

# HCV Symptoms: Imagined or Real?

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What is it about hepatitis C that makes so many of us complain about symptoms such as fatigue, nausea, body aches and pains, loss of appetite, and mood swings? Are they real or imagined?

Many would have us believe that these symptoms are merely a result of our prior “lifestyle” or that we just like to complain. In fact, many people view us as “whiners,” pure and simple. Until recently, this perception has been widespread within the medical community and the general public, and has resulted in less than adequate medical care and the denial of important resources such as disability benefits.

Yet as more and more studies have started to focus on quality of life issues, it is becoming apparent that our symptoms are not “all in our heads.” It is slowly being recognized that even so-called “asymptomatic” patients experience many symptoms related to hepatitis C. These quality of life issues are probably the most important area of current research in HCV, especially for patients who have been told over and over that many of our symptoms are in “all in our heads.”

Fatigue is the among the most common symptoms experienced by people with hepatitis C, along with muscle aches and pains, flu-like symptoms, depression, anxiety, and headaches—to name just a few. Fatigue and other symptoms are difficult to measure accurately and can also be subjective to the patient. But as many people with HCV know, severe fatigue can impact every area of one’s life.

I recently talked to a woman with hepatitis C who explained very clearly how fatigue has affected her life. She suffered from increasing fatigue over a period of several years. In order to sustain herself financially, she concentrated all of her energies on getting through her workday—which meant that all she could do was rest in her spare time, isolating herself from her family and friends. The result was depression and anxiety. In addition, she was too tired to prepare nutritious meals or exercise, so her health started to decline even more. She explained that the worst part of her experience with fatigue was that it was not validated by her physician, her family, or even her friends. For this woman, fatigue was a downward spiral and she lost hope that her life would ever improve. However, when she joined a support group her symptoms were validated, and she received advice on combating her fatigue and improving her quality of life.

## Quality of Life

Health is measured by the overall state of physical, mental, social, and spiritual well-being—not just the absence of disease. Quality of life in clinical medicine represents the functional effects that an illness and its treatment have upon a patient, as perceived by the patient himself or herself. In the past, the measurement of how a person’s health was impacted by hepatitis C was related to markers such as blood test results, treatment outcomes, or life expectancy. But as patients have become more involved in their healthcare and have begun voicing their opinions, it is becoming ever more apparent that the indicators that physicians looked at in the past have little or no correlation with people’s feelings or perceptions about their disease

and how it is impacting their lives. This has led many physicians and researchers to reevaluate the impact of hepatitis C and how treatment affects patients' overall health and well-being.

Until recently, quality of life instruments were not endorsed for routine use in patients with chronic hepatitis C. Now, some instruments—including the hepatitis quality of life questionnaire (HQLQ) and Short Form 36 (SF-36)—have been validated for use in people with HCV. The most extensively used, SF-36 measures a person's general health status. It consists of 36 items that measure eight domains: physical functioning, physical role limitations, energy and fatigue, general health perceptions, pain, social functioning, emotional role limitations, and mental health. The assessment is easy to administer, score, and interpret. It has been shown to have good reliability and validity among primary care and chronic disease populations, including those with chronic hepatitis C. However, SF-36 is limited in that it is not specific for hepatitis C. More specific assessment tools include the Fatigue Severity Scale (FSS) and the HQLQ. These tools attempt to evaluate what it is like to live with a medical condition such as hepatitis C.

## **The Impact of Hepatitis C on Quality of Life**

Even hepatitis C patients without cirrhosis experience reductions in quality of life, both physical and mental. Studies have shown that these reductions are clinically and socially relevant; they have been described as comparable to or more severe than those of a characteristic sample of type II diabetics. However, it has been difficult to tell whether this reduced quality of life is due to hepatitis C itself or to HCV coexisting with other diseases or conditions. People living with hepatitis C are more likely to be current or former injection drug users, to have a lower socioeconomic status, and to have a history of blood transfusions. In an effort to control for some of these factors, researchers have often excluded people with coexisting diseases or a history of drug use.

