

A LOOK INTO THE FUTURE

Lorren Sandt

Introduction

Hepatitis C is a major global health problem. More than 180 million people worldwide are infected with the *hepatitis C virus* (HCV). An estimated 3 to 4 million people are newly infected each year.¹ Yet hepatitis C is largely a preventable disease. Prevention requires multilevel education programs, rigorous efforts to protect the blood supply, and intervention programs for at-risk populations.

Despite significant advances in hepatitis C diagnosis and treatment, there is still much to be learned. Research is being conducted on several fronts in the race to gain control over the virus. *Advocates* are working diligently to raise public awareness and provide information to the millions of people infected with HCV. Healthcare providers from all healing disciplines are looking for better ways to treat people living with hepatitis C.

So, where do we go from here?

Information and Awareness

Despite the fact that most new cases of hepatitis C are preventable, the disease continues to spread globally. Many consider the worldwide HCV prevalence rate to be grossly underestimated. For example, current estimates for the United States do not include incarcerated, homeless persons, and others who do not participate in the mainstream healthcare system.

The number of people living with HCV demands the attention and intervention of public health professionals and advocates worldwide.

Multilevel education, public awareness, and effective, affordable testing are essential for disease prevention. When prevention fails, effective treatment is imperative.

The federal government is responsible for educating citizens of the United States about communicable diseases such as hepatitis C. The Centers for Disease Control and Prevention (CDC) is the principal agency managing this task. However, much of the HCV education and awareness efforts in the U.S. continues to be conducted by grassroots hepatitis C organizations and support groups throughout the country. Why is this the case?

Hepatitis C is largely an unfunded epidemic, meaning neither the federal government nor the private sector has earmarked funds for combating this public health problem. Remarkably, many decision makers are still unaware of the magnitude and severity of the hepatitis C epidemic currently threatening the health of hundreds of thousands of Americans. The seriousness of the HCV epidemic and the widespread suffering it is causing must become common knowledge if adequate funding to address this disease is to be obtained.

Both government and private funding are desperately needed to support HCV public awareness campaigns. Many grassroots organizations that conduct the majority of hepatitis C education and awareness programs are funded solely by

monies from pharmaceutical companies that manufacture drugs used to treat hepatitis C. While this had caused some people to mistrust the provided information, public awareness about hepatitis C would be even less than it currently is without this funding.

HCV Research

Remarkable advances in medical research have been made during the past six decades. Each decade seems to bring advances even more rapidly than the one before. Computer technology has been an incredible boon to the advancement of medical research, especially with respect to viral illnesses. Computer modeling of viral *genomes* has allowed scientists to carefully target and attack specific patterns of viruses. As our knowledge increases and pieces of the puzzle are put in place, a more complete picture is revealed.

We have learned much about HCV since it was first identified in 1989. But we are far from having a thorough and complete understanding of the virus. The factors that lead to persistent HCV infection are still poorly understood as are many of the mechanisms that contribute to disease progression, treatment response, and the relationship of HCV to liver cancer. Until additional information is available, we must do the best with what we have.

Treatment is available that is a cure for some (but not all) people with HCV. Some *antiviral* therapies offer the possibility of *viral clearance*, but may cause significant discomfort during treatment. Other therapies may improve quality of life, but offer no potential for viral clearance.

A few short years ago, people treated with interferon-based therapy had only a 12% chance of achieving a *sustained viral response*. Today, approximately 50% of people treated with *pegylated interferon* plus *ribavirin* are sustained responders. With long-term follow up data now in hand, the medical community is now using the word “cure” for those who experience a sustained viral response. This has been a significant cause for hope for many. Response rates may be as high as 80% for patients with specific *genotypes* using pegylated interferon-based therapy.

Chapter 8.4, Future of Allopathic Hepatitis C Treatment outlines many new drugs in development. As we look to the future, we hope for continued progress in HCV prevention, treatment, and access to care.

HCV and the Immune System: Is It the Virus or the Host?

Every day, HCV researchers around the world ponder the same questions.

