability to selectively inhibit HIV replication in infected T-cells and macrophages. Later Phase I & II studies in humans showed no duration of an antiviral effect.	Include: flu-like symptoms, elevation in muscle and liver enzymes, neurologic toxicity, and allergic reactions.
Curcumin The main active ingredient found in turmeric, a spice used primarily in curry.	A 1993 published study showed this compound might have promise in inhibiting Long Terminal Repeat (LTR) of HIV. (LTR is believed to be critically important to turning on and maintaining HIV replication.) There is no further clear evidence to date that curcumin has any real benefits.	
Echinacea A plant, the leaves and roots of which have been attributed to having broad immuno-stimulating effects.	Echinacin (a purified extract of Echinecea) has been studied in a clinical trials in Germany, where it was reported to have stimulated macrophages to release chemical messengers such as TNF, IL-1, and Interferon beta. An additional German study found that administration of Echinecea extracts to people stimulated cell-mediated immunity after a single dose, but that repeated daily doses suppressed the immune response.	CNS: stimulant Allergic: dermatitis, anaphylaxis

Garlic A member of the lily family, has been used for medicinal purposes from as early on as 3,000 BC. It is made up of sulfur compounds, amino acids, minerals like germanium, selenium, and zinc, and Vitamins A, B, & C. Allicin, a sulfur containing compound in garlic, is believed to be primarily responsible for most suggested benefits of garlic - along its odor.	Some researchers have postulated that garlic works as an antioxidant against free radicals. Claims of its' effectiveness against AIDS-related opportunistic infections are based on in-vitro studies that showed garlic was an anti-bacterial and anti-fungal agent. There have been no studies as yet that have looked closely at garlic for its' uses with immunomodulation.	Toxicity occurs when too much raw garlic is ingested. The high sulfur content can cause dermatitis, and colitis occurs by an overkill of the normal flora in the gut. In high doses, garlic also may inhibit blood clotting and interfere with proper thyroid function.
Ginseng An herb that has been used extensively throughout Southeast Asia and China for various treatments. There are 3 different families of Ginseng.	It has been considered by many to be the most prized of herbal remedies, containing a host of alleged benefits including anti-fatigue, anti-stress, and other systemic benefits. It has been suggested the Panax Ginseng may increase natural killed cell activity. However, in a double-blind human trial of 100mg Panax q12 hours x8wks in T4 and T8 cells function there was no significant change in either the placebo group or the group receiving the ginseng.	Ginseng can produce insomnia, diarrhea, nervousness, depression, and skin rash. It can amplify the MAO inhibitors effect of certain anti-depressant medications and, due to the small amount of estrogens in the plant, can effect menstruation in women.
Shiitake Mushrooms A traditional Oriental herbal remedy used in the process of making LEM (lentinan edodes mycelia), a component used to manufacture a powder purported in test tubes to keep T-cells HIV virus free and to cell-to-cell HIV infection.	There have been no human trials to date, and therefore no specific knowledge or information on the efficacy or side-effects of this remedy.	There have been no human trials to date, and therefore no specific knowledge or information on the efficacy or side-effects of this remedy.
SPV-30 A natural herb product extracted from an evergreen tree.	It is thought to reverse the declining level of CD4 lymphocytes in people with asymptomatic HIV. It is currently being studied in humans. A small phase I study in France demonstrated significant rises in CD4 cell counts, but no viral load measurements were taken and all participants had more than 250 CD4 cell counts.	Concern exists that SPV-30 may actually increase viral load.
Melatonin A naturally occurring hormone thought to reset the body's clock and help it sleep. It is secreted by the pineal gland.	Studies suggest that low-dose supplements can hasten sleep, and some researchers believe it can help counter the ravages of age. In test tube and animal experiments, it has been found to protect cells, strengthen the immune system, and slow the growth of some tumors. Its use and efficacy in HIV disease has not been studied	Some reported side effects in humans include nightmares, headaches, morning grogginess, mild depression, and low sex drive. Its use and efficacy in HIV disease has not been studied. Patients should be cautioned that it is a potent hormone that could have long-term effects, and that to date no one regulates the quality of what's sold on store shelves.

Update From San Francisco (cont. from page 1)

over monotherapy with AZT alone in previously untreated patients.

Efficacy of d4T (Stavudine)

The superiority of d4T versus AZT in patients with CD4 counts of 50-500 who had previously received AZT was demonstrated by measurement of clinical endpoints.

Protease Inhibitors Promising

Several presentations supported the effectiveness of new protease inhibitors (ie. saquinavir, indavir, ritonavir, and others) in lowering viral load, when used singly or in combination with RT inhibitors.

Ritonavir, when used in combination with saquinavir increased the peak serum concentration of saquinavir considerably. Although none of these agents have yet been released by the FDA, the preliminary data for their use in anti-HIV regimens is promising.

The Patient's Perspective

Why I'm An "Alternative" Kind of Guy

By: Terry J. Dubois

Having been asymptomatic now for approximately 13 years, I've always thought that traditional therapies have been geared for someone not as healthy as me. I've had my rounds with AZT, DDI, Bactrim, and even with experimental drugs, but I always felt worse after standard drug therapy: pale and anemic, fatigued and listless, with stomach discomfort and schedule disruption, with no appreciable results or kickbacks. A couple of years ago I took my last dose of AZT. I decided to keep conventional approaches on hold until, *and if*, I drop below my self-picked bottom line of 200 T-cells.

Then I can bring out the big guns.

