

June
2002

Volume 5
Issue 6

HCV Advocate

A monthly newsletter of the Hepatitis C Support Project
www.hcvadvocate.org

Can Interferon Therapy Significantly Reduce Liver Fibrosis in Hepatitis C?

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The primary goal of interferon-based therapies for hepatitis C is a sustained virological response (SVR), defined as the undetectability of HCV RNA in the blood at the end of treatment and for six months after treatment is discontinued. Using sensitive and specific tests for HCV RNA, it is clear that when an SVR occurs, the patient feels and functions better and serial liver biopsies over the ensuing decade demonstrate marked improvement in inflammation and reduction in liver fibrosis. Current peginterferon with ribavirin regimens offer tremendous hope for achieving an SVR, with SVR rates as high as 42 to 50% in genotype 1 infection and as high as 80 to 90% in non-1 genotypes. Genotype 1 infection clearly presents the greatest treatment challenge, presumably because of a complex and poorly understood interaction between the virus and the host immune system, allowing the virus to evade natural and interferon-ribavirin induced clearance.

When hepatitis C virus is detectable in the blood at the end of treatment and six months later, it is called a "non-response". Since the initial alpha interferon studies in the 1980's, it has been recognized that liver biopsies taken six months after the end of treatment show improvement in some non-responder patients. However, there is no data available to evaluate whether this effect is temporary or permanent, because these non-responder patients have not had long-term follow-up with repeat liver biopsies. Based on these observations, a small controlled study was done and suggested that continuing interferon therapy in non-responders may

maintain the improvement in liver biopsies. Other uncontrolled studies suggest that a course of interferon therapy may reduce the likelihood of primary liver cancer (hepatocellular carcinoma, HCC) or improve survival. None of these studies in non-responders were conclusive, however, in defining whether significant permanent reduction in liver inflammation or fibrosis occurs or is associated with improvement in liver function, or whether several years of treatment is safe and tolerable. For these reasons, and with the cost of interferon therapy, it is extremely important that non-responder patients receive long-term interferon therapy only after it is shown to be safe and effective.

Studies are now in progress in order to determine the safety and effectiveness of long-term interferon therapy in patients with significant liver fibrosis due to hepatitis C in whom the virus has not responded to interferon therapy. One of these studies, the HALT-C trial, is sponsored by the National Institutes of Health, NIH-NIDDK, conducted at 10 clinical sites around the U.S., and will enroll patients through the fall of 2002. You may be eligible to enter this study if you are 18 years or older; have hepatitis C and did not have a virological response to interferon treatment; your liver biopsy demonstrates

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Autoimmune Disorders & Hepatitis C

By Liz Highleyman
Contributing Editor

Many of the conditions associated with chronic hepatitis C are autoimmune disorders, in which the immune system attacks the body's own tissues. Some extrahepatic (outside the liver) autoimmune conditions seen in people with HCV include cryoglobulinemia, lichen planus, rheumatoid arthritis, Sjögren's syndrome, and thyroiditis. Other autoimmune conditions do not appear to be more common in people with HCV than in the general population. *Most people with chronic hepatitis C never experience serious HCV-associated autoimmune conditions.*

What Happens?

Normally the immune system protects the body from foreign invaders including bacteria, viruses, and toxins. The immune system employs a variety of mechanisms, including B cells that produce antibodies against specific foreign antigens and T cells that recognize and destroy specific invaders. Under normal conditions the immune system can recognize the body's own tissues - that is, it can distinguish "self" from "non-self." But in some autoimmune conditions, the immune system produces antibodies - called autoantibodies - that target the body's own cells. In other cases, certain T cells recognize and target body cells instead of foreign invaders. Researchers do not know what causes the immune system to "run amok," but several factors appear to be involved. These include genetic predisposition, sex hormones (women are much more likely than men to develop autoimmune conditions), environmental exposures, stress, certain medications, and exposure to infectious organisms (particularly viruses). The latter may explain why several autoimmune conditions are more common in people with HCV.

Autoimmune Conditions Associated with HCV

Several autoimmune disorders are either known or suspected to occur more often among people with HCV than among the general population. These include:

Antiphospholipid antibody syndrome - a

condition in which the immune system produces antibodies that target cellular lipids (fats). This can lead to blood clotting (thrombosis), thrombocytopenia, and other vascular manifestations.