## **Impact of HCV Diagnosis on Quality of Life**

An important area of study is how a diagnosis of hepatitis C impacts quality of life. One interesting study, done by Dr. Rodger from Australia, looked at a group of patients with long-standing infection; initially one-half were not aware that they had chronic hepatitis C. Both groups in this study had been infected with HCV for an average of 28 years. This study found that people who knew they had chronic hepatitis C had significantly worse quality of life scores than those who did not know their HCV status. Those who did not know scored poorly on only three components of the SF-36 evaluation—general health, vitality, and mental health—but did not perceive that their emotional or physical health limited their daily activities. However, this group did score lower overall compared with population norms, indicating that people with hepatitis C do indeed have a reduced quality of life even if they are unaware of their status. Even more interesting, however, is that the group that knew of their hepatitis C diagnosis had a significant reduction in quality of life compared with those who were unaware they had HCV. This result highlights the psychological impact of diagnosis. For instance, being labeled as having hepatitis C, knowing that you have a potentially life-threatening disease, and the implications related to discrimination can indeed significantly reduce well-being and quality of life.

## **Impact of Medical Treatment on Quality of Life**

One of the most accurate indications that hepatitis C is adversely affecting quality of life is if successful treatment of the disease leads to considerable improvement in quality of life; this suggests that the infection itself was the true cause of the reduction quality of life.

Dr. Gary Davis was one of the first physicians to measure the effect of HCV treatment on quality of life. Dr. Davis and colleagues studied patients who were treated with interferon monotherapy. They concluded that quality of life improved for the treated patients compared with those in the untreated control arm. An interesting finding of this study is that similar improvements in quality of life were observed in both sustained virological responders (those who maintained an undetectable level of HCV for at least six months post-treatment) and non-responders (those who did not clear the virus), suggesting that interferon treatment itself, regardless of outcome, led to improved quality of life in patients with hepatitis C.

In a study by Dr. Herbert Bonkovsky and colleagues, 642 chronic hepatitis C patients were treated with interferon monotherapy. In contrast to the results of Dr. Davis, this study found that sustained virological responders experienced significant improvements in perceived wellness and functional status, exceeding those observed in relapsers (those whose HCV recurred after initial suppression) and non-responders. The researchers concluded that successfully clearing HCV leads to an improvement in hepatitis C-related symptoms. Unfortunately, this study also found that even sustained virological responders did not achieve a completely normalized quality of life with eradication of the hepatitis C virus.

Dr. Ware and colleagues used quality of life measurements to evaluate changes in quality of life for interferon monotherapy relapsers who were later treated with a combination interferon plus ribavirin. This study also concluded that successful treatment (defined as loss of virus) was associated with improvements in vitality, social functioning, and health distress.

Results from these studies are very exciting to patients and medical practitioners because it appears that not only can treatment with interferon or interferon plus ribavirin successfully eradicate HCV, but can also improve patients' quality of life.

## **Treatment Side Effects and Quality of Life**

One area in which symptoms are widely acknowledged is how a patient feels while undergoing HCV therapy. Such symptoms have the potential to severely impact a person physically and psychologically while on treatment, but usually improve when therapy is stopped. Treatment-related symptoms are acknowledged because side effects must be monitored by medical practitioners in clinical trials and in actual practice. Of course, anyone who has ever been on interferon or interferon plus ribavirin knows that treatment can dramatically reduce quality of life by itself, and may possibly exaggerate HCV-related symptoms that people experience every day.

The new pegylated interferons offer hope that more positive strides can be made to improve patients' quality of life. Although there has not yet been enough time to properly study whether pegylated interferons will positively impact quality of life issues, many believe that improved treatment outcomes will lead to improvements in health and quality of life.

It is reassuring, as a person living with hepatitis C, to know that our symptoms are slowly being acknowledged and accepted as a part of the disease. It is clear that much more research is needed in order to fully understand and duly recognize the multitude of symptoms that people with hepatitis C experience. And it will take more scientific studies because it is unlikely, in this age of managed care, that many providers will have the time or opportunity to listen and truly understand what people with hepatitis C really experience—but that is another story altogether.