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Tips on Receiving the Best Medical Care

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All patients should be active participants in their own healthcare. Although medical professionals are highly trained and skilled, they are not mind readers. By taking an active role, patients can ensure they receive the best care possible.

Tips on choosing a doctor

It is very important that you feel comfortable with your medical provider. You should feel confident that he or she is knowledgeable in his or her field and has experience in treating patients with conditions similar to yours.

Try to gather information from many sources and in many forms—the more sources of information, the better—including: friends/family, your health benefits officer at work, fellow employees, and health plan network lists. Be sure to investigate the doctor's qualifications by reviewing the following:

* Education and Training: College (four years); Medical School (four years); Residency Training (up to seven years); Fellow-

ship Training (up to seven years); and Continuing Education (lifetime).

* Quality Measurements: Board Certification; Years in Practice; Disciplinary Actions by State Medical Boards and Medicare.

* Customer Satisfaction: Personal Attributes such as Doctor Gender and Age; Referrals from Colleagues/Friends.

* Doctor Affiliations: Health Plans; Quality of Affiliated Hospitals.

Most of this information can be obtained by contacting the state board of medical examiners either by phone or on the internet.

20 Tips to Help Prevent Medical Errors

The most important way you can help to prevent errors is to be an active member of your health care team. That means taking part in every decision about your health care. Research shows that patients who are more involved with their care tend to get better results.

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Medicines

* Make sure that your doctors—and every member of the health care team—are aware of each medicine you are taking. This includes prescription and over-the-counter medicines, and even dietary supplements such as vitamins and herbs.

* Make sure your doctor knows about any allergies and adverse reactions you have had to medicines. This could keep you from receiving a medicine that can harm you.

* When your doctor writes you a prescription, make sure you can read it. If you can't read your doctor's handwriting, your pharmacist might not be able to either.

* Ask for information about your medicines in terms you can understand—both when they are prescribed and when you receive them. What is the medicine for? How am I supposed to take it, and for how long? What side effects are likely? What do I do if they occur? Is this medicine safe to take with other medicines or dietary supplements I am taking? Are there foods, drinks or activities should I avoid while taking this medicine?

* When you pick up your medicine from the pharmacy, ask: "Is this the medicine that my doctor prescribed?" A study by the Massachusetts College of Pharmacy and Allied Health Sciences found that 88% of medication errors involved the wrong drug or the wrong dose.

* If you have any questions about the directions on your medicine labels, ask. Medicine labels can be hard to understand. For example, ask if "four doses daily" means taking a dose every 6 hours around the clock or just during regular waking hours.

* Ask your pharmacist for the best device to measure your liquid medicine. Also ask questions if you're not sure how to use it. Research shows that many people do not understand the right way to measure liquid medicines. For example, people use household teaspoons, which often do not hold a true teaspoon of liquid. Special devices like marked syringes help people to measure the right dose. Being told how to use the devices helps even more.

* Ask for written information about the side effects your medicine could cause. If you know what might happen, you will be better prepared if it does—or if something unexpected happens instead. This way, you can report the problem right away and get help before it gets worse. Written information about medicines can help patients recognize problem side effects and then give that information to their doctor or pharmacist.

* At least once each year, bring all of your medicines and supplements with you to your doctor. "Brown bagging" your medicines can help you and your doctor talk about them and find out if there are any problems. It can also help your doctor keep your records up to date, which can increase the quality of your care.

Hospital Stays

* If you have a choice, choose a hospital at which many patients undergo the procedure or surgery you need. Research shows that patients tend to have better results when they are treated in hospitals that have a great deal of experience with their condition.

* If you are in a hospital, consider asking all health care workers who have direct contact with you whether they have washed their hands. Handwashing is an important way to prevent the spread of infections in hospitals, yet it is not done regularly or thoroughly enough. A recent study found that when patients checked whether health care workers washed their hands, the workers washed their hands more often and used more soap.

* When you are being discharged from the hospital, ask your doctor to explain the treatment plan you will use at home. This includes learning about your medicines and finding out when you can get back to your regular activities. Research shows that at discharge time, doctors think their patients understand more than they really do about what they should or should not do when they return home.

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Adherence to HIV Regimens: 10 Vital Lessons

By Ann B. Williams, EdD, RN, C

During a recent visit to a patient with AIDS, a home care nurse asked the patient where she kept her drugs. The woman proudly pointed to a large mayonnaise jar filled with all of her loose pills and explained her medication regimen: "I take a handful twice a day and make sure to finish them all by the end of the month," she said.

How many times have you sat with a patient with a chronic illness and carefully reviewed the required medications, being sure to mention the possible side effects, the number of pills to be taken, and the dosing schedule, only to discover weeks later during a follow-up assessment that the patient either has not filled the prescriptions or has not taken the medications since your last meeting? What is the reason for this?

Nonadherence is common across all populations and diseases and is a familiar challenge in nursing practice. The percentage of patients who fail to self-administer as prescribed is somewhere between 20% and 80%.

Adherence rates among patients living with HIV and AIDS are no different from those among patients who suffer from other chronic diseases, but to the former, the consequences of imperfect adherence are grave. Patients with diabetes or hypertension who take only half of their prescribed doses will receive the full benefit of those medications as soon as adherence improves. In contrast, patients with HIV who take only half of their prescribed doses most likely compromise the future effectiveness of those and related medications, forfeiting the opportunity to benefit from potentially life-saving therapies. Even if these patients later attain perfect adherence, the virus will have developed resistance to the prescribed medications and possibly to other drugs in the same class.

The importance of near-perfect medication adherence in HIV infection was recognized in 1997 upon the advent of the protease inhibitors and antiretroviral "cocktails" of three or more medications, also known as highly active antiretroviral therapy (HAART), treatments that have decreased AIDS deaths by 46% in the United States and have greatly improved the quality of patients' lives.

As the new drugs and treatment strategies moved from the highly controlled setting of clinical trials into community practice, it became clear that patients needed support in the adherence to complicated and demanding drug regimens. HIV nurses turned to colleagues experienced in diabetes, hypertension, psy-

chiatric disorders, and public health for assistance in understanding the dynamics of adherence and for guidance in the techniques of assessing and improving it.

As HIV has transmuted into a chronic disease our understanding of the dynamics of adherence have deepened, and we've learned important lessons that can be applied to other chronic illnesses.

1. There is a Difference Between Adherence and Compliance

Although both of these terms signify the extent to which a patient follows a prescribed health care regimen, *compliance* suggests obedience to health care professionals. In contrast, *adherence* connotes the patient's participation and engagement in maintaining a regimen he believes will be beneficial, strongly implying a therapeutic partnership with providers that is essential to his success in taking medication. Because antiretroviral therapy requires a long-term commitment, the patient and provider must work together for many years in the selection and monitoring of a regimen that is potent and also well suited to the patient's lifestyle. For example, a long-distance truck driver found that he consistently forgot to take the mid-day dose of his thrice-daily medication. By switching to a regimen that did not require such a dose, he was able to improve his adherence to almost 100%.