Autoimmune hepatitis - a type of chronic liver inflammation in which the immune system attacks liver cells. Studies have shown that HCV can trigger autoimmune hepatitis, potentially leading to compounded liver damage.

Blood cell deficiencies - certain types of hemolytic anemia (low red blood cell count) and thrombocytopenia (low platelet count) are due to autoimmune reactions.

Cryoglobulinemia - a condition in which abnormal immune proteins called cryoglobulins form in the blood. These proteins clump together when the blood is cooled, which restricts the flow of blood, especially in the feet and hands. Internal organs may also be affected. (Cryoglobulinemia was discussed in the October 2001 HCV Advocate.)

Fibromyalgia - a condition characterized by generalized musculoskeletal pain and localized tender points. Other symptoms may include weakness, fatigue, sleep disturbances, gastrointestinal problems, and mental and cognitive dysfunction. Although the cause is not known, many experts believe fibromyalgia is due to an autoimmune attack on muscles and fibrous tissues, possibly triggered by an infectious organism.

Glomerulonephritis - a condition in which abnormal antibody complexes are deposited in the glomeruli, the small capillary beds in the kidneys where blood filtration takes place. The glomeruli become inflamed and lose their ability to filter the blood.

Lichen planus - an inflammatory condition characterized by bumps, blotches, or blisters on the skin and mucous membranes, including those lining the mouth and genital tract. While the cause of lichen planus is not known, many experts believe it is an autoimmune condition.

Psoriasis - an immune system condition that primarily affects the skin, causing red scaly patches called plaques.

Rheumatoid arthritis - a type of arthritis in

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Hep C Advocates and Activists Needed

By Alan Franciscus
Editor-in-Chief

Advocacy and activism are terms that are sometimes confused because the roles they entail can be similar and often overlap. Activism is defined as the theory or practice of assertive, often militant, action such as mass demonstrations or strikes as a means of opposing or supporting a controversial issue, entity, or person. Advocacy is defined as the act of actively supporting, that is, pleading or arguing in favor of something, such as a cause, an idea, or a policy.

Generally, when we think of activists, we think of people who are strongly assertive and demand immediate change. What generally comes to mind are civil rights activists, antiwar activists, and AIDS and breast cancer activists. In the case of these movements, there has been an undeniable need for immediate change. These dedicated individuals have spoken out and sometimes put their lives on the line to bring about social, economic, medical, and other necessary changes.

Activism and advocacy have taken many forms in the past. The first large-scale success in modern history was achieved by Mahatma Gandhi in his quest to gain the independence of India from Great Britain by direct, non-violent confrontation. The Reverend Martin Luther King, Jr. was able to draw from Gandhi's experience to challenge discrimination against African Americans in this country when he led the civil rights movement. In more recent times, AIDS activists have been able to use similar strategies to bring about much needed change for people living with HIV and AIDS. In fact, the AIDS activist movement, which developed in the late 1980s, was the first illness-related group to adopt non-violent, direct action to bring about social change. Since that time, other disease-related causes, such as the breast cancer awareness movement, have been able to learn from these activist/advocacy groups and have brought about changes using similar techniques.

Unfortunately, at this time, the HCV community has only a handful of activists in the U.S. who are trying to bring about greater awareness, more services, and better care for people affected by HCV. The majority of these activists have previously been involved as AIDS activists, and are mentoring and

joining the ranks of HCV activists. On the other hand, there are many HCV advocates across the nation. These individuals are mainly HCV-positive individuals who have been moved to respond to the lack of awareness and services on the part of the government and other agencies.

The HCV activist/advocacy community emerged in the mid-1990s to tackle many issues that had been largely ignored by the government and the public sector. The Hepatitis C Support Project, the Hepatitis Support and Education Project, Hep C Connection, and many others emerged to advocate for the HCV community by supporting and educating people with HCV and the general public. Some groups advocate for specific populations with HCV, such as prisoners. In the arena of HCV activism, the Hepatitis Action and Advocacy Coalition (HAAC) was started in 1998 to tackle issues that require direct confrontation with pharmaceutical companies and government agencies. There are many other organizations and dedicated individuals who have given selflessly of their time and energy to help bring about greater awareness and more services for the HCV community. However, many more are required to bring about needed improvements in care and services.

