

HCV and Complementary and Alternative Medicine: Strategies for Serving our Clients

Lucinda Porter, RN

THERE IS MUCH INTEREST in Complementary and Alternative Medicine (CAM). Patients living with HCV often have questions about this area of health. Most of us have minimal knowledge about CAM. How to work with interested clients, what to tell them, and finding the answers to their questions are issues that confront us. The following offers some strategies when working with clients who are interested in CAM.

Start by setting aside your own biases. Even if you are an expert on a subject, none of us knows everything. If

ship faster than a closed mind. Keeping our own minds open is the best tool we have if we want others to do the same.

Listen and understand the questions. If we have an open mind, this is easier to do. However, sometimes our thoughts are elsewhere or we are in a hurry, so we are not paying close attention to what is really being said. Sometimes it helps to reflect questions back to clients, such as, "Let me see if I understand you correctly. You want to know if..."

Always be honest. If a client wants to know something

or "I will see if I can find some information on that."

As for specific CAM practices, my rule of thumb is this: Pretty much everything that goes into the body goes through the liver. CAM that does not go into the body is usually low risk. The risks increase when we put things into our bodies. I give a hearty endorsement to clients interested in acupuncture, chiropractics, Qigong, massage therapy, meditation, Reiki, Tai Chi, Therapeutic Touch, visualization, Yoga and other body-mind-spirit practices.

Become more involved when clients express interest in herbs and supplements. Identify the factors that motivate your clients to consider CAM. Everyone has his or her own reasons. Perhaps they can't or don't want to go through conventional medical treatment. Doing anything might make them feel like they are exercising some power over their disease. If this is the case, promote forms of CAM that do not pass through the liver or those that are the safest.

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HEPSQUADS

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you are an expert and opinionated about it, that can be both a burden and an asset. Nothing will sour a relation-

about a subject you know little or nothing about, admit that. You can say, either "I don't know much about that"

HEPSQUADS NEWS ROUNDUP

Liz Highleyman

HEPATITIS C TREATMENT NEWS

Peg-Intron plus Ribavirin for Children

Pegylated interferon plus ribavirin effectively treats chronic hepatitis C in children, according to a report in the May issue of *Hepatology*. Stefan Wirth and colleagues from Germany studied 62 children and adolescents (age 2–17) treated with Peg-Intron plus ribavirin for 48 weeks; 23 subjects who did not show an early response stopped therapy after six months. After a 24-week post-treatment follow-up period, 22 out of 46 children (48%) with genotype 1 HCV achieved sustained virological response (SVR), as did all 13 subjects with genotypes 2 or 3, and one of the two with genotype 4. This regimen is not currently approved for children, but some doctors prescribe it off-label since it is the preferred therapy for adults.

Shorter Treatment for Some Genotypes

Standard therapy for chronic hepatitis C lasts 48 weeks for genotype 1 and 24 weeks for genotypes 2 or 3. But recent studies suggest shorter treatment may be effective for these easier-to-treat genotypes. In a study by A. Tabaru and colleagues from Japan (reported in the April *American Journal of Gastroenterology*), 25 patients with genotype 2a received conventional interferon monotherapy for six or 24 weeks. The SVR rates—58% and 54%—did not differ significantly

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based on treatment length. In a larger study published in the June 23 *New England Journal of Medicine*, A. Mangia and colleagues from Italy looked at 283 subjects with genotype 2 or 3 treated with Peg-Intron plus ribavirin. Patients in group 1 received treatment for 24 weeks; those in group 2 stopped after 12 weeks if they had a good early response. Overall SVR rates were 76% for group 1 and 77% for group 2, but the relapse rate was higher in group 2 (8.9% vs 3.6%). Patients receiving shorter therapy had fewer side effects, were

less likely to require dose reduction, and were less likely to stop treatment prematurely. In contrast, researchers at the May Digestive Disease Week (DDW) conference reported that a shorter course of therapy is *not* advisable for patients with genotype 1, even if they have low viral loads. Among 235 genotype 1 patients with viral loads of 2 million copies or less receiving Peg-Intron/ribavirin, those treated for the usual 48 weeks had an SVR of 71%, compared with 50% among those treated for only 24 weeks.

