

Living with Hepatitis C: Qualitative Interviews with Hepatitis C-infected Veterans

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BACKGROUND: Chronic hepatitis C (HCV) infection affects millions of people in the USA and prevalence rates are higher in US veterans. The consequences of HCV infection include reduced quality of life, liver damage, and reduced longevity.

OBJECTIVE: Our objective was to describe the experiences of US veterans living with chronic HCV infection and use this information in the development of an HCV self-management intervention.

METHODS: Twenty-two male HCV-infected veterans completed qualitative interviews. Participants were recruited via flyers and hepatitis C clinic providers at a major VA medical center. Participants were asked about their medical history, being diagnosed with HCV, and general experiences living with HCV.

RESULTS: The study gathered the following findings: the impact of HCV on interpersonal relationships was pronounced, recovery from substance use disorders and getting care for HCV were connected, receiving the HCV diagnosis was more troubling to non-IV drug users, participants had misconceptions about HCV and its treatment, psychological problems were prevalent as were barriers to participating in antiviral treatment and HCV care in general.

CONCLUSION: The themes derived from our analysis indicate that affected veterans may benefit from interventions or support to improve HCV-related health education, social/relationship issues, psychological issues, and exploration of the connection between substance use recovery and motivation to get care for HCV infection.

KEY WORDS: hepatitis C; HCV; veterans; treatment; impact.

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INTRODUCTION

Chronic hepatitis C (HCV) infection affects about 1.8% of the general US population^{1–3} and an estimated 5.4% of VA patients⁴ or three times the general population rate. Chronic HCV infection leads to severe medical consequences in about 30% of cases⁵ and is the leading reason for liver transplantation in the US. Overall, societal costs are projected to be as high as \$50 billion over the next decade⁶. In HCV-infected individuals not experiencing severe consequences, health-related quality of life is often impacted^{7–11,12}. Symptoms include fatigue, abdominal pain, nausea, weight loss, and functional limitations. Anxiety and depression can emerge after being diagnosed with HCV, or from living with a serious, potentially lethal chronic disease^{9,10}.

Antiviral treatment eliminates the virus in approximately 45% of patients^{13–15}, but most VA patients never receive treatment¹⁶, because they are either ineligible or refuse treatment. Recommendations for HCV patients who are not current candidates for antiviral treatment include adhering to follow-up appointments and following self-care guidelines^{17,18}. Unfortunately, many HCV patients have difficulty following these recommendations without additional assistance or intervention¹⁹. Self-management programs are one option for helping HCV-infected patients adhere to treatment recommendations. Self-management programs provide problem-solving and behavioral skills along with disease-specific information. They have been shown to improve chronic symptoms, increase health-supporting behaviors, and enhance overall quality of life^{20–22} while consuming few medical care resources^{23,24} with other chronic diseases. Despite the need for such approaches, relevant empirical data are limited. Our primary objective was to describe the experiences and challenges faced by VA patients living with HCV and inform the development of an HCV self-management program. These qualitative data provide the patient's perspective and were combined with input from HCV clinicians, researchers, and behavioral scientists in developing the HCV self-management program.

Patients' Views of Hepatitis C

Our approach was to use qualitative methods to gain insight into the experiences of HCV-infected patients, an approach that has proved informative in helping patients manage similarly challenging chronic illnesses, such as HIV²⁵. Qualitative methods have been used before to describe the experi-

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ences of people living with HCV, but have not focused on US veterans. Results suggest that being diagnosed with HCV produces distress; the disease carries an ominous prognosis and negative images are associated with contagious disease and stigmatized risk factor behavior^{10,26}. Patients may suddenly feel unclean regardless of their previous lifestyle, and find their new illness framed by shame and discrimination.

