

Belief Systems: One Person's Perspective

Lucinda Porter, RN, BA, CCRC

IN THE COURSE OF WORKING with others, sometimes we encounter beliefs that differ radically from our own. Some differences may seem downright absurd. Patients have told me about a variety of ways they have tried to restore their health. These included eating raw pig liver, drinking one's own urine, and wearing various objects. The fact that I use these examples exposes my biases. In short, I have a hard time believing that these approaches will positively influence anyone's health. They also may be dangerous, particularly if a patient simultaneously ignores medical advice.

It is human to form judgments. However, nothing will shut down effective communication more quickly than reacting with disapproval. It is unlikely that a client will reveal much if it is thought that the disclosure will be met with criticism. As health educators and community outreach workers, our professional and compassionate responsibility is to leave our judgments aside and to

maintain open lines of communication. I am not suggesting that we endorse or support a health practice that we don't believe in or agree with. What I am saying is that we must maintain respect and compassion while putting judgments aside.

A mentor once said "be careful not to take away anyone's image of God unless you offer something better to replace it with."¹ This concept may apply to other

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belief systems, such as beliefs about health. The power of belief may produce its own

kind of medicine. A good example of this is the *placebo effect*. A *placebo* is a pill or treatment that has no treatment value. It is used in research when studying something of potential therapeutic value. Research has shown that patients who believe a medication will work can have positive results if they believe they are taking the active study drug, even if that medication is basically a "sugar pill."

The reverse is also true. If patients doubt the therapeutic value of a drug, their thinking may influence the effectiveness of that medication. The belief can be negative or positive, as in trusting or doubting the ability of a treatment to succeed. If a medical provider maintains certain beliefs about a therapy, this may influence the outcome of that treatment. We give subtle, unconscious cues to patients.

Belief can't always influence an outcome. In other words, sometimes a medication won't work because it just isn't going to work.

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HEPSQUADS NEWS ROUNDUP

Liz Highleyman

NEW FDA APPROVALS FOR VIRAL HEPATITIS

On February 25, the Food and Drug Administration (FDA) approved Roche's Pegasys brand of pegylated interferon plus ribavirin (Copegus) for the treatment of chronic hepatitis C in patients coinfecting with HIV. The approval was based on data from the APRICOT trial showing that 40% of 868 HIV/HCV coinfecting subjects treated with Pegasys plus ribavirin achieved sustained virological response with a 48-week course of therapy (29% for genotype 1; 62% for genotypes 2 and 3). This is the first hepatitis C treatment to be approved for coinfecting individuals; the combination was also recently approved in Europe.

The following month, on March 29, the FDA approved Bristol-Myers Squibb's nucleoside analog entecavir (brand name Baraclude) for treatment of chronic hepatitis B in adults with active HBV replication plus either persistently elevated ALT or histological evidence of liver disease progression. Studies have shown that entecavir lowers HBV viral load more than lamivudine (Epivir-HBV) in subjects with hepatitis B alone, and is also effective in HIV/HBV coinfecting patients previously treated with lamivudine. Full prescribing information for entecavir is available at www.baraclude.com.

PEGYLATED INTERFERON FOR HEPATITIS B

According to a large international study, a mainstay of hepatitis C treatment also works against chronic HBe-Ag-positive hepatitis B. As reported in the January 8 issue of *The Lancet*, Schering-Plough's Peg-Intron brand pegylated interferon produced sustained response rates "as high as or higher than that reported for any other therapy" for HBV. In this study by H.L. Janssen and colleagues, which included 300 subjects in 15 countries, patients receiving both Peg-Intron and lamivudine achieved comparable virological response rates six months after the end of therapy (35% vs

36%, respectively), although subjects in the combination arm were more likely to experience an end-of-treatment response.

As is true for HCV, response rates varied according to HBV genotype. Another study, reported in the February 15 *Annals of Internal Medicine*, found that the Peg-Intron/lamivudine combination was more effective than lamivudine monotherapy (SVR 36% vs 14%, respectively). Roche's Pegasys was recently approved in Europe for the treatment of chronic hepatitis B; U.S. approval is expected later this year.