Hepatitis C Treatment and Advanced Liver Disease

Because of their overall unstable health, it has traditionally been recommended that people with advanced liver disease should not receive interferon-based treatment for hepatitis C. But researchers continue to look for safe ways to treat this population. In the July *Journal of Viral Hepatitis*, F. Marrache and colleagues reported on a study of 80 chronic HCV patients with bridging fibrosis or cirrhosis treated with Peg-Intron plus ribavirin. The overall SVR rate was 36%. No serious clinical adverse events were observed, but 19% stopped therapy prematurely. The authors concluded that combination therapy “seems effective” in this population and “is safe with appropriate monitoring.” Even patients with decompensated cirrhosis may benefit from treatment, according to data presented at DDW. In a trial of 32 patients with decompensated cirrhosis treated with pegylated interferon/ribavirin (78%), pegylated interferon monotherapy (13%), or conventional interferon/ribavirin (9%), the overall SVR rate was 31% (21% for genotype 1; 54% for other genotypes). Most patients (84%) experienced some adverse event and 19% discontinued due to side effects. But five patients (16%) were taken off the transplant waiting list due to improved liver function—very encouraging news for patients with end-stage liver disease.

Genes Predict Interferon Response

In the early May issue of *Gastroenterology*, Limin Chen and colleagues reported that a pattern of genes in the liver may help predict which individuals will respond to interferon. The researchers used PCR testing to analyze gene expression in liver biopsy specimens from 16 HCV positive interferon responders, 15 HCV positive nonresponders, and 20 HCV negative subjects. Out of some 19,000 genes examined, they identified 18 that differed significantly between all responders and all nonresponders. A subset of eight genes

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COMPLEMENTARY AND ALTERNATIVE MEDICINE

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If your client wants to take something “*because it is natural*,” teach them that *natural* does not mean *safe*. If your client wants to try a supplement based on a friend’s endorsement, teach them that supplements are like drugs—one size does not fit everyone.

Try to give something rather than take something away. For instance, if an HCV client wants to use colloidal silver—which can cause serious side effects—suggest other options. Perhaps something safer such as daily meditation and visualization will appeal to them. It will also save them some money. If your sense is that they really just want to take a pill, then vitamin E might be a better choice. However, all dietary substances carry risks and none has been proven to have any benefit to HCV patients.

Assemble an arsenal of resources. Reliable Internet resources are good ways to obtain information that can be printed and given to clients. Identify your local experts. Obtain literature from reputable sources, such as the Hepatitis C Support Project.

Locate free or low cost CAM providers in your area. There are a number of CAM programs across the country. Some are affiliated with major colleges and universities, such as Stanford and Harvard. Clinical trials sometimes need volunteers. Occasionally there is even a small amount of money given to cover transportation expenses.

Schools that teach massage therapy and body work sometimes offer free or low-cost services. The same is true for schools of acupuncture and Chinese Medicine. Some CAM practitioners have sliding fee scales, some occasionally waive their fees for extreme hardship cases. These options are not advertised. Encourage your clients to ask individual providers if fees are negotiable.


Many community hospitals and health centers have health libraries. The public library is another resource. In addition to books and magazines, most libraries offer free Internet access. If you need some guidance, librarians are generally very helpful.

Remember that your clients are free to make their own choices, even if those choices have risks attached to them. If they still want to pursue options, after all you have done to inform them, maintain your compassionate professionalism. If your client did not follow your advice but has a successful outcome, this is cause for celebration. Admitting we learned something new can deepen our relationships. If there is a negative outcome, never, ever say, “I told you so.” This can cut off trust, which is the foundation of healing relationships. Maintaining neutrality may influence your client’s decisions to follow your advice in the future.

For more information about CAM, see the HCSP Factsheets:

- CAM: Complementary and Alternative Medicine
- Hepatitis C and CAM: Complementary and Alternative Medicine Resources
- Hepatitis CAM: CAM Information and Finding a Practitioner

Clinical Trial Resources:

- Check local newspapers
- CenterWatch: www.centerwatch.com
- National Institutes of Health (NIH) Clinical Trials: www.clinicaltrials.gov
- National Center for Complementary and Alternative Medicine (NCCAM): nccam.nih.gov
- NCCAM Clearinghouse, P.O. Box 7923, Gaithersburg, MD 20898-7923 (888) 644-6226; TTY (for deaf and hard-of-hearing callers) (866) 464-3615 

Important Notice to our Readers

The Hepatitis C Support Project (HCSP) training workshops continue to expand across the United States. In the beginning HCSP made a commitment to provide a hard copy of the HepSquads training newsletter free of charge to all HCSP certified trainers. However, since we now have over 3,000 HCSP certified trainers, the cost of printing and mailing the newsletter has become prohibitive. After reviewing our files we have found that over 98% of the subscribers have access to the internet to download the newsletter for their personal and professional use.