Living with HCV often entails significant physical, cognitive and emotional adjustments as well. Debilitating symptoms and the medications used to treat HCV may impair daily activities, social roles, and work performance^{26,30}. For example, fatigue is common to HCV-infected individuals and interferes with many daily activities, however, the severity of fatigue varies widely among individuals²⁷. Social support is critical for adjustment, but its receipt is complicated. Relationships may be strained by worries about sufferers' uncertain health; partners, family, and friends may withdraw out of fear of infection or distaste, and physical and cognitive impairments may limit social interaction²⁸. Healthcare professionals play a major role in providing supportive guidance for HCV-infected patients yet patients have also reported significant strains in these important relationships²⁶. Zickmund and her coworkers have found that conflict and communication problems were not uncommon in HCV patients' accounts of their clinical care^{29,30}.

Since IV drug use is the leading cause of new HCV infections³¹, qualitative researchers have focused on topics such as prevention^{32,33}, the diagnosis experience³⁴, and the experience of living with HCV among IV drug users³⁵. Results suggest that knowledge about the risk of HCV infection was fairly good but needle sharing and risky behaviors still occurred when safer options appeared limited. Despite knowledge of the risks, homeless IV drug users were often shocked and angry after receiving a positive diagnosis³⁴ and these negative feelings persisted for years.

Finally, the experience of antiviral treatment for HCV has also been studied qualitatively^{36,37}. These studies used participant narratives to describe the side effects of antiviral treatment and associated emotional reactions.

METHODS

Participants

Participants were 22 HCV-infected veterans recruited during 2004–2006. VA patients with chronic HCV-infection were recruited by healthcare providers at the VA San Diego Hepatitis C clinic and through flyers posted at the VA San Diego Medical Center on public bulletin boards and near the Alcohol and Drug Treatment Program. To participate in the study, VA patients needed a verified diagnosis of HCV-infection. The VA San Diego Hepatitis C clinic sees about 350 HCV-infected veterans annually.

Procedure

Semi-structured interviews were conducted by two researchers with experience conducting clinical health assessments. Questions were designed to focus on three broad areas: medical history, experiences of contracting and being diagnosed with HCV, and the ways in which HCV affected their lives. The

respondents were encouraged to expand on these issues and redirect the conversation if they desired. The interviews averaged about 40 minutes in length and were audiotaped, transcribed, and de-identified for analysis. The interviewers made detailed notes and summarized each interview shortly after it occurred. Interviews were conducted in English.

Assessment Instrument

The semi-structure qualitative interview consisted of 11 questions (see [Appendix A](#)). The theoretical construct of health-related quality of life was used to guide the development of the interview questions^{38–40}. The questions were also influenced by two secondary sources: a) input from clinicians at a VA Hepatitis C Clinic; and b) domains covered by published qualitative studies of HCV-infected individuals.

Data Analysis

Means and proportions were obtained for the sociodemographic and available clinical characteristics of participants. Interview transcripts and notes were independently reviewed and coded by two researchers. Prior to beginning coding, the researchers underwent training on the theoretical concepts of health-related quality of life. They also reviewed existing qualitative literature on HCV infection and conferred with clinicians from the local VA HCV clinic. For the analysis, interview texts were first examined and each sentence or idea was classified into topics. Next, broader themes were independently identified by each reviewer and the two lists of themes were compared and discussed by the two reviewers. When discrepancies among themes arose, the researchers referred to the theoretical principles of health-related quality of life. Each reviewer's reasons for creating and labeling the themes were discussed and data were re-reviewed until a common theme label was agreed upon or a new theme was created. Discrepancies centered around the number of themes created. For example, one reviewer created a theme for emotions such as fear, anger, and guilt. After discussion, the emotions were subsumed under existing themes/contexts to which the emotions were linked (diagnosis, relationship, treatment). In addition, a new theme was created for contracting HCV because one reviewer noticed differences in internal versus external attributions of control.

RESULTS

Participant demographics are described in Table 1.

The themes that were agreed upon by the reviewers are summarized in Table 2. Participant quotes and narratives are presented below and correspond to the themes that were identified.