2. Adherence Really Does Matter

Studies suggest that patients who adhere to their regimens have better outcomes: they live longer, enjoy a higher quality of life, and suffer with fewer symptoms than those who do not. Many surveys of HIV-infected patients reveal that those who report missing fewer doses of HAART are more likely to have undetectable viral loads. Conversely, nonadherence is linked with higher levels of HIV and to greater mortality.

The necessary threshold for medication adherence in HIV infection is 95% in most patients. Even a few days of missed doses can result in viral resistance to the medication.

Adherence to other drugs in the regimen is also important. For example, nonadherence to prophylactic medication for *Pneumocystis carinii* pneumonia (PCP) leads to increased numbers of episodes of this type of pneumonia.

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3. Adherence is Not Predictable

Health professionals cannot accurately predict which of their patients will adhere most closely to their regimens, and in one study, nurses erred in predicting adherence in 30% of their patients. It's natural to make assumptions about people we meet, including our patients, yet such suppositions usually rest on stereotypes.

Nor are demographic factors such as age, race, or sex good predictors of adherence. Although some studies have shown, for example, that women and adolescents are at risk for nonadherence does not correlate with income or education levels. Indeed, the HIV and AIDS epidemic has taught us that even those who are homeless and suffering with drug addiction can adhere to demanding medication regimens.

4. Behavior-Change Models Can Help Elucidate the Dynamics of Adherence

Two popular models of health behavior change are the health-belief model and the transtheoretical model.

The health-belief model, a conception of social psychology, posits certain factors that influence health-related behavior. It suggests that the patient's adherence to medication regimens is contingent on how seriously he regards the consequences of nonadherence, on how vulnerable to its effects he perceives himself to be, and on his beliefs regarding the medication's effectiveness, costs, and benefits.

The transtheoretical model, grounded in social cognitive theory, describes a continuum of behavior change that can be applied to medication adherence. The model include six stages of change: precontemplation (unawareness of the need for it), contemplation (consideration of it), preparation (readiness to embrace it), action (remedial steps are taken), maintenance (changes have been in effect for six months), and relapse (a regression to former behavior that can occur at any stage).

The transtheoretical model is especially useful to clinicians in the design of intervention programs for the improvement of adherence because it recognizes in the stages of change the motivation that characterizes each, while also acknowledging that the movement through them is not necessarily linear.

5. There is No Gold Standard in the Monitoring of Adherence

Approaches to monitoring include directly observed therapy and electronic monitoring (via microprocessors embedded in the caps of medication bottles). However, direct methods such as analyzing expensive,

time-consuming, and unstandardized, and have not been shown to encourage adherence. Indirect methods such as pill counting and the use of questionnaires vary in degree of convenience and effectiveness.

A nurse can ask the patient to bring all drug bottles to the clinic, allowing her to see if the supply of pills has depleted at approximately the correct rate. This strategy can also identify medications that should have been discontinued or that have been prescribed by providers at other clinics.

Nurses who review medications at the patient's home may be able to gain access to the medicine cabinet. Sometimes the information gathered there may be quite important and unexpected—such as that revealed in the case of the woman who stored all of her pills in a mayonnaise jar and took two handfuls a day. It would have been difficult to discover this unusual nonadherence behavior through questioning alone; the patient had assured the clinic nurse that she was taking all her doses. The primary strategy for monitoring adherence is the direct questioning of patients: "When did you take the last dose of this medication?" "What about the dose before that?" "When was the last time you didn't take this medication?" While many patients tend to overestimate their adherence, thoughtful and non-judgmental questioning in regard to specifics can yield information on both the level of adherence and the barriers to it. In being asked about each medication and dose specifically, patients are encouraged to reflect on the day, potentially revealing information that would not be elicited by a more general question, such as, "Do you ever forget to take your pills?" *Techniques of Questioning that Promote Adherence* lists questions that can help determine adherence levels in patients with any chronic disease.

6. Nonadherence Follows Many Patterns

Patients adjust their medication doses and schedules according to their own assessments of a medication's strength and side effects. "You're the professionals, but I know my own body," is commonly heard from them. It's important to ask about specific dose and schedule adjustments made because patients may not volunteer such information, especially if they expect a reprimand. While many patients with HIV reduce their medication doses in the belief that the drugs are too strong, some increase the number of pills they take under the mistaken assumption that "more is better." These same phenomena occur among patients with other chronic illnesses.

Drug holidays, as long as a month or more, are occasionally appropriate, but only upon approval of the health care provider. Sometimes patients independently choose to temporarily stop taking their medications in response to anniversaries, holidays or stress. One HIV-positive woman, normally very adherent to her regimen, stopped taking all drugs one July because she thought they made

her “look heavy in a bathing suit.” With HIV medications, a complete drug holiday may lead to fewer long-term consequences than does on-again, off-again adherence for a few days. This is because the low blood levels of antiretroviral medications resulting from partial adherence suppress the predominant HIV strain (wild type), allowing the resistant mutated viral strains thrive. When the patient takes a complete drug holiday, the wild type HIV strain will continue to predominate and will have remained sensitive to antiretroviral medications when reintroduced.

7. Patient Education is Necessary

Patients who understand how their medications help them are more likely to adhere to their regimens. For example, patients who recognize that antiretroviral medication limits or “turns off” viral replication, causing CD4+ cell counts to rise, are more likely to adhere.

Using reports or graphs that demonstrate the medications’ impact on each patient’s clinical markers can be a powerful motivating tool. Viewing a graph that illustrates a fall in HIV RNA (viral load) from 50,000 copies/mL to 5,000 copies/mL over a one-month period is wonderfully rewarding to the patient who has worked hard to adhere to a medication regimen.

A patient’s understanding of the possible side effects of medications and the management of them also has a significant effect on adherence. In one study, patients who were told how to manage GI distress and diarrhea were successful in beginning and maintaining their regimens. Without this information, patients may either stop following them or reduce the doses without consulting their providers.

It’s also important that patients know all the names of their medications, as a number of HIV drugs have three names (for example, AZT, zidovudine, and Retrovir are the same), and several of them have similar names (Retrovir, the trade name of AZT, resembles ritonavir, the generic name of one of the protease inhibitors). This can be quite confusing to both the nurse and the patient—it helps if the nurse lists all drug names for the patient’s reference.

8. Keep it Simple, Please

The more complicated the medication schedule, the more difficult it is for the patient to keep to it. Although HIV drug therapy has been evolving from thrice daily dosing to twice-daily dosing, and once-daily dosing is clearly on the horizon, it continues to involve many large pills and capsules that patients find difficult to take.

Although some medications are available in liquid formulations, these do not necessarily simplify the regimen, as liquids must be measured carefully and some-

times refrigerated. At least two antiretroviral drugs (didanosine and indinavir) require an empty stomach for adequate absorption, but they cannot be taken together, and a regimen that includes both, while effective will not be easy to integrate into daily schedules.