Beginning October 2005, the HepSquads newsletter will be web-based only. We will make every effort to provide the newsletter to people who do not have access to a computer. If you do

not have access to a computer, please fill out the attached form and mail it to HCSP, PO Box 427037, San Francisco, CA 94112. Donations to help defer some of the costs will be greatly appreciated.

NAME

ADDRESS

CITY/STATE

ZIP CODE

NEWS ROUNDUP

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accurately predicted treatment response for 30 of the 31 HCV positive subjects. The authors predicted that in the future, a simple blood test might be used to predict who will respond to interferon, sparing likely nonresponders the side effects and expense of treatment.

DRUG SIDE EFFECTS AND INTERACTIONS: READ THE FINE PRINT

Newspapers have been full of stories recently about dangerous and unexpected medication side effects. Adverse effects and drug interactions are a special concern for people with liver disease, since a damaged liver can have trouble processing drugs. Detailed information about potential side effects and interactions can be found in the package insert that comes with all approved medications. The July *HCV Advocate* offers some helpful tips for deciphering this often confusing information.

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SEAFOOD SAFETY

For many people, summer means seafood. But eating raw or undercooked seafood can be risky for people with hepatitis C or other types of liver disease. Seafood may be contaminated with a variety of disease-causing organisms, including *Vibrio* bacteria and hepatitis A virus; shellfish such as oysters, clams, and mussels carry the greatest risk. While the most common consequence of seafood poisoning is abdominal distress, people with liver damage or compromised immune systems are at much higher risk for serious illness and death. See the July *HCV Advocate* for more information on seafood-borne illness and how to prevent it.

CANNIBUS CAUTION

Medical marijuana was front-page news this summer, as the Supreme Court ruled on June 7 that the federal government may prosecute medical cannabis users and providers despite state laws. While many patients successfully use medical marijuana for indications such as relieving chronic pain and

combating wasting, a study the July *Hepatology* suggests people with hepatitis C should be cautious about cannabis. Researchers from France examined liver biopsy specimens from 270 HCV positive subjects. Those who used cannabis daily were more likely to have severe fibrosis and were at higher risk for rapid fibrosis progression compared with those who used marijuana only occasionally or not at all. While this association does not necessarily imply that marijuana causes fibrosis, the researchers suggest that patients with chronic hepatitis C should “refrain from regular cannabis use.”

DEPRESSION MANAGEMENT

In the June *Journal of Hepatology*, Martin Schaefer and colleagues from Berlin reported on a study of pre-emptive antidepressant therapy to prevent depression during hepatitis C treatment. Before starting pegylated interferon/ribavirin, 14 patients with pre-existing psychiatric conditions received 20 mg daily of the SSRI antidepressant citalopram (Celexa), which they continued to take during anti-HCV therapy. Subjects who took citalopram were significantly less likely to develop major depression during the first six months of anti-HCV treatment, compared with HCV patients with pre-existing psychiatric disorders who did not receive an antidepressant and patients without psychiatric risk factors (14%, 64%, and 55%, respectively). In an editorial in the same issue, Yves Horsmans concluded that new insights into the mechanisms and treatment of interferon-induced depression should allow more patients to be effectively treated for hepatitis C.

CONFERENCE COVERAGE

The 2005 European Association for the Study of the Liver (EASL) conference took place in Paris April 13–17, followed the next month by the annual DDW meeting, May 14–19 in Chicago. For more extensive coverage of these meetings, see the May, June, and July issues of *HCV Advocate* and the Conference Reports section of the *HCV Advocate* web site.

Factors Affecting Treatment Response

While many promising agents are in development, pegylated interferon—Peg-Intron or Pegasys—remains the mainstay of hepatitis C treatment; researchers at both conferences presented new data from both older trials and more recent trials. EPIC3 is an ongoing study evaluating Peg-Intron/ribavirin in nonresponders and relapsers. After 48 weeks, 21% of 978 patients achieved SVR (14% for genotype 1, 56% for genotypes 2 or 3). Previous relapsers were more likely to achieve SVR than complete nonresponders (41% vs 14%), and people with mild-to-moderate fibrosis had a higher SVR rate than those with more advanced liver damage (26% vs 15%).