But until then (right now I'm hovering above 200, stably, and have been for years), my immune system is mine...all mine. In the meantime, I am employing my own homespun strategy for boosting my immune health. I don't need a prescription, and insurance claim form, or an appointment, the effects almost always make me feel better, and I can mend my body "from the inside" in ways that no other human on the outside of me could.

Simply put, my strategy is to live well.

First, I EXERCISE, I do water aerobics three times a week, I bike, hike, and swim in the summer, and I do snow shoveling workouts in the winter. After a workout, I feel like a million bucks and I'm as hungry as a healthy horse. This has got to be good for my immune system, even if a scientist can't measure it, right? Oh, pulled muscles are a pain, and the right sportswear is expensive, but it sure beats nausea and anemia... and it's fun!

Second, I EAT. I'm into bean soups right now; lentils, black beans, and split pea too. It's generally accepted that infected persons burn more nutrients just to keep up with the fight against viral replication, so I insist that I eat well at every meal...and on time. (Not just the fat grams either. Fat is definitely taxing to one's immune health. The best way to fight wasting syndrome is a healthy diet, not a pot belly.) No down side here.

Third, I SAY NO. These days I do not get roped into too many social chores, because I've trained my loved ones to expect me at home..."comfortably resting." I'll often choose to do something fun, but on my own terms, when I'm well, rested, and strong. I avoid "Got-to-Do's", and consider "saying no" as tangible and concrete as a hit of AZT. Most people seem to understand that I am fighting for a long life.

Forth, I BELIEVE. HIV is not pretty, but I am marching straight ahead and I find that my internal optimism feeds itself. I believe in the specialness of my immune makeup and that I have a great chance at prolonged survival.

Empowerment... (cont from Page 2)

and loneliness is missing the experience of knowing that people are "with them". It takes courage to truly try to "be with" someone in a devastating place, yet to take that risk is one of the greatest gifts we as helpers can offer. We can let them know that we care enough to be with them if only during brief office visits by acknowledging the mutuality of the helping relationship and respecting them as the true managers of their lives. Any small amount of control they can take back from this disease, even if it's a decision to make a cup of herbal tea at a certain time of the day or make and keep an acupuncture or massage appointment is something that they are choosing to do, not because someone is saying that they have to, but because it's something they can try if they want and decide for themselves if it is helpful. A human being wants to live and die with a full sense of his/her own identity, not as an AIDS victim being managed by professionals. A team approach to treatment can reinforce this dialogue as we remember that the person with HIV/AIDS is at the center of his/her own care.

"...empowerment means a process of dialogue through which the client is continuously supported to produce the range of possibility that he/she sees appropriate to his/her needs; that the client is the center for all decisions that affect his/her life."

Rose, SM, 1990

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Save the Date!

June 5, 1996
AIDS Consultation Service Symposium

More info to follow

Acadia Health Education Coalition and AIDS Consultation Service Form Outreach Education Partnership

The Acadia Health Coalition (AHEC), part of the Maine AHEC System, has received another year of funding for the **New England AIDS Education and Training Center (NEA-ETC)** through the University of Massachusetts Medical Center. Although the funding remains the same as in previous years, it provides important resources for providing HIV/AIDS educational programming for health professionals throughout Maine. This year the AIDS Consultation Service at Maine Medical Center will become a partner in the organizaiton of provider and outreach HIV education.

Under the AIDS/ETC grant AHEC sponsors HIV/AIDS educational programs for all levels of health professionals. AHEC also supports mini-residencies for primary care providers who are interested in spending a day with a medical practice serving primarily AIDS patients. Past participant have been unanimous in their praise for these mini-residencies. The skills they learn help them deal with their own patients when they return home.

If you are interested in an educational program in your area, a mini-residency, or would if you would just like more information about AHEC call (800)439-5774

Peabody House

By Marla Saxx, Director Peabody House

Peabody House is Maine's first comprehensive model of shelter, support, and care for people in the advanced stages of HIV disease. It is a comfortable boarding home located in Portland for six men and/or women. Frannie Peabody, co-founder of Peabody House became a strong voice for people living with HIV/AIDS in 1983 after the death of her grandson. While her daughter, Barbara, nurtured and cared for her dying son during the end stages of the disease, it became obvious to the Peabody family that there were many men and women who lacked the emotional support of family and resources to be cared for with dignity during the final stages of AIDS.

Peabody House is the culmination of those early realizations and experiences. Its mission is "to provide a supportive, holistic, home-like environment for people in the advanced stages of the HIV disease".

The goal of maximizing human dignity and individual autonomy is accomplished through a client-centered approach for care supported by nurses, physicians, social workers, and community spiritual leaders. This model of care places the resident of Peabody House in the central position of director of all decisions regarding treatment. Respect for the right to self-determination allows the client to choose the type and amount of care to be received. This model allows the resident of Peabody House to live with as much freedom and independence as their health allows.

An adjunct to the comprehensive services provided at Peabody House is the support offered to the residents by a large staff of volunteers, including direct care, house-keeping, meal preparation and maintenance of the gardens. Volunteers also offer their skills in massage, relaxation, and music therapy as part of the holistic supportive techniques offered to residents.

"To try to change or cure death is complete foolishness. To simply care for the dying is the ultimate accomplishment. Yet it is an accomplishment that deserves no merit." The Tao of Dying.

We at Peabody House strive to be supportive and nurturing throughout the living and dying process of the Peabody House's resident's lives.

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