Most people believe that it is difficult and time-consuming to be involved in activism or advocacy. This is true for some efforts, but there are many actions that require little time or involvement. An important aspect of activism or advocacy is that it can help those with HCV feel that they can take control of their lives and effect change that benefits both the individual and the community as a whole. In addition, people from every economic, social, racial, and political group are needed for fair representation.

What You Can Do -

Educating Individuals and the Public

As they say, information is power, and people who educate can move mountains. Learn as much as you can about HCV and educate people and organizations where appropriate. Make sure you know your facts and pick your fights carefully. Be prepared to back up your views with solid facts, and have copies of reports or studies available to hand out.

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Activists

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Support Groups

HCV support groups were one of the first advocacy efforts to emerge. A support group setting can help people with HCV learn about the disease, coping strategies, and other important areas. Starting and continuing a support group can be one of the best steps you can take to advocate for the community.

Helping Individuals

Helping others can be a very rewarding experience. Many people with HCV have many unmet needs. It may not seem like much, but simply listening, running errands, helping sort through insurance issues, or accompanying someone to a medical appointment can be a tremendous help. If you decide to take on this type of responsibility, be sure to define your role in the relationship from the beginning. It is also important to make sure that you can carry out any commitments you make.

Political Advocacy

Involvement in local and national politics can have a tremendous impact. Check with your local city or county health department or agency and attend meetings addressing HCV-related issues. Putting together a petition to submit to a local government can be highly effective. Become involved and know your local candidates; send them letters about issues that affect the community.

Direct Action

AIDS activists pioneered the use of direct action to influence government officials, drug companies, religious leaders, and others. Such actions have included demonstrations to influence public opin-

ion, confrontations with government agencies such as the National Institutes of Health to demand more research, and visits to drug companies to demand lower prices. HCV activists have followed this lead, for example, by calling for better care for people with HCV in prisons and demanding reduced prices and unbundling of HCV drugs.

Community Advisory Boards/ Committees

A community advisory board is a group of individuals who represent a community and provide informed recommendations, for example, to a pharmaceutical company or a research team. Local governments, private companies, and charitable organizations often have committees that can benefit from the input of members of affected communities. The level of involvement required varies from group to group. Sometimes a voice from the community is all that is needed, but other boards and committees demand a great deal of time and energy. Do your homework ahead of time and take your responsibilities seriously. Remember you represent the community, and act accordingly.

We can all make a difference in our own way. Many times, I have heard people remark that one person cannot possibly make a difference. This type of sentiment could not be further from the truth. In my advocacy work, I have met extraordinary people who have taken action and made remarkable progress in bringing about more awareness, education, and improvement in the quality of life for people with HCV. Are you ready for the challenge? You can make a difference - all you need to do is to make an effort and follow your heart.

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Hepatitis C Support Project - A Tides Center Project

Living with Hepatitis C: Managing Common Symptoms Part Two

By Lucinda K. Porter, RN, CCRC

This is the second article of a two-part series. The first part appeared in the May 2002 HCV Advocate.

Emotional Concerns

Some people with chronic HCV infection complain of problems that affect their overall sense of well being and ability to function. These can include depression, irritability, insomnia, difficulty concentrating and even some confusion. If any of these problems occur, discuss them with your doctor. It is important to rule out other

causes for these complaints. Consider trying meditation, moderate exercise, Tai Chi, Qigong, Yoga, or

stress management techniques. Reserve your “best times” for activities that require the most concentration. Do not neglect your recreational needs. Find ways to laugh. Humor has no side effects except perhaps a few laughs.

Cognitive Issues

Patients with chronic HCV infection occasionally report mental or cognitive impairment. Among patients this is referred to as “brain fog.” There are many factors that can impact our mental acuity, including stress,

depression and fatigue. If you are experiencing “brain fog,” try to analyze your situation. Are you experiencing stress? Are you getting sufficient sleep? Are you depressed?

When it comes to health improvement, the brain is sometimes left out of the equation. However, the brain is an essential component of health and needs to be included in health maintenance. Here are suggestions for keeping the brain healthy:

- * Reduce stress
- * Regularly practice mental relaxation
- * Maintain a physical activity program
- * Identify your best thinking time and use this time when you need to be thinking your sharpest. This is usually when you feel rested or relaxed.
- * Learn, learn, learn
- * Read, read, read
- * Challenge your brain with games, puzzles
- * Cultivate skills that use fine-motor-control skills

Social and Sexual Issues

The diagnosis of chronic hepatitis C can have a negative impact on one’s sexual relationships. The issue of transmitting HCV to another can create both real and emotional concerns. It is essential that everyone engaging in sexual activity (with or without a potentially transmissible disease) practice safer sex.