SEXUAL TRANSMISSION OF HCV

The issue of sexual transmission of hepatitis C continues to generate controversy. Most studies show very low rates of sexual transmission within monogamous heterosexual couples, but the picture remains less clear for men who have sex with men (MSM). In the past year several new HCV infections among gay and bisexual men in the U.K. and France have been potentially linked to sexual activity. At the 2005 Conference on Retroviruses and Opportunistic Infections (held February 22-25 in Boston), researchers from Necker Hospital in Paris presented data on a cluster of 12 HIV positive men diagnosed with recent HCV infections. Male-to-male sex was "the only significant risk factor" reported. Ten out of the 12 had genotype 4d, suggesting a common source of infection. Also, in a study of 1,347 initially HCV negative heterosexual subjects and 1,542 gay or bisexual men in the Swiss HIV Cohort, the HCV incidence rate was 0.2 per 100 person-years among the heterosexuals and among gay or bisexual men who did not report unprotected sex. But among the gay or bisexual men who did report unprotected sex, the rate was 0.7 per 100 person-years.

However, in the largest study to date of HCV transmission among MSM, researchers in Montreal found little evidence that sex plays a role. They looked at 1,085 men tested for HCV between January and September 2001. Most (92%) reported anal sex and a majority (63%) reported unprotected anal sex; more than 40% reported at least 50 lifetime sexual partners. Within this sexually active group, only one new HCV infection was detected during the eight-month follow-up period (an incidence rate of 0.038 per 100 person-years), occurring in an injection drug user who reported sharing needles. After controlling for injection drug use, sexual behavior was not significantly associated with hepatitis C. The researchers concluded that, "Sexual transmission of HCV among MSM appears to be rare."

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Other times a placebo might seem effective when there may be other factors at play. The ability to use one's mind to influence matter is not reliable. It's important to guard against the belief that we can think our way through any situation or disease. If that were true, we wouldn't need the medical profession and we would live forever. And although the mind is a powerful ally, we can use this concept against ourselves if things don't work out the way we hoped. We may be tempted to blame ourselves for not being positive enough. This thinking just makes us feel bad and feeling bad about ourselves is counterproductive—moving us further away from health.

So how do we support those whose beliefs differ from our own, especially if that someone is practicing a behavior that is potentially dangerous? Start by examining your own ego, and motives, along with your own belief systems. Knowledge is power and it can be tempting to use that power to try to influence others. If you are well-educated, you have been given a gift, but even a fabulous education does not give anyone the right to exercise personal power over others. Ask yourself if you believe your education and knowledge have bought you the right to influence others. I don't believe so. My opinion is that relationships are built on trust and trust needs to be earned. Knowledge can be a tool to help build that trust. Knowledge can also be the step used after trust is earned. But without trust there is no place for knowledge to take root.

Also check to see if your own ego is invested in the process. Look very carefully here. It may seem perfectly innocent to say our goal is "to help people" but sometimes this motive can be a disguise for our own egotistical drives. We all have egotistical tendencies. However, if you believe in client-centered healthcare, then leave your ego out of the relationship.

Now let's look at some practical matters. Say that your client has just told you that she heard that eating fresh butterfly wings every day will cure hepatitis C (HCV). She asks you for your opinion on this. First and foremost, do not laugh or let your face register any horror. If you do react, promptly explain that although you have trouble believing the idea will work, you are not laughing at her. Only say this if it is the truth. If the picture of your client prancing around meadows with a butterfly net is just too much to bear, you may have to excuse yourself for a minute in order to recompose yourself.

Here are some suggestions on how to stay composed:

- Tell yourself that this patient may be frightened. Fear can drive people to consider desperate measures.
- Keep in mind that your client is looking for a way to

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hepatitis C **BASICS**

hcsp
• **FACT** •
sheets

easy **C** *facts*

*are publications of the
Hepatitis C Support Project.*

*They are a series of fact
sheets written by experts
in the field of liver disease.*

*They are available for printing
in English and Spanish at*

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**To see the dates and locations of upcoming
HCSP Trainings, please visit**

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exercise power over her health. She may be in pain, dying, or afraid she may be dying.