Because AIDS patients are often dealing with multiple health problems, their medications often include antidepressants, anxiolytics, drugs to prevent opportunistic infections, and those to manage the side effects of antiretrovirals. In addition, many people living with HIV are committed to complementary therapies, particularly vitamin and nutrition supplementation, which compounds the complexity of daily pill management. For example, a patient with HIV may spend 15 minutes each morning preparing herbal tonics for the day, in addition to keeping account of 14 antiretroviral capsules.

9. One Size Does Not Fit All

Because individualized strategies to promote adherence work best, nurses should customize regimens according to each patient’s needs and ability to tolerate structure. However, there is actually little room for flexibility; doses should not be skipped and should be taken within two hours of the scheduled time. Patients who cannot tolerate structured schedules may do better with a once-daily regimen, when it becomes available. In one study, only 32% of patients who said their medication regimens did not suit their daily schedules were adherent, compared with 67% of those who said their medication regimens fit “extremely well.” The nurse can review a patient’s daily activities and suggest how to integrate medication administration into them. For example, when medication is taken in coordination with habit, it is likely to be overlooked or forgone. Some patients schedule medications to coincide with a regular activity such as walking the dog or watching a television program. It’s also important for the patient to know which medications to take with meals and which are to be taken on an empty stomach for better absorption.

Be alert to changes in routine that may occur on weekends and holidays and during travel, which can lead to doses being missed. Some patients may spend time regularly at the home of a significant other or family member, and it’s a good idea to recommend that they keep a duplicate set of medications at the other location.

Adherence strategies involve education, the teaching of skills, psychological reinforcement, and the enhancement of social support. Continuing education programs for health care professionals can help them increase their awareness of adherence issues and familiarize them with patient-education tools.

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General Health Maintenance Strategies

Have you ever heard someone say, "I don't want HIV to take over my life. My life is more than my HIV status?" Perhaps you've had similar feelings or felt overwhelmed with trying to manage your health. This article provides a different way of thinking about health than what many people may experience at a doctor's office. The goal is to offer a framework for thinking about the big picture of well-being and provide a path for developing a long-term strategy to promote and maintain overall general health.

Studies have looked at similarities among people who are long-term survivors of HIV and other life-threatening conditions. People who have spontaneous remissions from serious conditions or improving outcomes over time are people who are most likely to proactively address health on all fronts. This doesn't contradict findings that people who see an HIV-experienced doctor are more likely to live longer and healthier lives with HIV infection. Nor does it disregard that some people might not progress to AIDS as quickly due to genetic factors, the virulence of the virus they were initially infected with and other factors. Yes, sometimes outcomes in HIV infection might just come down to luck. In the biggest picture, however, people who proactively address health on all fronts have a tendency to do better than people who do not.

What is Health?

What is health and how does someone address health on all fronts? Is it possible to come up with strategies to address health on all fronts without it becoming a full time job? Sometimes health crises arise and managing them can take over a large part of a person's life. Part of the goal of a general health maintenance strategy, however, is finding the right balance. It's not about health maintenance interfering with life—it's about healthy living.

Project Inform ascribes to a model of health as it concerns the whole being—a biopsychosocial model of health. This includes physical (biological), mental (psychological), spiritual and social health and assumes that each of these areas of health impacts the others.

At the biological level, health is freedom from disease or injury and any limitations these might impose. Merely avoiding disease; having healthy bones, skin and teeth; and staying out of harms way doesn't reflect the complexity of our lives. We are more than the sum of our parts and we can be healthy without being perfect. As the definition of health expands to include how our whole body is functioning, a picture

of health that includes a mind-body connection emerges. It doesn't stop there. Health includes a state of mind, a peace and harmony with ourselves and our physical and social environments.

Developing a Strategy: Building a Strong Foundation

A general health maintenance strategy addresses the mind, body, spiritual and social connections of who we are and how we live. By viewing health this way, the idea of a general health maintenance strategy being something that overwhelms one's life begins to fade away. Through both action and inaction people make choices daily about their health. You likely have general health strategies that you are implementing all the time. Taking a moment to look at what those strategies are, name them, refine them and explore ways to improve them is the very foundation of health.

No single strategy works best for everyone. Rather, the best answers are those that fit you best. There are resources, tools and some basic principals to consider. A good strategy includes goals you can achieve, is tailored to your needs, fits into your life and makes you feel better as you implement it. That doesn't mean that your strategy is failing if you come down with the common cold or if you have a bad day. A general health strategy is not something one achieves or completes, it's an ongoing process that needs to be revisited periodically, adjusted as your life changes—as you change.

Biological Health

Your basic biological health is something that a doctor can help you to understand and develop tailored strategies for promoting and improving. While people living with HIV often see a doctor four times each year, many times both HIV specialists and patients can forget about basic health screening and maintenance. This includes physical examinations, vaccinations, other preventive health measures as needed and age appropriate health screening.

For information on what is looked for in a routine physical examination, what's meant by age appropriate screening, general recommendations on vaccinations and a list of special health considerations, call the Project Inform hotline. Also, information on standard tests, vaccines and issues to deal with during a first visit to a doctor after finding out that you're living with HIV.

Taking care of your biological health includes more than seeing a doctor. Here are a few examples:

Nutrition: The body needs nutrients in order to work effectively. Often when people are really hungry they'll

get a headache, feel dizzy or may find themselves in a bad mood. How often and what do you typically eat in a day? What does good nutrition mean to you and what can you do to improve your nutrition? Realistic nutritional goals that fit with your life and lifestyle are key to success. What this often means is incremental improvements. For example, if a normal breakfast for you is a cup of coffee and a pastry on your way out the door, is it possible also to add a glass of juice? While it's great to consult with a nutritionist (especially one who specializes in HIV), there are probably ways you can improve on your general nutrition now. For some this means eating more, for others eating less and for others it's about eating different foods.

Exercise: A few pounds of muscle mass (lean body mass) can make a difference in whether someone recovers from a severe life-threatening infection. There are many reasons why exercise is good for us, from helping muscles and bones remain strong to improving the function of our heart and lungs. Are there ways you can improve how you exercise or the amount of exercise you get each day? Some people love to go to the gym and workout; others wouldn't set foot in a gym if someone paid them. If you typically don't set aside any time for exercise, consider taking a walk for twenty minutes each morning and/or at the end of the day. Perhaps you'll never go to the gym, but you may enjoy going for a hike, bike riding or simply taking the stairs in your building. What can you do to improve the kind or quality of exercise you get each day?

Sleep: When we sleep, our bodies heal. In general it's recommended that people get eight hours of sleep each night. The amount of sleep needed differs to some degree between individuals and can also vary based on other things going on in a person's life. When someone is depressed they might sleep more or have trouble sleeping. Often when someone is fighting an infection their body demands more rest. Do you get enough sleep each night? If you are sleeping too much it is important to figure out why—are you depressed, fighting an infection, do you have low red blood cell counts (anemia)? If you are sleeping too little it's also important to figure out why—are you depressed, drinking coffee or other caffeinated beverages too late at night, or is something else going on? If you find your life is just too busy to find time for sleep, strive for incremental improvements. If you're sleeping only 5 hours a night, is it possible to make time for 5 1/2—6 hours?