- Why do some people infected with HCV develop *acute hepatitis* that quickly resolves while others develop *chronic hepatitis*?
- How does HCV infect the cell?
- Why do some people develop *cirrhosis* and/or *liver cancer* as a result of chronic HCV infection while others do not?
- Why do some chronically infected patients have only mild disease with few *symptoms* while others experience severe symptoms and disability as a result of the disease?

The ability of the hepatitis C virus to reproduce itself (a process called *replication*) is staggering. In a **single** day, in **one** HCV-infected person, there may be more copies of the virus produced than there have been humans on Earth since civilization began! Considered another way, an HCV viral particle can replicate roughly 600 to 900 generations each year. By comparison, it is estimated there have been only 300 generations of humans on Earth since civilization began. The numbers are so large, it is almost impossible to comprehend them.

Virologists (scientists who study viruses) generally believe characteristics of the hepatitis C virus are primarily responsible for the harm caused by chronic infection. However, many immunologists (scientists who study the immune system) conducting HCV research have a different thought. They believe limitations of the host's *immune system* are primarily responsible for the severe consequences some people experience in response to HCV infection. Western

researchers are studying people who spontaneously clear HCV to identify regions of the virus particle that may be involved in triggering a specific and successful immune response. This work is providing potential targets for the development of *vaccines* that may be used to prevent or treat HCV infections.

In the end, most HCV researchers agree that **both** the virus and the host's immunological capabilities play a role in the natural history of the disease in any given person.

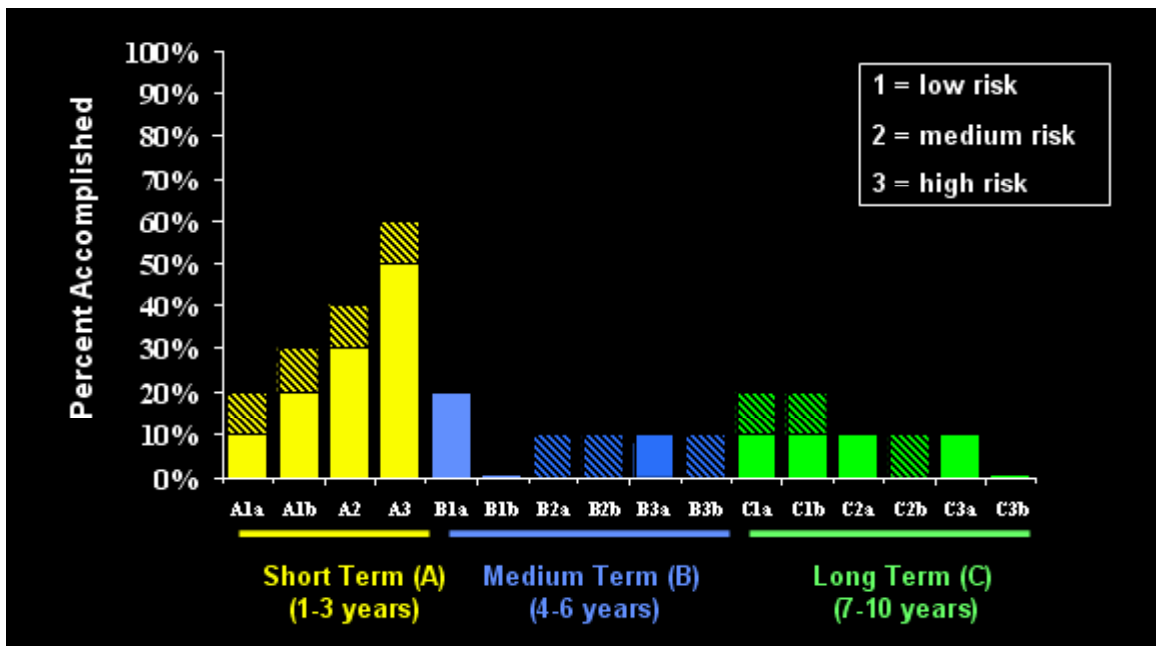
Research Frontiers

To address the burden of liver diseases in the United States, the National Institutes of Health (NIH) developed the Action Plan for Liver Disease Research. The plan, originally launched in 2004, calls for coordination between the NIH and industry to avoid overlap and maximize results. The primary goals for research are to develop practical, safe, and effective means of prevention, treatment, and control of viral hepatitis. Areas of HCV research in the plan include:

<p>Short Term (0 to 3 years)</p>	<ul style="list-style-type: none"> ● develop a cell culture system that is fully permissive for HCV replication ● fully define the pathways of interferon induction and effector action against HCV in vitro and in vivo ● define basis for interferon resistance of HCV in humans ● to better define the optimal dose and duration, rates of response, early predictors of response, and safety and tolerance of current regimens of therapy for hepatitis C in special populations, such as children, patients with solid organ transplants, renal failure, HIV-coinfected individuals, and persons with problems of substance abuse and psychiatric illness
<p>Intermediate Term (4 to 6 years)</p>	<ul style="list-style-type: none"> ● develop small animal models of HCV replication and liver disease ● identify new targets in viral replication and the host for development of small molecule therapeutics ● fully define early events during HCV infection ● define whether longterm interferon therapy is beneficial in nonresponders with HCV
<p>Long Term (7-10 years)</p>	<ul style="list-style-type: none"> ● develop HCV vaccine ● develop ways to prevent reinfection after liver transplant for HCV ● achieve sustained response rate of over 90 percent in chronic hepatitis C ● evaluate new approaches to therapy in hepatitis C

The complete plan is available online at: www2.niddk.nih.gov/AboutNIDDK/ResearchAndPlanning/Liver_Disease/Action_Plan_For_Liver_Disease_Intro.htm. An in-depth progress report was released in 2006 (see Figure 1). The complete progress report can be viewed at: http://www2.niddk.nih.gov/NR/rdonlyres/A5CD343D-6E5D-49D1-8CB3-6BB903D1DCA0/0/EntireDoc_3282007.pdf

Figure 1. Estimated Progress on Viral Hepatitis Research Goals, 2006 (Year 2)
 [Crosshatching indicates recent year's progress.]



Complementary and Alternative Medicine (CAM) Research

The use of *complementary and alternative medicine (CAM)* treatment approaches is common in many countries of the world. CAM use is increasingly popular in western countries as well. This is particularly true among people with hepatitis C. Much of upsurge in interest in these therapies has been facilitated by easy access to information via the Internet. However, there are concerns about the use of CAM therapies among people with chronic hepatitis C. The National Center for Complementary and Alternative Medicine (NCCAM) was established by the National Institutes of Health (NIH) in 1998. The mission of NCCAM is to:

- Explore complementary and alternative healing practices in the context of rigorous science.
- Train complementary and alternative medicine researchers.
- Disseminate authoritative information to the public and professionals.

NCCAM has four primary areas of focus:

Advancing scientific research	NCCAM has funded more than 1,200 research projects at scientific institutions across the United States and around the world.
Training CAM researchers	We support training for new researchers as well as encourage experienced researchers to study CAM.
Sharing news and information	We provide timely and accurate information about CAM research in many ways, such as through our Web site, our information clearinghouse, fact sheets, Distinguished Lecture Series, continuing medical education programs, and publication databases.
Supporting integration of proven CAM therapies	Our research helps the public and health professionals understand which CAM therapies have been proven to be safe and effective.

Research to establish the safety and efficacy of various CAM therapies for a variety of ailments is a priority for NCCAM. *Clinical trials* are needed to establish the actions of herbs and nutritional supplements in the body. While NCCAM is conducting research on some herbal therapies and other CAM practices, they cannot possibly look into all of the thousands of products currently available.

NCCAM currently states, “No CAM treatment has yet been proven safe and effective for treating hepatitis C. There are many CAM treatments for which benefits for health are claimed. Clinical trials are needed of CAM therapies that may show some potential for benefit for hepatitis C, such as milk thistle.” For this reason, NCCAM is currently sponsoring a clinical trial of milk thistle.