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NEWS ROUND UP

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Researchers studying Pegasys/ribavirin in 422 patients with persistently normal ALT found that younger individuals were more likely to achieve SVR: 54% for genotype 1 subjects under age 40 vs 34% for those over 40 (79% vs 69%, respectively, for those with genotypes 2 or 3). Not surprisingly, good adherence also leads to better treatment outcomes. An analysis of two large Pegasys/ribavirin studies (569 subjects) found that 66% of patients who took greater than 97% of their recommended dose of ribavirin achieved SVR, compared to only 33% who took less than 60% of their prescribed ribavirin dose; ribavirin is known to help prevent relapse.

Being overweight is associated with lower response rates, but body weight is not the only culprit. Looking at 2,404 patients in two multinational Pegasys studies, researchers found that heavier patients were also more likely to be male and Black, were more often infected through injection drug use, and were more likely to have cirrhosis—all factors associated with poorer treatment response—illustrating the importance of controlling for confounding variables in clinical trials. Finally, researchers reported that African-Americans who previously did not respond to therapy may benefit from more aggressive treatment with higher doses of pegylated interferon. Among 113 African-American subjects in the RENEW trial, 16% of those retreated with weekly high-dose (3.0 mg/kg) Peg-Intron achieved SVR, compared with just 4% of those retreated with 1.5 mg/kg.

Experimental Agents

Researchers at both EASL and DDW reported on several investigational drugs for hepatitis C. For an overview of the HCV life cycle and how experimental drug classes work, see the June *HCV Advocate*.

Viramidine is a prodrug of ribavirin that causes fewer side effects. Researchers at EASL reported on a study of 171 previously untreated patients who received either 1000–1200 mg daily ribavirin or else 400, 600, or 800 mg viramidine twice daily (all in combination with pegylated interferon). The 600 mg dose of viramidine performed best; SVR rates for genotype 1 (treated for 48 weeks) were 27% for viramidine and 35% for ribavirin; rates for genotype 2 or 3 (treated for 24 weeks) were 62% and 73%. Hemolytic anemia was less common in the viramidine arm. Larger Phase III trials are underway.

Albuferon is a form of long-acting interferon combined with albumin (a human blood protein). In a Phase II study of 56 previously untreated genotype 1 patients receiving Albuferon, HCV viral load decreased by 99.9%

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Upcoming Trainings

August 9th
Columbus, Ohio

August 11th
Columbus, Ohio

August 22nd
Detroit

August 24th
Decatur, Georgia

August 26th
Valdosta, Georgia

September 20th
Newark, New Jersey

September 21st
Camden, New Jersey

September 22nd
Atlantic City, New Jersey

October 6th
Boston, MA

Coming in 2005

Syracuse, NY

Buffalo, NY

Nashville, TN

Sacramento, CA

The Hepatitis C Support Project Train the Trainer Workshops have certified over 3,000 individuals as Basic HCV Educators

NEWS ROUND UP

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after four weeks; after 42 days, 23% of subjects remained HCV negative. The drug appeared safe and well-tolerated. Because it has a long half-life in the body, the researchers concluded that Albuferon could be injected every 2–4 weeks. Human Genome Sciences recently announced the start of a Phase IIb trial of Albuferon plus ribavirin.

Researchers at DDW presented data from a Phase Ib placebo-controlled dose-ranging study of **Actilon** (CPG 10101) in 42 nonresponders to previous anti-HCV therapy (most with genotype 1). The greatest decline in HCV RNA was seen with the 20 mg twice weekly dose; subjects in this arm achieved a maximum 96% reduction in HCV viral load within four weeks, and five out of six saw at least a 90% decrease. The drug was generally well-tolerated. Coley Pharmaceutical Group plans further studies of CPG 10101 both as monotherapy and in combination with interferon/ribavirin.

Idenix Pharmaceuticals' **valopicitabine** (NM283) is an oral nucleoside analog that works by interfering with the HCV polymerase enzyme. Preliminary Phase IIa data were presented at EASL for nine previously untreated genotype 1 patients who completed 24 weeks of treatment with valopicitabine plus pegylated interferon. HCV RNA declined more than 99.9% and no serious adverse events were reported. A larger trial of valopicitabine in pegylated interferon/ribavirin nonresponders is underway.

Promising data on **VX-950**, an oral protease inhibitor, caused a stir at DDW. In a Phase Ib study, 34 genotype 1 patients (treatment naive or previous nonresponders) and eight HCV negative volunteers received 450 mg VX-950 thrice daily, 750 mg thrice daily, 1250 mg twice daily, or placebo, for 14 days. The three-times-daily 750 mg dose was most effective, producing a median 10,000-fold reduction in viral load. No serious adverse events were reported and there were no treatment discontinuations. Vertex Pharmaceuticals is planning further studies of VX-950 both alone and in combination with currently approved anti-HCV medications.