Relax: Chemicals produced by the body when people experience stress can weaken the immune system, leaving cells more susceptible to infection and crippling the ability of the immune system to rebuild itself. It's virtually impossible to completely avoid stress, but efforts to minimize and manage stress are important to our physical

and mental health. Can you identify things that cause you stress that you could eliminate from your life? When the things that cause you stress are unavoidable, are there things you can do to minimize or manage that stress better? Some find that exercise decreases stress levels. Getting a massage, taking a hot tub, talking with friends, laughing, getting out of the house and going to a movie, spending time with people you love, reading a good book, finding a good support group and/or finding a good therapist are all possible ways to decrease and better manage stress. Keep trying different methods until you find what works best for you and then find ways to incorporate it into a daily, weekly or monthly routine.

Psychological (Mental) Health

Each of the issues discussed above, nutrition, exercise, rest and relaxation can affect mental health. By highlighting this, perhaps it's easier to see how health is more than just healthy bones, teeth and skin, and how it is that our physical, social, spiritual and mental health are connected. It's great to seek counsel and guidance from a therapist who is experienced in dealing with HIV issues. General mental health ranges from self esteem to addiction issues, from your emotional outlook to the relationships you have with other people. The paths to examining these issues and developing strategies that are right for each individual are varied.

Addiction: Is addiction a mental or a biological health issue? Some people are genetically predisposed to alcoholism and other forms of addiction, because of the way that their body processes (or doesn't process) certain chemicals. Regardless of genetic predisposition to alcohol addiction, there is evidence of chemical changes in the brain that leaves people alcohol-dependent after consuming alcohol for a long period of time over days, months and/or years. Addiction comes in many forms. Alcohol and drug addiction are perhaps the most commonly spoken of. There are also people with addiction to food, sex, the internet, video games, gambling, nicotine, shopping and the list goes on and on. Whatever the case, anyone with an addiction who is speaking candidly about it can tell you how the addiction interferes with their life, their relationships and their health. Depending on the addiction there may be medical interventions, twelve-step programs, one-on-one therapy options, in-patient programs and harm reduction programs to explore. In many instances the first step is recognizing that you have an addiction and then seeking support, guidance and expert advice on plotting a course of action.

Depression: Studies show that the most common psychiatric diagnosis among people living with HIV is

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depression. As in the general population, some studies suggest that is most common among women. Depression can be caused by chemical imbalances and it can be a side effect of some medications used to treat HIV and related conditions. Depression can be caused by HIV infection itself, HIV-related conditions and even changes in the body (such as menopause and/or decreases in testosterone production). The key to successful treatment of depression is identifying the possible causes. Another step is recognizing depression in the first place. When someone is depressed they may experience extreme fatigue, sleep disturbances, changes in appetite, and generally lose an interest and enjoyment in participating in life. Some of these conditions are interrelated as extreme fatigue can cause depression, sleep disturbances can also cause fatigue and depression, not eating well can impact mental and biological health and be associated with fatigue. Especially when you're depressed, finding the strength to pay attention to sleep, nutrition and exercise is important to avoiding a cycle of ever-worsening problems. If you experience depression, seeking strategies to deal with it is critical. For some this might include antidepressant medication and for others this might simply involve spending time with people who they love or doing things they enjoy.

Self esteem and emotional outlook: Another common theme that unites many people who are long-term survivors with HIV disease is that they have a philosophy of well-being. Often they believe that what they are doing today will make a difference for their tomorrow. They have a hopeful approach to the future. The road each of us must travel to believe in ourselves and the value of our voices and choices is unique. For some, a strategy to improve self esteem and emotional outlook might include seeking a therapist. For others it might include spiritual soul searching or it might include going to the gym to improve body image. For those who feel like they have a positive outlook and good self esteem, what are you doing to maintain that? A philosophy of well-being doesn't mean that when you're angry, depressed or upset that you're supposed to think positively. It's about experiencing those feelings, working through them and finding a way to embrace them as part of the picture, but not the whole picture.

Spiritual Health

Defining what spiritually means to most people is nearly impossible because it means something different to every person. For those who embrace forms of spirituality in their lives, most would contend a discussion of health without a discussion of spirituality is incomplete. Others, particularly those who have had negative feelings about spirituality and religion may be offended by any discussion.

Each person's path to exploring spiritual health is unique and very personal. Spirituality is not necessarily religion. A few examples: for some spirituality is the religion they were raised with, for others spirituality is founded on a harmony with nature, a notion of a Higher Power, The Goddess and/or balance with the energies of the universe. Spiritual health involves exploring your spiritual beliefs and examining your life, your actions and inactions, accordingly. What matters isn't what your personal spiritual choices are, but that you're living your life consistent with your beliefs.

Social Health

Social health is not only having healthy personal relationships with others, but also includes one's relationships to their communities and the health of the community.

While some people enjoy and are energized by social and group activities, others are not. Social health doesn't always mean participating in large group activities or even attending large-scale social events. It does mean, however, cultivating deep, rewarding and meaningful relationships and includes contributing to and participating in community. Social health is about giving and receiving support from community and loved ones.

The paths to promoting and maintaining social health are varied. Sometimes it starts with simply sitting down and thinking about personal relationships, identifying which relationships are most meaningful and why. Are you happy with your friendships and what might you do to strengthen those you have and/or cultivate new ones? Are you being the kind of friend you want to be and do you have the kinds of people in your life who support you? What kinds of things can you do to participate in community? Volunteer to help teach children to read? Write a letter to an elected official advocating for an issue of importance to your community? Help your neighbor with his/her groceries?

Discussion

Developing a strategy for good general health provides a strong foundation upon which to build strategies for dealing with HIV disease. There is a difference between medications, health and healing. Medications treat specific biologic conditions, health is an experience and healing is a process. Medications have their place in an overall strategy for healthy, but they are merely one piece of a much larger puzzle.

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HCV/HIV Bites

VA Launches New Web Site on Hepatitis C

A new, comprehensive Web site on hepatitis C – www.hepatitis.va.gov – will be formally launched Feb. 25 through a collaboration between the Department of Veterans Affairs (VA) and the University of California at San Francisco's Center for HIV Information (CHI).

"Hepatitis C is another reminder that veterans rely on VA to care for a wide variety of illnesses and battle-field injuries," said Secretary of Veteran Affairs Anthony J. Principi. "This web site will help both veterans and medical practitioners to understand this complex, long-term illness."

Hepatitis C is the most common blood borne infection in the United States, affecting 2 percent of the population. VA cares for more hepatitis C patients than any other medical system, with more than 200,000 patients since 1996. The department has the largest screening, testing and care program for hepatitis C in the nation.