- Put yourself in your client's shoes. How would you feel if you consulted a professional and they sneered at one of your questions or ideas?
- Remind yourself that the client is in control of her wellbeing. Your client is free to accept or reject your advice. You may have the power to influence her choices, but ultimately not the control. If you bruise the relationship by being judgmental, you will lose the power to inspire change.
- Caution yourself that although you believe the idea has no merit, you really don't know for sure until you research the idea.
- If it is too difficult for you to maintain a compassionate and professional composure, refer the client to someone else. However, before doing that, contact your referral and see how they feel about the particular situation. Before contacting your referral, make sure you comply with your agency's privacy disclosure regulations, particularly HIPAA².

It may be useful to find out how the client acquired this notion. For instance, if it was something that the owner of the local health store told her, I might volunteer that I personally don't act on advice from people who work in retail. I figure that they are in the business of selling products. They may believe in the products they sell, the products may be excellent, and perhaps they even work, but I don't act on the opinion of salespeople or manufacturers. I prefer to act on independent research. I suggest the client return to the source of information and try to obtain some resources on the subject. In short, I use the opportunity to teach some critical thinking.

If there are cultural reasons for the use of butterfly wings,

I tread very carefully. Many cultures have their own beliefs that have been around for centuries. Being judgmental of a cultural practice can really damage a relationship.

I would proceed by telling the client what I know about the subject. If I know absolutely nothing, I readily admit that. However, if I actually know something, then I will discuss it.

Caution yourself that although you believe the idea has no merit, you really don't know for sure until you research the idea.

If the client asks me to find out more about the effect of butterfly wings on HCV, then I will try to do this. If I don't have the time to do this, I encourage the client to do her own research. Some communities and hospitals have health libraries and resource centers. Public libraries usually offer free Internet service. I may offer to review any literature that she obtains.

At no time do I convey any disapproval. My goal is to build trust and then, when the client is ready, she may take my advice. I try to keep my approach as non-threatening as possible. Since belief is a powerful force, I want to be included in the client's belief system.

There is an old joke that says what is written on the hypochondriac's tombstone is, "See? I told you I was sick." This joke goes a step further than mere amusement, it imparts a little wisdom. Perhaps the cause of death for the hypochondriac was aided by a negative belief system. Or perhaps the hypochondriac's time was up. We'll never know.

1 This may have been first said by Sigmund Freud, but I was unable to find any documentation to support this.

2 HIPAA stands for the Health Insurance Portability and Accountability Act of 1996. HIPAA regulates how health organizations handle patient information.

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- Identify persons at risk or needing care for HCV.
- Create a counseling plan for prevention and management of HCV in persons at risk, needing treatment, or receiving treatment.

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NEWS ROUNDUP

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COINFECTION AND DISEASE PROGRESSION

Another issue that has provoked ongoing debate is whether HCV infection worsens HIV disease progression. While some studies suggest that coinfection accelerates immune system decline and progression to AIDS and death, others have reached the opposite conclusion. In a prospective study of the Women and Infants Transmission Study cohort (published in the March 15th *Clinical Infectious Diseases*), which enrolled 652 pregnant women with HIV (29% coinfecting with HCV) between 1989 and 1995, R.C. Hershow and colleagues found that HCV/HIV coinfecting women did not experience faster HIV disease progression. The coinfecting women had viral loads similar to those of women with HIV alone, and had slightly higher CD4 cell percentages. The researchers concluded, "In this large cohort of HIV-infected women, we found no evidence that hepatitis C virus coinfection hastens progression of HIV disease."

On the other hand, evidence continues to accumulate that HCV-related liver damage progresses faster in people with HIV. At the February Retrovirus conference Mark Sulkowski and colleagues presented some of the clearest evidence yet that liver disease can progress surprisingly fast in HCV/HIV coinfecting individuals. They followed 67 coinfecting subjects who received paired liver biopsies an average of two years apart. More than one-quarter (28%) had fibrosis scores that increased by at least two stages from one biopsy to the next. Patients who experience a two-stage or greater increase in fibrosis score were more likely to have higher HIV viral loads, but there was no significant association between rapid progression and use of anti-HIV therapy or CD4 count. The researchers said their data "do not support the application of current HCV treatment guidelines"—which state that people with minimal fibrosis generally can defer hepatitis C therapy—to coinfecting individuals, and recommended that "such patients should be closely monitored for liver disease progression."