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Symptoms

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Having said this, sexual transmission of HCV among monogamous sexual partners is very uncommon. Communicate your fears and concerns of transmission with your sexual partner. If you need additional information about this, contact your local public health department, Planned Parenthood, or health care provider.

Sometimes fatigue and fear can lead to isolation. Make every attempt to avoid isolation. The value of support cannot be minimized, especially a hepatitis

C support group. Patients can be experts of a very special kind. They are true authorities on how to live with this disease. Learning how to cope can make all the difference in the world. As the saying goes, "pain is inevitable; suffering is optional".

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Fibrosis

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significant scarring; your liver disease is stable and you have had no major complications of cirrhosis or other unstable major medical diseases or conditions; and if you have not recently abused alcohol or illicit drugs. The study is designed to determine if peginterferon alfa-2a (Pegasys(r), Hoffman-LaRoche), a new form of long-acting interferon, administered once weekly for up to 4 consecutive years can suppress the hepatitis C virus, prevent progression to cirrhosis, prevent liver cancer, and reduce the need for liver transplantation. This study is randomized (patients who participate agree to be randomly assigned to be treated in one of two different ways) and controlled (there will be a comparison group that will help to determine if the active treatment is effective). Patients whose disease has failed to respond to previous treatment with either interferon, interferon and ribavirin, peginterferon, or peginterferon and ribavirin will initially be re-treated with peginterferon alfa-2a and ribavirin daily for 24 weeks. Patients who respond to this treatment and their blood tests negative for HCV will continue therapy for 48 weeks. Patients who remain infected with HCV and their blood tests positive at treatment week 24 will be randomly assigned to either continue treatment with peginterferon alfa-2a alone or to stop treatment and be followed for up to 4 years. Among the first 268 patients who entered this study, 42% demonstrated a week 24 virological response to re-treatment with peginterferon alfa-2a and ribavirin. The likelihood that these patients will develop a sustained virological response, however, is not yet known.

The combination of peginterferon alfa-2b (Pegintron(tm)) plus ribavirin has recently been approved by the FDA for treatment of chronic HCV. Patients who meet the HALT-C trial eligibility criteria, who have received at least six months of peginterferon alfa and ribavirin, and whose virus remains detectable (non-response) may enter the HALT-C trial directly and be randomized.

This study is designed to provide statistically meaningful data as to whether or not long-term peginterferon therapy will affect the development of cirrhosis, liver decompensation, hepatocellular carcinoma and survival in patients with significant liver fibrosis due to hepatitis C. The tolerability and safety of treatment and effect on quality of life will also be assessed. In addition, intensive data collection will be done to address other important scientific and clinical questions such as the relationship between viral sequence structure and immune control, serum markers of liver fibrosis and cancer, quantitative assessment of liver function, iron overload, cognitive effects of long-term interferon, risk factors for liver disease progression (nutrition, obesity, smoking and alcohol) as well as other areas. For patients accepted as a candidate in this study, the study drugs will be supplied free of charge and the cost of care will be partly subsidized by this NIH study. It is anticipated that all 1800 study patients will be enrolled by the fall of 2002, so interested patients should contact their nearest study site as soon as possible. For information, visit the HALT-C trial website at www.haltctrial.org or call 1-800-411-1222.

The Diagnosis of Hepatitis C's Impact on Health Related Quality of Life, Part Two

By Alan Franciscus
Editor-in-Chief

The concept of “quality of life” is biased and difficult to not only define but also measure. Health is the state of complete physical, mental, social and spiritual well-being not merely the absence of disease. Quality of life in clinical medicine represents the functional effect of an illness and its therapies upon a patient, as perceived by the patient

In Part 1 of the HRQOL (Health Related Quality of Life) series we discussed the tests that have routinely been used to measure HRQOL in studies including the tests that have formally been used in trials related directly to hepatitis C.