The new hepatitis C web site has a section for veterans and non-medical employees that includes general information and links to other websites. It also offers information for health care providers that is searchable by topic and includes best practices, guidelines and slides.

"Hepatitis C is an important public health issue for our nation," said Dr. Lawrence Deyton, VA's chief consultant for public health, who oversees VA's hepatitis C programs. "VA is pleased to join with CHI, a world-class medical website developer, to provide a user-friendly resource on hepatitis C for providers, patients and public health authorities."

CHI, based at the San Francisco VAMC, is directed by Dr. Laurence Peiperl, a medical staff member of both the university and the San Francisco VAMC. Dr. Paul A. Volberding, chief of the medical service at the San Francisco VAMC, chairs the CHI Advisory Board.

Source U.S. Department of Veterans Affairs
Contact: U.S. Department of Veterans Affairs, Office of Public Affairs, +1-202-273-6000
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FDA Approves Pegasys Prefilled Syringes

Roche announced that the U.S. Food and Drug Administration (FDA) has approved prefilled syringes of Pegasys (Peginterferon alfa-2a) for the treatment of chronic hepatitis C.

Pegasys, a pegylated alpha interferon, and Copegus (ribavirin, USP) were approved by the FDA in December 2002 for use in combination for the treatment of adults with chronic hepatitis C who have compensated liver disease and have not previously been treated with interferon alpha. Patients in whom efficacy was demonstrated included patients with compensated liver disease and histological evidence of cirrhosis.

Pegasys is the most prescribed interferon therapy in the United States for the treatment of chronic hepatitis C.

Roche expects Pegasys prefilled syringes to be available in pharmacies by the end of the month. Prefilled syringes will be packaged four per box. Pegasys is currently available in vials as a premixed solution.

"Taking a medication by self-injection can be challenging for some people," said Dr. David Bernstein, director of hepatology, North Shore University Hospital. "Reducing the number of steps involved can make the process less intimidating for patients and reduce the risk of errors."

This article was prepared by AIDS Weekly editors from staff and other reports.
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HIV Patients Get Long-Term Boost with Short, Intermittent Drug Regimen

National Institutes of Health (NIH) scientists report that brief, widely-spaced courses of the experimental immune-boosting drug interleukin-2 (IL-2) allow people with HIV to maintain near normal levels of a key immune system cell for long periods. The researchers, from NIH's National Institute of Allergy and Infectious Diseases (NIAID) and the Warren G. Magnuson Clinical Center, describe their findings in the May 1 issue of the journal "Blood".

"These data provide strong evidence that IL-2 therapy, which can be self-administered by patients, could be an important adjunct to highly active anti-retroviral therapy (HAART)," says NIAID Deputy Director John R. La Montagne, Ph.D.

The new report summarizes the experience of 77 HIV-positive individuals who enrolled in extension phases of three long-running AIDS clinical trials. Participants were taught to inject themselves subcutaneously with IL-2 twice daily in 5-day-long cycles. Cycles were initiated as often as necessary to maintain levels of immune cells called CD4+ T cells. Without enough of these "helper" immune cells, people with HIV disease have a hard time fending off infections. IL-2 can boost CD4+ T cell levels, with the goal of improving overall immune health.

Because HIV infection causes progressive immune destruction, it stands to reason that immune-stimulation therapy, such as IL-2, might play a substantial role in treating patients with this condition, notes Richard Davey, Jr., M.D., an NIAID AIDS clinician who headed the studies reported in "Blood". Indeed, during the early 1980s NIH physicians pioneered the use of long courses of IL-2 to treat individuals whose immune systems had mysteriously failed. Scientists now know those people were suffering from AIDS, but at the time the virus causing AIDS had yet to be identified.

Although NIH physicians have accumulated over 20 years of experience with IL-2 therapy, the most impressive results began to appear in the early 1990s when the doctors started treating patients with short, intermittent cycles of the drug, Dr. Davey says. Today, HIV patients receiving IL-2 therapy typically begin with 5-day-long cycles every other month while taking drugs, such as HAART, on a sustained basis. According to Dr. Davey, this regimen often raises an HIV patient's CD4+ T cell levels well into the normal range after only a few cycles. The new

research suggests IL-2 therapy can then be administered much less frequently without loss of benefit.

Most studies to date have looked at IL-2 therapy only over relatively short periods, says Dr. Davey. In contrast, the average length of patient follow-up described in the current paper is about six years. Patients in these trials have received an average of 10 IL-2 cycles during the course of their involvement, with most of the cycles occurring in the initial years of participation. Of the original 77 volunteers, 61 achieved and maintained normal or nearly normal levels of CD4+ T cells for periods ranging from two to 91 months between IL-2 cycles. During the most recent period of study, the average time between cycles was more than 3 years. (Of the 16 people no longer participating, one died, one developed non-Hodgkin's lymphoma, eight elected to follow other treatment plans and six experienced CD4 cell count declines that did not respond to IL-2 therapy.)

"Patients described in this study are still being followed," says Dr. Davey. "There are also trials planned or underway to learn if IL-2 therapy could delay or obviate the need for continuous HAART, thereby sparing persons with HIV disease from the serious side-effects that HAART can cause. The early experience from some small preliminary studies in this area suggests that this may indeed be a possibility, although larger trials are clearly needed to explore this fully."

For information about AIDS treatment or to enroll in a clinical study, please contact <<http://www.AIDSinfo.nih.gov>> or call: 1-800-HIV-0440 (1-800-448-0440).

This NIH News Release is available online at: <http://www.nih.gov/news/pr/apr2004/niaid-26.htm>

Fibromyalgia and Hepatitis C

Liz Highleyman

Many people with hepatitis C experience symptoms such as fatigue, muscle and joint aches, "brain fog," and depression, either due to HCV itself or as side effects of treatment with interferon. But some hepatitis C patients also have fibromyalgia (FM), a condition marked by widespread bodily pain. An estimated 3-6 million Americans have FM, and the condition is most common in middle-aged women.

Fibromyalgia (FM) refers to pain in the muscles, tendons, and ligaments. It is characterized by pain and stiffness throughout the body, but especially at tender points located mostly over muscles and tendons (e.g., the base of the jaw, the back of the neck, the upper and lower back). FM does not involve inflammation or muscle damage and is not progressive (although it is chronic). Pain may range from mild to severe and typically waxes and wanes over time, exacerbated by factors such as stress, physical exertion, and inadequate sleep.

Most people with FM have various other conditions including:

- ◆ fatigue
- ◆ sleep disturbances
- ◆ headaches
- ◆ cognitive impairment or "fibro fog" (e.g., problems with memory or concentration)
- ◆ paresthesias (numbness, tingling, or burning sensations)
- ◆ restless leg syndrome (involuntary muscle jerking during sleep)
- ◆ irritable bowel syndrome
- ◆ severe premenstrual syndrome (PMS) or menstrual cramps
- ◆ unusual sensitivity to heat, cold, noise, light, and/or odors
- ◆ neurally mediated hypotension (low blood pressure when standing or sitting upright)

Causes of Fibromyalgia

Despite years of research, the cause of FM is not fully understood. Because symptoms are usually invisible, many FM patients have been told the condition was "all in their heads." But today most doctors understand that FM is not a psychosomatic disorder. Although many people with FM have anxiety or depression, these generally arise due to the pain and functional limitations associated with the condition.