RISK FACTORS FOR LIVER CANCER

Several recent studies have looked at various risk factors for hepatocellular carcinoma (HCC), a type of liver cancer linked to chronic viral hepatitis. Among them: alcohol, tobacco, and obesity, which appear to interact in a synergistic way. In a study published in the February 2005 *Journal of Hepatology*, Jorge Marrero and colleagues reported that alcohol ups the risk of HCC by 6-fold, tobacco by 5-fold, and obesity by 4-fold. A study in the April 2005 issue of *Gut* found that diabetes is associated with a 2- to 3-fold increase in HCC risk. Obesity, insulin resistance, and diabetes are associated with steatosis (fatty liver) and worsened liver

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one day workshops 2005

April 28, 2005 – Philadelphia

April 29, 2005 – Philadelphia

May 3, 2005 – Seattle/Tacoma

May 3, 2005 – Las Cruces, NM

May 5, 2005 – Las Cruces, NM

May 25, 2005 – Espanola, NM

May 27, 2005 – Albuquerque, NM

August 9, 2005 – Columbus, OH

August 11, 2005 – Columbus, OH

coming soon

Nevada

St. Louis, MO

Nashville, TN

Atlanta, GA

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fibrosis. For a thorough review of liver cancer risk factors, see the February 2005 *HCV Advocate*.

HEPATITIS C IN INJECTION DRUG USERS

The April 15 supplemental issue of *Clinical Infectious Diseases* was devoted to hepatitis C in injection drug users (IDUs). Noting that "[m]ost HCV infections are due to injection drug use, and most IDUs have HCV infection," Sulkowski and D.L. Thomas concluded that this population "require[s] considerable, multidimensional support." Quantifying the problem, M. Fireman and colleagues found that 93% of nearly 300 patients at a Portland veterans' hepatology clinic had a current or past history of at least one psychiatric disorder; the most common were depression (81%), post-traumatic stress disorder (62%), substance use disorders (58%), and bipolar disorder (20%). Surveying IDUs in three U.S. cities, Stephanie Strathdee and colleagues found that while more than 80% were interested in HCV treatment,

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M. Backmund and colleagues discussed the need for interdisciplinary collaboration among hepatologists, addiction specialists, social workers, and psychotherapists. They found that IDUs receiving drug substitution (e.g., methadone maintenance) can do as well on hepatitis C therapy as non-IDUs. Australian researchers found that patients who continue to inject drugs infrequently can still achieve sustained response to HCV treatment. However, C.A. Fleming and colleagues, describing their experience at Boston Medical Center, characterized their attempts to treat hepatitis C in a population of HCV/HIV coinfecting IDUs as "largely unsuccessful," due to barriers such as patients' limited ability to navigate the health-care system and pay for services, failure to attend scheduled clinic appointments, active psychiatric conditions, continuing drug or alcohol use, anxiety about treatment-related side effects, and inability to tolerate therapy. However, they concluded, "Many of these barriers to treatment are potentially modifiable, leading to the possibility that, with appropriate interventions, treatment rates may be increased."

To this end, Strathdee's team recommended improved communication between patients and providers, and integration of hepatitis C and substance abuse treatment programs. Brian Edlin and colleagues presented an overview of how successful programs—whether in primary care settings or correctional facilities—can integrate substance-abuse treatment, psychiatric care, social support, liver disease evaluation, and medical management of hepatitis C. Presenting a successful example of such a strategy, L.E. Taylor reported that in one such integrated program—in which HCV/HIV coinfecting IDUs were given directly administered pegylated interferon at weekly clinic visits and a week's worth of ribavirin in pill boxes—none of the patients had to stop therapy due to ongoing drug use, addiction relapse, or psychiatric complications.

For more information on HCV management in IDUs, see the Hepatitis C Harm Reduction Project's new brochure, "Nine Tips for Treating Hepatitis C in Current and Former Substance Users," available at www.hepcproject.typepad.com/hep_c_project/9_tips_brochure.pdf.