Even though hepatitis C is often asymptomatic (without any symptoms) many patients suffer from fatigue, nausea, pruritis (itching), body aches, anorexia (lack or loss of appetite) and mood changes all of which in one way or another could impact a patient's HRQOL. In addition to the symptoms of hepatitis C, the burden of having a disease or being labeled as “being infectious” can significantly impact a person's HRQOL. In this part of the HRQOL series we will be discussing the impact of the diagnosis of hepatitis C on HRQOL.

There is some disparity as to the prognosis of patients with chronic hepatitis C. Some suggest that most patients with chronic hepatitis C will have a normal life span and not suffer consequences of this disease. On the other hand, it has been shown that patients with hepatitis C infection have a reduced health-related quality of life (HRQOL).

Even patients without cirrhosis show reductions that manifest in both mental and physical HRQOL. These reductions have been judged to be clinically and socially pertinent, and are comparable with or more severe than those for a characteristic sample of type II diabetics. Although it appears that patients with chronic hepatitis C have reduced HRQOL, it is uncertain whether this is caused by the disease or by its related comorbidities (a disease coexisting with another disease).

Patients with hepatitis C are more likely to be intravenous drug users, to come from low socioeco-

omic status, and to have a history of blood transfusions. In efforts to address this issue, some studies adjust for some comorbidities, whereas others disqualified subjects who reported a history of drug use. The majority of studies concluded that subjects with hepatitis C had reduced HRQOL.

However, it remains possible that differences could continue because of other unmeasured effects such as socioeconomic status, actual (as opposed to reported) use of intravenous drugs, factors leading to blood transfusion, or other health-related issues. One technique to address this issue is to analyze the effect of eradicating the infection on HRQOL. If curing the disease leads to considerable improvement in HRQOL, it suggests that the infection was the true cause of the reduction. The area of interferon therapy in the treatment of hepatitis C and in the impact of HRQOL will be covered in later parts of the HRQOL series.

This article is going to concentrate on the reports that highlight the diagnosis of HCV on HRQOL. There was some very interesting work done by Dr. Rodger from Australia who looked at a group of patients with long-standing infection, only approximately half of whom were aware that they were hepatitis C HCV RNA positive (had chronic HCV disease) at the time that the quality of life scores were measured. Dr. Rodger's study investigated the impact of HCV diagnosis on HRQOL and compared the difference in the scores between those aware of their serostatus and those that were not aware.

This study was part of a retrospective cohort study investigating the natural history of chronic hepatitis C and found that individuals with chronic hepatitis C who were cognizant of their serostatus before the retrospective follow-up had a significantly worse HRQOL compared with the population who were not aware of their serostatus. Both groups in this study had an average time of being chronically infected for 28 years.

The reduction in the HRQOL scales in those aware of their serostatus was almost widespread and affected variables measuring both emotional and physical

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Autoimmune Disorders

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which the immune system attacks the lining of the joints leading to pain, swelling, deformity, and loss of movement. Rheumatoid arthritis may also affect the heart, lungs, nerves, skin, and connective tissue. (Rheumatoid arthritis was covered in the May 2002 HCV Advocate.)

Scleroderma - a disorder characterized by the production of scar tissue, which leads to hardening or thickening of the skin and blood vessels. Internal organs may also be affected. Many people with scleroderma develop Raynaud's phenomenon, a condition characterized by poor blood circulation to the fingers and toes.

Sjögren's syndrome - a condition in which the immune system attacks and damages the body's moisture-producing glands, leading to dry eyes, dry mouth and throat, dry skin, and vaginal dryness. Internal organs nerves, and blood vessels may also be affected.

Systemic lupus erythematosus (SLE) - a disorder in which the immune system attacks various tissues and organs including the skin, joints, blood vessels, kidneys, lungs, heart, and brain.

Thyroid disease - various autoimmune conditions affect the thyroid gland, which helps regulate the body's metabolism. Hashimoto's thyroiditis is chronic inflammation of the thyroid accompanied by insufficient production of thyroid hormones. Grave's disease involves overstimulation of the thyroid by the immune system, leading to enlargement of the gland and overproduction of thyroid hormones.

Vasculitis - a variety of conditions involving inflammation of the blood vessels. In autoimmune vasculitis, the immune system attacks and damages the blood vessels, leading to reduced blood flow.