Theme 1 – Reaction to Diagnosis

The mean self-reported amount of time since first diagnosis was 7.3 years (sd=6.9). Initial reactions to the diagnosis of HCV included fear, denial, and/or shame. Other reactions mentioned were relief, guilt, anger, depression, hopelessness, and worry about death. One participant described his reaction as: *"I was a little depressed knowing there's no actual cure ... I*

Table 1. Participant Demographics and Descriptive Statistics

Variable (n=22)	Mean (sd) or % (n)
Age	52.1 (6.1)
Years since diagnosis	7.3 (6.9)
Gender	
Male	100% (22)
Education	
9–11	18% (4)
High School or equivalent	38% (8)
Some college	41% (9)
Missing	5% (1)
Ethnicity	
Caucasian	77% (17)
Hispanic	9% (2)
African-American	9% (2)
Native American	5% (1)
Employment	
Unemployed	41% (9)
Disabled	32% (7)
Retired	9% (2)
Full time employment	9% (2)
Missing	9% (2)
Marital status	
Married	23% (5)
Widowed	5% (1)
Divorced	41% (9)
Never married	32% (7)
History of alcohol abuse	82% (18)
History of IV drug use	64% (14)
Currently abstinent from alcohol/drugs	82% (18)
Mental health	
PTSD	23% (5)
Mood disorder	50% (11)
Schizophrenic	9% (2)
None	32% (7)
Previously received HCV antiviral therapy	36% (8)

hear it's not a great process to go through. There's depression and suicidal tendencies." Another participant reported that when he received the diagnosis, he thought HCV was like HIV. "... I'm gonna die" he thought, and "I've been waiting to see if anything would go wrong with me." Another participant reported that he was attempting to quit using IV drugs when he was diagnosed, and thought... "What's the point? I'm either going to die from drugs or from liver disease." He noted that immediately after his diagnosis he began using drugs again. Conversely, one participant reported feeling relief at the diagnosis. He said: "On a scale from 1–10, probably 9 on relief.... [T]here is a reason why I feel so @#!%*!." While some participants reported being surprised or shocked when first diagnosed, others were not surprised at all, usually because of their pattern of IV drug use.

Theme 2 - Method of Contracting HCV

When participants were asked if they knew how they contracted HCV, some assumed that their IV drug use was to blame, while others sought alternative explanations and insisted they always used clean needles. One participant said "Either, by doing IV drugs or being a lifetime long-term nursing aide.... Other than that, I have no idea. I never shared needles with anybody." Similarly, "I used intravenous drugs, but they were always clean. I would use them fresh out of the package."

Another explanation for contracting HCV was through immunization guns used during the Vietnam War. Three

different participants claimed that large numbers of soldiers were immunized in succession without needle sterilization. One participant said, "[B]ecause of the (immunization) guns they used back when they were shooting us. You know for a bunch of shots and stuff.... I don't use intravenous drugs. I did, but that was probably 30 years ago.... [T]hat was just for a short period of time...that or tattoos.... [T]here's sex."

Another said, "I might've gotten it through those air injectors? The military used those air guns." In summary, participants acknowledged that their behavior likely contributed to contracting HCV, while others reviewed all possible causes for acquiring HCV and focused on their efforts to use clean needles.

Table 2. Primary Themes from Qualitative HCV Interviews

Themes	Summary description
Diagnosis	IV drug users were often not surprised at their diagnosis and sometimes felt they deserved it. Non-IV drug users were surprised by the diagnosis and very worried about the future effects until they became more educated
Contraction of HCV	Beliefs about how they contracted HCV may impact participant mood and contribute to an understanding of coping mechanisms
Information/Education needs	Most participants eventually received appropriate HCV education from trained professionals but some still reported misconceptions and would appear to benefit from additional education
Quality of life (symptoms, functioning, relationships)	Participants had difficulty with social and sometimes occupational functioning, but some received valued support from others for their condition. Fatigue was frequently reported but its link to HCV was unclear. Living with chronic HCV often had a psychological impact
Substance use/Recovery	Having HCV was often tied to drug /alcohol use and getting medical care for HCV and self-managing their HCV was also tied to staying clean & sober/being abstinent
Psychiatric and other medical co-morbidity	Psychological problems were prevalent and were a potential barrier to getting treatment. Most participants had other medical co-morbidity that could influence their course of treatment and could benefit from lifestyle changes via HCV self-management
Interferon treatment	Most participants who had been treated tolerated it well. Some had misconceptions about side effects, efficacy, etc., and most wanted to learn more about getting treated
Self-management	Almost all participants expressed interest in learning more about HCV and learning ways in which they can improve their own health and prevent transmission to others