CALIFORNIA CITIES APPROVE NEEDLE SALES

In the wake of last fall's passage of a new California law (SB1159) allowing cities and counties to authorize the sale of up to 10 syringes in pharmacies without a doctor's prescription, several localities have moved to implement the legislation. On March 22, the San Francisco Board of Supervisors voted to allow Walgreens and Rite-Aid pharmacies to sell non-prescription needles. The Los Angeles City Council approved non-prescription needle sales on March 9, and the Board of Supervisors of Alameda County (which includes Oakland and Berkeley) followed suit on March 29. Sharing needles to inject drugs is one of the most common routes of hepatitis C, hepatitis B, and HIV transmission. Many studies have shown that wider availability of clean needles reduces disease transmission without increasing drug use.

FEDERAL HEPATITIS C LEGISLATION REINTRODUCED

In March, Senator Kay Bailey Hutchison (R-TX) reintroduced the Hepatitis C Epidemic Control and Prevention Act (S-521). The bill, which was originally introduced in 2003 but so far has failed to pass, calls for a comprehensive federal hepatitis C program which would include counseling and testing, early detection, epidemiological surveillance, public education, training of health-care professionals, and increased research. The program was conceived by the National Hepatitis C Advocacy Council, a coalition of 20 hepatitis C organizations including the Hepatitis C Support Project. The bill is cosponsored by a dozen senators from both major political parties. Companion legislation, known as HR-1290, has also been introduced in the House of Representatives. □

easy C facts

African Americans & HCV

Hepatitis C affects some groups of people differently than others. There are differences in the number of people infected with hepatitis C and how well current HCV medicines will work in certain groups. This fact sheet is about African Americans and hepatitis C.

More than twice as many African Americans have been infected with hepatitis C than whites. That means that out of the 4 million Americans infected with hepatitis C, 880,000 are African Americans.

African Americans are also more likely to be infected with a certain strain of hepatitis C called genotype 1. In the general population with hepatitis only about 7 out of 10 people have genotype 1, but about 9 out of 10 African Americans are infected with genotype 1—the hardest genotype to treat with current HCV medicines.

The good news is that many experts believe that hepatitis C disease may advance more slowly in African Americans than in whites. The reason for this is not clear and there needs to be more information to really confirm this fact.

In general, it is more difficult to treat or get rid of HCV in African Americans than it is for whites with current HCV medicines, but the types of medicines called pegylated interferon (once a week injection or shot) when taken with ribavirin (pill and capsule) are a great improvement over medicines in the past.

Make sure that you talk with your doctor about ways to keep yourself healthy and whether you should be treated with the new medicines.

Feeling Tired?

Some people with hep C say they feel tired a lot. The medical term for this is fatigue. Hep C can make people feel tired. But so can a lot of other things. If you have hep C and are often tired, don't blame it on the hep C unless you are sure nothing else is causing your fatigue.

Here are a few things that can cause fatigue:

- Not enough or poor quality sleep
- Certain drugs and alcohol
- Stress and depression

- Other diseases
- Pain
- Not enough exercise
- A poor diet
- Not drinking enough water and fluids

If you have fatigue, here are some suggestions:

- Talk to your doctor. Make sure you don't have another health problem.
- Avoid or reduce alcohol and non-prescribed drug use.
- Find ways to relax.
- Ask for help.
- Try to rest before you get too tired.
- Spend 5 or 10 minutes in the sun.
- Practice deep breathing for a minute whenever you feel tired.
- Drink lots of water. A half to a whole gallon a day is about right for most folks.
- Try to eat the healthiest foods you can. Fruits and nuts are good choices.
- Try some light exercise every day. Start with 10 to 15 minutes one or two times a day. You don't even have to do this all at once. A 5 minute walk is better than no walk at all.
- Take short naps—no more than 20 minutes and not close to bedtime.
- Take a shower. Change water temperatures from hot to cold.



Medical Writers' Circle

is a publication of the Hepatitis C Support Project. It consists of a series of articles written by medical professionals about the management and treatment of hepatitis C. The articles are available for printing at the Hepatitis C Support Project website.

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