Many (but not all) FM patients report that their symptoms began after a physical injury, surgery, viral or bacteria infection, exposure to a toxin, or an emotionally stressful event. FM has not been linked to any specific pathogen such as Epstein-Barr virus (EBV), mycoplasma, or human herpes virus 6 or 7 (and there is no evidence it can be transmitted from person to person). These triggering events do not seem to directly cause FM, but rather set in motion physiological processes that lead to symptoms. This may occur in people who have a genetic predisposition, since FM runs in families.

These processes may involve changes in immune, endocrine, or neurological function. Some studies have shown immune changes in people with FM such as altered cytokine (chemical messenger) levels and decreased natural killer cell activity, but data is conflicting. FM does not appear to be due to either immune suppression or autoimmunity. Research indicates that people with FM have certain endocrine abnormalities, including low levels of growth hormone and cortisol, a hormone produced by the adrenal glands when the body is under stress. FM also appears to involve changes in the way the central nervous system processes pain. Imaging and EEG studies show that people with FM have altered activity in pain-processing parts of the brain. They also have elevated levels of substance P, a chemical that transmits pain signals. These changes may cause hyperalgesia, or heightened sensitivity to pain (and sometimes other types of stimuli as well).

Most people with FM have sleep disturbances including trouble falling asleep, waking during the night, or restless leg syndrome. Brain wave studies show that people with FM may not enter the deepest stages of sleep. Thus, despite being in bed for 8 - 10 hours, they may still feel exhausted in the morning (called non-refreshing or non-restorative sleep).

It is likely that FM involves the interaction of multiple factors. Once symptoms develop, patients may avoid physical activity (causing their muscles to become deconditioned, or out of shape), get depressed, and have even more trouble sleeping, which in turn can make symptoms worse.

Fibromyalgia, CFS, and HCV

FM appears to be closely related to other conditions

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characterized by chronic pain, fatigue, cognitive impairment, and heightened sensitivity to stimuli. These include chronic fatigue syndrome (CFS, also called CFIDS), multiple chemical sensitivity (environmental illness), and Gulf War syndrome. Some experts believe these are, in fact, different manifestations of the same underlying disorder. As many as 75% of people with FM also have CFS, and vice versa. The symptoms of these conditions overlap to a large degree, but there are some differences: people with CFS are more likely to have flu-like symptoms such as fever and tender lymph nodes, while people with FM have characteristic tender spots.

Because some symptoms of FM and CFS are similar to those of hepatitis C, researchers have explored whether and how these conditions might be related. In a 250-person study, D. Buskila and colleagues found that 16% of HCV patients, 3% of patients with cirrhosis due to other causes, and no HCV-negative patients without liver disease met the diagnostic criteria for FM. Almost all of the HCV positive individuals with FM were women. Conversely, J. Rivera and colleagues detected HCV antibodies in 15% of a group of 112 patients with FM, compared with 5% in a matched groups of rheumatoid arthritis patients. More recently, E. Kozanoglu and colleagues found that 19% of HCV patients had FM, compared with just 5% of uninfected controls. Interestingly, patients who had both HCV and FM reported more tender spots and more intense pain than those with FM alone. Interferon can cause symptoms similar to many of those associated with FM and CFS, but none of the HCV patients in Buskila's study were receiving interferon (Rivera and Kozanoglu did not report interferon use in their abstracts). In another recent study, M. Thompson and colleagues described several cytokine alterations seen in both hepatitis and FM that can cause hyperalgesia and other symptoms common to these two conditions. Buskila suggests that since there is no evidence that specific pathogens cause FM or CFS, it is more likely that infection in general, including HCV, is among the many possible triggers for these conditions.

Fibromyalgia Diagnosis and Treatment

There is a two-part definition for diagnosing FM:

- ◆ Pain in all four quadrants of the body (i.e., on both sides and above and below the waist) for at least 3 months
- ◆ Pain in at least 11 of 18 defined tender points

There are no laboratory tests that specifically indicate FM. However, FM can resemble several other condi-

tions, which should be ruled out using appropriate tests if suspected. These include Lyme disease, lupus, rheumatoid arthritis, multiple sclerosis, and hypothyroidism (which is sometimes associated with interferon therapy).

There is no known cure for FM, so therapy is aimed at relieving symptoms and improving quality of life. Education is key to helping patients adjust their lifestyle to accommodate pain and fatigue. Many of these measures will be familiar to people living with HCV: pacing activities, simplifying tasks, scheduling time for rest, setting realistic expectations, and asking for help. Don't try to do too much on "good days," since this can lead to over-exertion and a flare-up of symptoms.

"A gentle program of stretching and aerobic exercise is essential to counteract the tendency for deconditioning that leads to progressive dysfunction in fibromyalgia patients," says FM expert Robert Bennett, MD. Complete bed-rest might be tempting, but is likely to lead to worse fatigue and disability. Regular, low-impact exercise can improve muscle tone and promote deep sleep. Start slowly with just a few minutes of gentle stretching per day; if possible, work up to 20-30 minutes daily.

Many medications can help promote sleep and manage pain. For insomnia, antihistamines and melatonin may be tried first, followed by stronger medications such as zolpidem (Ambien) or temazepam (Restoril). Clonazepam (Klonopin) is used to control restless leg syndrome. Over-the-counter pain medications are not usually very effective, but low-dose tricyclic antidepressants such as amitriptyline (Elavil) or doxepin (Sinequan) can both relieve pain and improve sleep, as does trazodone (another type of antidepressant). If these measures are not adequate, stronger pain medications such as tramadol (Ultram) or narcotics (e.g., Vicodin, OxyContin) may be used. Injection of lidocaine at tender points can also help with flare-ups. Patients in constant, severe pain should consult a specialized pain management clinic. Importantly, patients with FM are often especially sensitive to the effects of drugs, so it is prudent to start with low doses and increase them as needed.

People with FM often find alternative therapies helpful, including acupuncture, t'ai chi, therapeutic massage, physical therapy, hot baths, biofeedback, and relaxation techniques. In addition, many can benefit from peer support groups or professional counseling.

While FM is a chronic condition and complete recovery may not be possible, many people do experience

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some improvement over time. Some people are able to resume work, and if not, may be eligible for disability benefits.

As with many conditions, a combination approach seems to work best. Pacing activities, gentle exercise, good sleep habits, and stress reduction can help keep pain and fatigue under control.

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- Rivera, J. et al. Fibromyalgia-associated hepatitis C virus infection. *British Journal of Rheumatology* 36(9): 981-5. September 1997.

Thompson, M. and A. Abarkhuizen. Fibromyalgia, hepatitis C infection, and the cytokine connection. *Current Pain and Headache Reports* 7(5): 342-347. October 2003.