Symptoms and Diagnosis

Autoimmune disease are diagnosed on the basis of symptoms, laboratory tests, physical examination, and medical history. While each autoimmune disorder has its own set of symptoms, several symptoms - including fatigue, generalized pain, and low-grade fever - are common to a number of different autoimmune manifestations. Because these symptoms also occur with many other types of

illness - including chronic hepatitis itself - diagnosis of autoimmune conditions is often difficult. The symptoms of autoimmune conditions can range from mild to disabling to life-threatening. Sometimes multiple autoimmune conditions occur together. Many people experience recurring cycles of worsening symptoms (flares) followed by prolonged improvement (remission).

Treatment and Disease Management

Autoimmune conditions are typically chronic and usually cannot be cured. Treatment is aimed at ameliorating symptoms and preventing tissue destruction. Measures include plasmapheresis (a procedure in which damaging antibodies are filtered out of the blood) and various drugs.

Medications used for autoimmune conditions may include nonsteroidal anti-inflammatory drugs (NSAIDs) such as acetaminophen and ibuprofen; corticosteroids such as prednisone; and stronger antiinflammatory drugs such as azathioprine and cyclophosphamide. Some of these drugs can cause severe side effects. The goal of treatment is to dampen the immune response against the body's tissues while retaining the immune system's ability to fight foreign invaders.

Unfortunately, immunosuppressive drugs may increase HCV replication and may thus be risky for people with hepatitis C. In addition interferon - a standard treatment for chronic hepatitis C - may worsen autoimmune conditions by further stimulating the immune system. In addition to medical treatments, various measures may be taken to help people cope with autoimmune conditions. These include stress management, pacing activities to deal with fatigue, adequate rest, and a healthy diet. Support groups are available for people living with autoimmune diseases.

People with autoimmune conditions should report any changes in their symptoms to their healthcare providers.

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HRQOL

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health and also those measuring the impact of health on daily activities of living. Those uninformed of their diagnosis scored poorly in only 3 modalities (general health, vitality and mental health in the SF scores as compared with population norms); in addition they did not perceive their emotional or physical health impacted in any way on daily activities.

The fact that the unaware group did differ from population norms in the areas of vitality and general health suggest that the commonly reported symptoms of fatigue and tiredness in those with hepatitis C may be secondary to a physiological, but yet uncertain mechanism rather than any psychological process. It is not clear how much of the reduction in HRQOL is at variance to chronic HCV and how much is associated with psychological disturbance, previously documented in injecting drug users which can adversely affect HRQOL. In this study all patients were previous injection drug users (although none had injected in the previous 24 months) so that in of itself cannot be held responsible for the differences in HRQOL between the groups.

What is very apparent from this study is that patients who have been diagnosed with HCV had a universal and significant reduction in HRQOL compared to individuals with HCV who have not yet been diagnosed. Even though confusing factors may have some impact it is unlikely that any factors other than the diagnosis of hepatitis C could have led to this observed difference.

In this study those that were aware of their positive serostatus did not differ sociodemographically, clinically, virologically or serologically from those who were unaware. All had asymptomatic liver disease and none had been treated with interferon. There was no relation between HRQOL scores and objective measures of ill health and in all cases HCV diagnosis had not been made as a result of the presence of symptoms.

Although infection with hepatitis C and/or a history of injection drug use may be associated with impaired HRQOL, from this study the fact that there was a globally reduced HRQOL in the diagnosed group suggests that there may be also partially due to an effect of the “labeling” by which diagnosis of a

chronic disease affects subjective psychological well-being.

Experiences in the healthcare setting can have an effect on a person’s quality of life. In conventional medical and health service practice there is a continued focus on physical functioning - this focal point does not acknowledge that HRQOL is complex and subjective, and that people with hepatitis C may have a broad range of needs, some of which can be addressed in health settings.

Many people with hepatitis C have no symptoms, but for others the infection can be differentiated by the unpredictable onset and progression of symptoms. As a consequence, people may experience a lack of confidence regarding their future health. Physical symptoms without doubt affect HRQOL.

Other issues, such as possible discrimination, loss of social support, inadequate income, uncertainty of the future and feeling “infected” have also been recognized as serious concerns for people with hepatitis C. With all these factors in mind, perhaps appropriate and sensitive management of the process of discussing diagnosis of HCV may help to reduce the negative effects of diagnosis.

The potential role of interferon treatment for hepatitis C and the effect that treatment has on HRQOL in hepatitis C will be the focus of Part III.

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