Product manufacturers and other proponents of CAM must get involved in funding clinical trials that will allow for more careful definition of the risks and benefits of these products and services. While it is important that medical research be scientifically sound, many people question the need for randomized, double-blind, *controlled clinical trials* for complementary therapies to establish reliable *clinical* information. Randomized, controlled trials are very costly and time-consuming. While it is true that research on CAM therapy can be a compromise, the same is also true of western research. The best information will come when there is true collaboration between CAM and western practitioners. Until research data are available on the efficacy and safety of CAM approaches, few western doctors are willing to recommend them out of concern for potential harm. Often, people interested in using CAM therapies must seek information on their own. Unfortunately, a significant amount of the information available on the Internet and from other sources is unreliable, inaccurate, and sometimes, deliberately misleading. The lack of easily accessible and reliable information was one of the primary reasons *Hepatitis C Choices* was written — to give people accurate information upon which to base their treatment decisions.

If you are considering using CAM products, you should use the same precautions you would with a prescription medicine. Just because a product is “natural” does not mean it cannot harm you. If you intend to use CAM in your hepatitis C management approach, gather information from someone who is trained and knowledgeable about CAM therapy.

Always be sure to let all your healthcare practitioners know about each and every product, supplement, medication, and practice you are using.

The Future Of Medicine – An Integrated Approach

Can, should, or must we explore combining CAM and western treatments? Would this provide potentially less expensive and more effective treatments with better quality of life, not only for people in the U.S., but for the rest of the world’s population as well?

As we move forward in the 21st century, the general public, CAM practitioners, and western doctors are increasingly accepting the idea of *integrative medicine*. As CAM therapies and interventions are incorporated into western medical education and practice, the exclusionary term “complementary and alternative medicine” will hopefully be replaced with the more inclusive term “integrative medicine.”

A number of respected healthcare institutions, medical schools, and teaching hospitals are setting up or have already set up integrative medicine clinics. Some doctors-in-training are being taught not only about western medical treatments, but also about the many herbs, supplements, and other forms of treatment their patients are using and/or requesting. Respected professionals from all healing disciplines are talking, listening, and working together as colleagues, much like the authors of this book. We hope that in the not too distant future, integrative medicine will be seen as providing novel insights and tools for whole body health.

The Role of the Patient Advocacy Community

Patient advocates play a major role in the hepatitis C community. HCV advocates have been largely responsible for the hepatitis C public awareness and information programs that currently exist. They work in communities and in prisons. They work with military veterans. They work with police and firefighters, and with IV drug users. They speak before Congress and state legislatures, appear on television, and reach out to other media outlets. They have been responsible for setting up testing sites where people can be screened for HCV free of charge. They are encouraging states to develop their own testing plans to help prevent the continued spread of this disease. They are organizing the development of community-based HCV task forces.

Advocates are clearly a necessary and vital component in the fight against HCV. But HCV is a huge problem. Many people are needed if we are going to continue to make strides for the good of all those living with HCV.

We encourage you to get involved with one or more of your local HCV groups. Volunteer your time if you can. Just a few hours a week can make a big difference. If you do not have time to volunteer, you can still help by writing your state and local representatives. Tell them you want hepatitis C moved to the top of their healthcare agenda.

Financial support is also needed. Public awareness campaigns, offering free or low-cost testing, conducting educational programs, and all of the many other activities advocates perform daily require funding. If you can help the HCV advocacy community do its work through a financial contribution, we encourage you to pick up the phone or get online today to make your donation.

Giving Hepatitis C a Face and a Voice

Each and every day, HCV advocates hear stories from the community of people living with hepatitis C about the negative stigma associated with the disease. Stigmatization and prejudice are often based on two factors: ignorance and impersonalization or “facelessness.” While people may have heard of HCV, many have little knowledge about the disease, or worse yet, have mistaken notions about the disease.

Ignorance often leads to fear, which is expressed as prejudice. For example, a commonly held misconception is that you can catch hepatitis C through casual, day-to-day contact with someone who has HCV. Of course, this is not true. But someone who holds this mistaken notion may develop a prejudice toward people with HCV as a result of his or her unwarranted fears. This is just one example of how lack of knowledge can contribute to stigmatization.