Theme 3 – Information/ Education Needs

Although all participants reported receiving education about HCV from VA staff, many retained misinformation from potentially unreliable sources. One participant reported that he had “heard horror stories” about HCV treatment when he was in jail. Another asserted, “I’m more cautious ...[W]hen I go over to my family’s house to eat ..., I make sure I always have something that I throw away, not a regular plate.” Other participants’ included, “I avoid drinking out of the same glass as other people” or “I can’t see how I could’ve gotten it cause of what I’ve eaten or anything like that.” These responses suggest that the participants may incorrectly believe that HCV, like hepatitis A, can be transmitted by saliva or food products.

Theme 4 – Impaired Quality of Life

Participants reported experiencing fatigue, abdominal pain, and occasionally weight loss or muscle aches. One participant said, “I’ve had a lot of sluggishness and fatigue for a long time.” Another participant reported, “[S]ame area as my liver, sharp abdominal pain. It’s there all the time. I don’t know if it’s because of the pain, but I get tired all the time” Another participant said “I noticed that my feet started swelling up. There are days that I do feel extra tired. No energy....” Most participants only mentioned psychological symptoms when asked about receiving the diagnosis of HCV. However, one participant reported that HCV resulted in long-term “irritability, not being able to control stuff, emotional issues.”

Many participants stated that having HCV had impacted their interpersonal relationships. One participant said, “It embarrasses you, especially in relationships.... [Y]ou gotta tell the person. Especially if you want to get intimate...” Another said “[A]s far as the sexual thing.... I don’t want to transmit it someone. So, I have to live with that. That’s sort of a depressing situation. You’re trying to be honest with yourself.” Another participant reported that his marriage has been significantly affected. “... a bunch of arguments over the hepatitis C thing. She swears I got it from screwing around with some girl...I haven’t had sex with my wife since she found out I had HCV.”

Of interest, participants with families experienced them as being supportive. One said: “I don’t believe it has [harmed his relationships].... My brother has it, my step brother, he has it, my best friend has it....[T]hey are very supportive. They know all about the interferon that I went through, ...that it’s incurable....” Another participant suggested it had brought him closer to his family: “[E]ven the kids showed increased concern.... Asking me what’s going on and asking me what’s going on with the doctors. And I’ve got friends that really developed strong presence you know, it’s kind of neat, I like it.”

Theme 5 – Substance Use Disorders and Chronic HCV

Participants were asked about a history of alcohol and IV drug use and they were asked about how they contracted HCV. A separate theme that emerged was the connection between motivation for recovery from substance use disorders and motivation to seek medical treatment for chronic HCV infection. Some participants reported that they ignored their hepatitis C status until they became clean and sober, and only then were they able to actively get medical care or do

anything about their hepatitis C. “When I first I got diagnosed with it..., I didn’t want to take the hepatitis C treatment cause I didn’t think it was all that bad.... Then when I got sober, ... for a couple of years, then I decided to do something.” Another said, “[I]t wasn’t until ...I was getting sober.... that I found something I could do about it”. Others reported that getting diagnosed with hepatitis C gave them motivation to either initiate or stay active in substance abuse recovery. “[I]t’s an added reason to stay sober....a good excuse not to drink, I can’t party with ya anymore.” Another said, “[F]inding out about that (HCV) was what really regimented me... into the program by staying clean and sober. I go back to the drugs and just turn back on the treatment and everything that has to do with HCV. I mean I’d die a lot quicker....”