Web Resources:

- Arthritis Foundation: 800-283-7800, www.arthritis.org
- National Fibromyalgia Association: 714-921-0150, www.fmaware.org
- National Fibromyalgia Partnership: www.fmpartnership.org
- National Chronic Fatigue Syndrome and Fibromyalgia Association: www.ncfsfa.org
- CFIDS Association of America: 704-365-2343, www.cfids.org

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Tips on Receiving the Best Medical Care (cont.)

Surgery

* If you are having surgery, make sure that you, your doctor, and your surgeon all agree and are clear on exactly what will be done. Doing surgery at the wrong site (for example, operating on the left knee instead of the right) is rare. But even once is too often. Wrong-site surgery is 100% preventable.

Other Steps You Can Take

- * Speak up if you have questions or concerns. You have a right to question anyone who is involved with your care.
- * Make sure that someone, such as your personal doctor, is in charge of your care. This is especially important if you have many health problems or are in a hospital.
- * Make sure that all health professionals involved in your care have important health information about you. Do not assume that everyone knows everything they need to.
- * Ask a family member or friend to be there with you and to be your advocate (someone who can help get things done and speak up for you if you can't). Even if

you think you don't need help now, you might need it later.

- * Know that "more" is not always better. Find out why a test or treatment is needed and how it can help you. You could be better off without it.
- * If you have a test, don't assume that no news is good news. Ask about the results.
- * Learn about your condition and treatments by asking your doctor and nurse and by using other reliable sources. For example, treatment recommendations based on the latest scientific evidence are available from the National Guidelines Clearinghouse. Ask your doctor if your treatment is based on the latest evidence.

You should be the most important participant in your healthcare. Ask as many questions as you need in order to feel comfortable with the care provided. Be confident and be sure you understand what is happening. After all, it is your body.

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HCV Genotype & Quasi-Species

Alan Franciscus, Editor-in-Chief

With respect to hepatitis C, the term genotype refers to different, but related strains of the hepatitis C virus. Approximately 200-400 years ago the virus began to develop variations in its genetic make-up. These variances have been classified into different genotypes. There are six major groups, or genotypes, numbered 1 to 6, although many experts believe that there may be as many as 11. Within each genotype are further divisions called subtypes (for example 1a and 1b) and quasi-species.

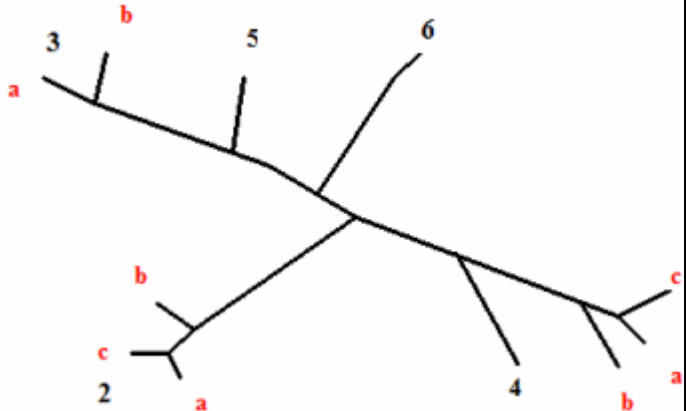
HCV constantly changes and mutates as it replicates—more than 1 trillion hepatitis C virions replicate each day. During the replication process, the hepatitis C virus will make 'bad' copies or errors in the genetic make-up of the newly replicated viruses. The process of constant mutation helps the virus evade the body's immune response—when the dominant quasi-species is eradicated, another quasi-species emerges. This requires the immune system to constantly identify and kill the newly emerged variants. This is why so many people develop chronic disease. Scientists believe there are literally millions of different HCV quasispecies in everyone infected with hepatitis C, which are unique to every individual. In addition, it has been suggested that quasi-species play a role in disease progression and treatment response, but this is still very controversial and more studies are needed to fully appreciate the role of quasi-species.

This variability (genotype, subtypes and quasi-species) of hepatitis C has made it difficult to treat and to develop a vaccine that will protect against all HCV strains, although recent advances in vaccine development have been encouraging.

Genotype Distribution

HCV genotypes and subtypes are distributed differently in different parts of the world, and certain genotypes predominate in certain areas. Genotypes 1-3 are widely distributed throughout the world. Subtype 1a is prevalent in North and South America, Europe, and Australia. Subtype 1b is common in North America and Europe, and is also found in parts of Asia. Genotype 2 is present in most developed countries, but is less common than genotype 1. Some studies suggest that different types of HCV may be associated with different transmission routes. Subtype 3a appears to be prevalent among injection drug users and it is believed that it was introduced into North America and the United Kingdom with the widespread use of heroin in the 1960s.

Genetic Diversity of Hepatitis C - Genotypes



Genotype Distribution Worldwide

HCV Genotype	Distribution
1, 2, 3	Worldwide
4	Middle East, Africa
5	South Africa
6	Southeast Asia

Genotype Distribution in the USA

Genotype	% of Population	U.S. Population
1	~70 %	2,800,000
2	~15%	600,000
3	~12%	480,000
4	~2%	80,000
6	~1.5%	60,000

Importance of Genotype Information

HCV Genotype information is important because of the role it plays in predicting HCV medical treatment response, treatment duration, and the dose of ribavirin. However, it should never be used as a reason to deny treatment.

Prediction of Treatment Response

Genotype information is important because it can be used as a predictor of a positive treatment outcome or response. The sustained virological response rates for pegylated interferon plus ribavirin are much higher in genotypes 2 and 3 compared with genotype 1.

Other predictors of treatment response include:

- ◆ Age of Patient—younger patients respond more favorably.
- ◆ Sex of Patient—women are more likely to respond to therapy than men.
- ◆ Histology (health of the liver) —people with minimal damage respond better to treatment.
- ◆ Viral Load—the lower the viral load (less than 2,000,000 IU/mL) the more likely one is to respond to medications.
- ◆ Weight—heavier weight is associated with lower treatment response rates.

Genotype and Treatment Response

Genotype 1 is considered the most difficult to treat with current HCV medications. However, treatment response rates with the newer forms of pegylated interferon plus ribavirin have been remarkably high, with up to a 52% sustained virological response rate (SVR—undetectable viral load six months post treatment). Genotypes 2 and 3 respond even better to current medications—up to 80%.

Genotype and Treatment Duration

Genotype is also a factor in the period of time required to treat with current HCV medications. Generally, genotype 1 is treated for 48 weeks and genotypes 2 and 3 are treated for 24 weeks. However, there are studies underway to determine the optimal treatment duration based on certain factors. For instance, some experts believe that people with genotype 1, high viral load should be treated for 72 weeks instead of 48 weeks to maximize treatment response rates. There are also studies evaluating treating people with genotypes 2 and 3 for 12 weeks.