Impersonalization is also a factor in stigmatization and prejudice. It is often easy to hold on to judgmental thoughts about others when we think of them as a group, separate and distinct from ourselves. We often use phrases such as “those people” or “what they’re like” when describing groups of people with whom we feel no sense of connection. Lacking a sense of connection, we are just a step away from forgetting the humanity we share with “those people.”

This type of “facelessness” can contribute to the stigmatization of people with hepatitis C. But such stigmatization often quickly fades when one realizes that “those people” are not separate, but are one’s friends, neighbors, and loved ones. Understandably, the stigmatization associated with hepatitis C has caused many people living with the disease to remain silent. However, we’ve all heard the old adage and have certainly experienced its truth at some point: “The squeaky wheel gets the grease.”

Becoming Involved in the Hepatitis C Community by Working With an HCV Advocacy Organization has Many Potential Benefits:

- You will be contributing to the process of raising public awareness and knowledge about hepatitis C. Increased public awareness and knowledge will help contain the spread of HCV, and will decrease the stigmatization associated with ignorance and misconceptions about the disease.
- Involvement with the community is likely to expand your own support system while at the same time providing help for others facing similar challenges.

- Giving a face to hepatitis C will help others see that those living with HCV are people just like their friends, neighbors, and loved ones. This is often a powerful antidote to stigmatization and prejudice.
- There is strength in numbers!
In an ideal world, facts and need should speak for themselves. In the real world with many competing interests vying for a limited number of funding dollars, it is often those who are most vocal and have the support of the largest numbers of people who are heard. As noted earlier in the chapter, the success of future HCV prevention, research, and treatment are dependent upon an infusion of governmental and private funds to support these efforts. We need to join our voices together so that decision makers can gain an understanding of the problems at hand. We must also let them know the hepatitis C community is **strong**, and we will not settle for insufficient resources to meet the needs of those who require our help.

You are an important part of the hepatitis C community, and we need your help!
C the Problem and Become Part of the Solution.

The National Hepatitis C Advocacy Council

The Caring Ambassadors Hepatitis C Program mission statement addresses the need to motivate HCV advocacy organizations to work together. In the summer of 2000, all the existing HCV advocacy groups were invited to participate in a meeting to determine if a collaborative approach would benefit people living with HCV. The meeting resulted in the formation of The National Hepatitis C Advocacy Council (NHCAC).

Since NHCAC was formed, it has grown into a 27-member, national organization with three additional advisory organizations. NHCAC is a forum for discussing common goals and developing strategies to become a formidable national force to advance the issues of importance to all people affected by hepatitis C.

NHCAC has established ethical guidelines for all participating groups. The guidelines promote a better quality of life for people living with hepatitis C, and stress that all member organizations must act responsibly and provide accurate, unbiased information.

NHCAC is working on a variety of issues. Currently, the primary focus is to increase the capacity of member organizations to deliver HCV prevention, education, and patient care services to all persons affected by hepatitis C.

For more information on the National Hepatitis C Advocacy Council, visit www.hepcnetwork.org. The *Resource Directory* lists the members of NHCAC as well as many other educational resources.

Summary

Much has been learned about hepatitis C, but there is still much yet to discover.

For the vast majority of people, infection with HCV is not fatal. In fact, most people with HCV will not die **from** the virus, but **with** the virus. Given enough time and financial support from the government and private sectors, researchers will undoubtedly answer many of the questions nagging scientists today.

Even if all the scientific questions were answered tomorrow and effective treatments were available for everyone infected with HCV, there would still be hundreds of thousands of people worldwide who already have the disease, and hundreds of thousands more to whom it could be spread. Prevention is crucial if we want to control the spread of hepatitis C. A critical need for information exists and will continue to exist for a long time to come.

We, as individuals and as organizations, have the opportunity to play a pivotal role in putting the spotlight on this slowly progressive, insidious, and potentially devastating disease. It will take a concerted effort on the part of everyone

involved — researchers, government agencies, the private sector, patient advocates, and the public at large — if we are to overcome hepatitis C.

So many of our dreams at first seem impossible,
then they seem improbable,
and then, when we summon the will,
they soon become inevitable.
~ Christopher Reeve

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