Theme 6 – Psychiatric and Medical Co-Morbidity

Many participants reported past psychological problems. Participants viewed psychological issues as being very important when considering treatment options. The following excerpts show the concern two participants had about getting treatment. “I was in Vietnam, my PTSD has gotten me way out in left field. And I’ve talked to people who’s taking that same treatment (Interferon and ribavirin). It’s f**ed them up... really bad.” Another said...“they were going to give the interferon 2 months before I got it, but I was so anxious about taking it... I was having problems with my PTSD and taking Prozac, Dr...., she recommended me to see the psychiatrist.”

Other medical co-morbidities made disease self-management and treatment decisions more complex for both participants and health care providers. Participants listed a variety of conditions when asked about what other medical problems they faced. Comments included the following “I’m not going for ... back surgery for ..., a herniated disk. And I won’t take spinal taps either... I’ve had my leg worked on, I broke my ankle, they put a plate in there. I got my jaw broke and I got a plate up here.” Others said the following: “I got degenerate arthritis, I have emphysema...”; “Probably heart disease and um, ..., emphysema”; “Congestive heart failure, I have severe arthritis on my left knee, due to injury.”

Theme 7 – Antiviral Treatments

Of the 22 participants, eight reported having been treated with antiviral medications. Despite hearing “horror stories” about antiviral treatment, three participants reported that treatment was not as bad as expected. “About the worst thing I’ve experienced was some nausea... but it’s not near of what they said. Even the tape that they show you when you go to the educational class, ... its not near as (bad as that)....” Four of eight participants reported milder symptoms, while another two reported moderate symptoms such as “a lot of fatigue after taking my shot” but found treatment tolerable. Finally, two participants reported that their side effects were severe enough to stop treatment. One participant with a history of depression described his treatment experience as follows: “The first week ...it was ok. ... Second week was flu like symptoms, feeling hot all the time. I couldn’t sleep. ...then it accelerated and the third week... I was up and down, irritable, pissed off, then I would be crying and then I’d be happy. ... the fourth week is when I was late for work ... I felt bad, I wanted to kill, I just wanted to kill somebody. Too much stress. ...I informed my

supervisor ... that I was on (interferon). I saw the psychologist, ... and that's when I volunteered to go to a psychiatric ward."

Theme 8 – Self-Management

Almost all participants expressed a desire to learn more about how they could prevent further liver damage and prevent transmission to others. *"I have to make sure that if I cut myself... no blood will transfer. ... I diet, I try not to eat a lot of fatty type of meals. My family's from the South...."; "I've quit drinking, I've quit smoking, I've quit drugging.. I was 297 lbs and I'm down to 262...because I was told that it'll help my liver."; "... before HCV, I was like... let the medical community take care of it.... I really didn't do my part.... [S]ince I've found out about HCV and became set in my mind,... it's like I set up a habit."*

DISCUSSION

The interviews we conducted with HCV-infected veterans produced important data that was used in the development of a HCV self-management program and may help clinicians better understand the problems and needs of people with HCV. Previous qualitative studies of HCV-infected individuals have not included veterans and have tended to focus on specific subtopics. Although our data are limited to a small convenience sample of HCV-infected US veterans and results are not readily generalizable, our broad focus on all aspects of living with HCV, and lack of restriction on participant responses produced interesting and novel results. We note also that the characteristics of our sample were similar to those of a broader sample of 129 consecutive patients from the VA San Diego HCV clinic⁴¹ and another large study of VA patients with HCV⁴². That sample was 97% male, 77% white, 48% previously married (divorced/widowed), 69% with alcohol disorder, and a median age of about 50 years.

Despite previous studies of HCV-infected persons which concluded that knowledge about the risks of IV drug use was fairly good^{32,33}, our results suggest that participants still have misconceptions about HCV. Recent efforts by the VA National HCV Program address this need⁴³, but more education appears needed. Participant conceptions about "using clean needles," transmission of the virus, the benefit of lifestyle changes, and antiviral treatment can also be addressed through a recently developed self-management program that provides interactive skills training in addition to basic information on HCV.