Genotype and HCV Medication Dosage

Genotype information is also important for establishing the appropriate dose of ribavirin. For instance, people with genotypes 2 and 3 are given 800 mg a day of ribavirin, whereas the ribavirin dose for people with genotype 1 is dosed by body weight (1000 or 1200 mg/daily).

Mixed Genotypes

A person can become infected with more than one genotype. Data is almost non-existent on infection with more than one genotype, but some experts believe it may affect treatment response and HCV disease progression.

Steatosis and Genotype

Steatosis (fatty infiltrates of the liver) is a well-recognized feature of hepatitis C infection. Steatosis can contribute to HCV disease progression although the exact mechanism is not completely understood. People with HCV genotype 3 are more likely to develop steatosis and it is believed that HCV genotype 3 is an independent risk factor and may actually play a direct role in the development of steatosis. It has been reported that when genotype 3 individuals are successfully treated that steatosis will generally improve, and that for many steatosis will disappear.

Genotype and HCV Disease Progression

With regard to genotype and HCV disease progression, early limited data suggested that genotype 1b was associated with a more severe disease progression than in genotypes 1a or 2, but further studies have not been able to confirm this observation.

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Pegasys plus Copegus: Newly Published Data

Reports Highest Overall Sustained Virological Response Ever - 63%

Alan Franciscus, Editor-in-Chief

The *Annals of Internal Medicine* recently published an article on the clinical trial data results from a large international multicenter phase III clinical trial in order to assess the safety and efficacy of 24 or 48 weeks of treatment with Pegasys plus Copegus at low or standard ribavirin dose.

The study was a randomized, double-blind trial that enrolled 1,311 hepatitis C positive patients from 99 international centers. The lead author of the study was S.J. Hadziyannis, MD, for the Pegasys International Study Group.

All patients were treated with Pegasys 180 µg /week and were randomized into four treatment arms:

- ◆ 24 weeks - Pegasys plus ribavirin 800 mg/daily.
- ◆ 24 weeks - Pegasys plus ribavirin 1000 or 1200 mg/daily.
- ◆ 48 weeks - Pegasys plus ribavirin 800 mg/daily.
- ◆ 48 weeks - Pegasys plus ribavirin 1000 or 1200 mg/daily.

The primary endpoint of this study was end of treatment response and sustained virological response at the end of treatment and during the 12 to 24 weeks of follow-up.

It is well known that certain co-factors can influence treatment outcome: low viral load, minimal liver disease progression and infection with HCV genotypes 2 or 3 are all factors that predict a more favorable treatment outcome. This report will focus on the overall sustained virological response rate ((SVR) - undetectable HCV RNA or viral load achieved 24 weeks post treatment) - as well as on the SVR based on genotype, viral load and degree of HCV disease stage or progression. This is important since the majority of people in the United States are infected with genotype 1 with a high viral load, and these patients are considered the most difficult to treat with current HCV medications.

High viral load is defined as over 2,000,000 copies; low viral load is defined as under 2,000,000 copies.

Results: Genotype 1 - The Most Difficult to Treat

The authors reported an overall 52% SVR for all genotype 1 patients, and the study confirmed that the optimal dose of ribavirin is 1000-12000 mg/daily with treatment duration of 48 weeks.

The study also analyzed the treatment outcome by low viral load (65% SVR) and high viral load (47% SVR).

The authors further analyzed the SVR rates of patients according to the extent of fibrosis at baseline and found that patients without cirrhosis attained a 57% SVR versus 41% SVR for patients with cirrhosis or bridging fibrosis.

Results: Genotypes 2 and 3

As expected the SVR rates for people infected with HCV genotypes 2 and 3 were much higher than those attained by genotype 1 patients. The study also confirmed the results of previous Pegasys/Copegus studies that showed that a 24 week treatment duration and a ribavirin dose of 800 mg/daily produced the optimal sustained virological response rate for people with genotypes 2 and 3. The overall SVR for genotypes 2 and 3 was 84%. Results based on viral load were: 88% SVR for patients with genotypes 2 and 3, low viral load; and 82% SVR for patients with a high viral load.

The analysis by histology found that 87% of those patients without cirrhosis or bridging fibrosis achieved an SVR, as opposed to 75% for those patients with bridging fibrosis or cirrhosis.

Safety

The reported adverse events (side effects) were mild to moderate in severity and were typical of those reported in previous clinical trials of Pegasys plus Copegus.

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Conclusion

The authors of this study concluded that the study demonstrated that treatment with Pegasys plus Copegus may be individualized by genotype.

Key Points

Sustained virological response (SVR) rates:

Overall SVR was 63%, which is the highest response rate ever re-reported in a hepatitis C treatment clinical trial.

- ◆ Genotype 1 = 52% SVR.
- ◆ Genotype 1, high viral load = 47% SVR.
- ◆ Genotype 1, low viral load = 65% SVR.
- ◆ Genotypes 2 and 3 = 84% SVR.

- ◆ Genotypes 2 and 3, high viral load = 82% SVR.
- ◆ Genotypes 2 and 3, low viral load = 88% SVR.

Treatment Duration and ribavirin dosage:

- ◆ Genotype 1 - 48 weeks with ribavirin dose of 1000-1200 mg/day.
- ◆ Genotype 2 & 3 - 24 weeks with ribavirin dose of 800 mg/day.

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*Real joy comes not from ease or riches or from the praise of others,
But from doing something worthwhile.*

Sir Wilfred Grenfell, English Medical Missionary

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10. Social Support Helps

The persisting stigma associated with AIDS induces many patients to conceal the diagnosis from friends

Adherence to HIV Regimens (cont.)

and family, making it impossible for them to seek their support. Patients may be reluctant to take medications openly and to store them in a common household area.

Family members and significant others can provide great support in the patient's adherence to the medication regimen by incorporating it into the routines of shared domesticity; those without such support often struggle alone.

For those without such a support network, peers, "buddies," and support groups can be useful and are often found through local community agencies and AIDS action groups. Many patients find information and support through the Internet. A patient's primary nurse can also help to establish an alternative support network by arranging for home visits and telephone calls.

A number of ongoing studies are examining the effectiveness of these interventions. In one model, as pre-

sented at the 13th annual conference of the Association of Nurses in AIDS Care (ANAC) in November 2000, a nurse and a peer educator visit patients at home to discuss medication regimen adherence, identify potential problems, and develop solutions. Preliminary results show that this approach promotes the development of self-care behavior conducive to medication regimen adherence.

Nurses have long been aware of the discrepancies between prescription and adherence in regard to medication regimens because they are charged with the responsibility of ensuring that treatments are carried out. Perhaps the most important point regarding adherence that nurses can take from their experience with HIV is that they already have the skills needed to help patients improve. At the beginning of the epidemic, nurses said, "Good AIDS care is good nursing care." This remains true as HIV transmutes into a chronic disease.

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*Walk on a rainbow trail,
walk on a trail of song,
and all about you
will be beauty.*

*There is a way
out of every dark mist -*

Over a rainbow trail.

Navajo Song