While much of this research appears promising, drug development is a painstaking process, and it may be five years or more before these agents are commercially available. Thus, it is important for people who need hepatitis C treatment now—those with progressing liver damage—to start with what's currently available, rather than waiting for something better to pop out of the pipeline.



ATTENTION HCSP TRAINERS: *Recertification Forms Now Online*

In an effort to help simplify the training recertification process we are providing a mechanism for recertification through the mail.

Please go to the HCV Advocate Web site Online Education Page at www.hepeducate.org/certification/index.php for instructions on how to obtain recertification by mail.

You will be instructed to:

- Fill out the Application for recertification
- Complete one of HCSP's HCV Advocate online courses (copy of certificate required)
- Complete "POA Outcome Efforts" by listing (in detail) how your last Plan of Action objectives were completed
- List three **NEW** objectives on the "Plan of Action" form (in detail).

Send a copy of the documents to:

Hepatitis C Support Project

PO Box 427037

San Francisco, CA 94142-7037

Enhancing Hepatitis C Presentation Skills

Heather Lusk

AN EFFECTIVE PRESENTER

has a strong knowledge base about hepatitis C, skills to convey information in a clear and concise way, an ability to connect with groups and involve them in the learning process, and is comfortable with public speaking. Strong presentation skills allow the message to be heard, while a weak presentation style detracts from the content to focus on the delivery. The goal is to achieve a seamless presentation style where participants do not notice the skills used to share hepatitis C information, or any verbal or nonverbal distractions, but are able to focus on integrating the new knowledge.

Nonverbal presentation skills include body language, eye contact with participants, hand movements, physical position in the room, and the amount of movement during the presentation. While it may be intimidating to think about participants looking at you constantly during the presentation, they are—so you might as well think about this while planning the presentation. Some presenters even consider the color of their outfit or the impact of patterns on learners, or they wear flashy jewelry to maintain attention. Be aware of any habits you may have that could distract the participants, such as playing with your hair, biting your nails or covering your mouth.

If possible, rotate your eye contact to connect with as many participants as possible—

it helps them feel connected to the process. This is especially important when a participant is talking; make sure to pay attention to them by nodding or with other active listening techniques. Your posture should be relaxed, and smiling can encourage the group to relax. Moving around keeps people engaged, especially in large rooms where many participants are far away from the presenter. Walking around the sides of the room, if possible, connects you with

flexion, speaking pace and articulation, speaking volume and projection. Engaging presenters are aware of their voice tone and find a balance that is neither a boring monotone nor a high-pitch squeal. Using different inflections and emphasis on particular words help participants remember key points, and clear articulation and pronunciation decrease confusion. Finding a balance in regards to how slowly or quickly you speak is impor-

tant, especially for participants for whom English is a second language. Most nervous presenters tend to speak quickly which may make it challenging for participants to follow along. Taking frequent deep breaths can help slow down the pace of speaking. There may be times (such as after lunch) when the energy is low in the room and speaking quickly may increase alertness.

to speak loudly, projecting to the back of the room. Asking participants periodically if they can hear you in the back is important as people can't be engaged in learning if they cannot hear. Make sure to turn and speak towards different parts of the room, especially if you are unable to move around the room to include the entire group. Pay attention to any "filler words," such as like, um or you know. These seemingly benign words start to affect learners' ability to stay focused on content once they have been uttered 20 or 30 times during a presentation.

Getting feedback on your presentation style is essential. Ask friends and colleagues to give you specific feedback on what you did well and what you can work on. Many experts in the field of hepatitis C have lost their audiences because of a lackluster presentation style. Once you are comfortable with the hepatitis C content you are presenting, spend time assessing your personal style to figure out what you will need to balance in order to not distract from your message. While there is no one perfect presentation style, the more you practice and focus on presentation techniques, the more likely the audience is to learn from your knowledge and insight about hepatitis C. □

Verbal presentation skills include voice tone and inflection, speaking pace and articulation, speaking volume and projection. Engaging presenters are aware of their voice tone and find a balance that is neither a boring monotone nor a high-pitch squeal.

more participants than standing behind a podium the entire time. Silence can be a powerful tool, allowing the group to contemplate the topic and encouraging group participation. Many presenters suggest videotaping a session to review for body language and other nonverbal traits, and others suggest practicing in front of a mirror to see what participants see during your presentations.

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Making a Difference in Your Community.

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