Social/relationship issues emerged as an important and common theme. Patients reported difficulty with a variety of encounter types including dating, telling people about their HCV, family interactions, and long-term/marital relationships. This is consistent with previous data suggesting that relationships are strained by worries about future health and fear of infection transmission and that such concerns may lead to reduced social interaction²⁸. To address this need, the HCV self-management program includes modules on improving both general and patient/physician communication skills. Participants who reported positive experiences, such as families being brought together and participants getting helpful social support, can serve as peer models for others with difficulty.

VA patients have higher rates of substance use disorders and higher rates of hepatitis C than the general US population^{4,44}. Not surprisingly, high rates of past IV-drug use (73%) were reported (Table 1). The most interesting finding that emerged from the data was the psychological or motivational connection between IV-drug use. Some participants only became willing or motivated to get treatment for their substance use disorders once they knew they had HCV, and conversely, others reported that they were unable or unwilling to do anything about their HCV infection until they became abstinent from substances. This information could have important implications for clinical care and intervention development and has not been described in prior studies with IV drug users^{34,35}. Programs may be more effective if they address both substance use and HCV at the same time. Substance use is addressed on multiple occasions in the HCV self-management program through educational sessions, and in a separate module from a harm reduction perspective.

Similar to previous qualitative studies on antiviral treatment for HCV^{36,37}, some patients reported experiencing serious side effects and intense emotions, but others reported that treatment was very tolerable and listed strategies for getting through them. Some participants obtained information about antiviral treatment from potentially unreliable sources and expressed fear about treatment. Worry was alleviated by obtaining reliable information, and treatment was often less stressful than participants had feared. To address this need, we created a self-management treatment discussion section, where HCV healthcare professionals and peers who have undergone treatment talk about their experience and answer questions for self-management participants.

Similar to previous studies^{10,26,34}, we found that most participants reported a variety of negative feelings when first diagnosed with HCV. Interestingly, we found that reactions to being diagnosed with HCV tended to be less intense or even relief when IV-drug use was present. Regardless of participants' initial reaction, their responses indicated that obtaining reliable information, support, and access to resources from a healthcare professional right away was important. VA patients typically obtain health information and supportive care through their local primary care or hepatitis C clinic but many eligible patients do not seek services. Information and education about HCV are also currently available to VA patients nationwide through a patient Website⁴³.

Consistent with prior studies,^{26,27,30} health-related quality of life was impacted in a number of ways including physical symptoms, psychological symptoms, and impaired occupational functioning⁴⁵. The experience of fatigue was common, but it was often unclear how much of the fatigue was due to HCV versus normal aging or lifestyle (substance use, diet, depression). Previous studies debate whether psychological and cognitive symptoms related to HCV-infection can be attributed to the biological disease process or mainly result from the stress of living with a serious chronic illness^{46,47}. Regardless, psychological symptoms were prevalent in our sample and in previous studies, and therefore deserve attention. Some participants' locus of control in explaining their infection was external while others internalized this attribution. It is unclear whether accepting responsibility for becoming infected is helpful or harmful. Physical and psychological symptoms are addressed in the HCV self-management

program using many different modules including “dealing with difficult emotions,” depression management, fatigue management, relaxation techniques, pain management, and self-talk.

Our study has a number of limitations that should be acknowledged. A small convenience sample was used, so it is difficult to generalize to broader groups. However, the characteristics of our sample are similar to those of other studies of VA patients with HCV^{4,42}. Another limitation was that the interviews were conducted by researchers with clinical health assessment training. Prior experience with more structured approaches may have limited or influenced the qualitative data that were collected.

The interviews produced rich qualitative data on the impact that HCV had on the lives of 22 VA patients. Similar to previous studies, we found that the initial HCV diagnosis was difficult and impactful, that interpersonal relationships and quality of life were affected throughout the HCV experience, and that side effects of antiviral treatment were often significant. Unlike some previous studies, some participants were lacking basic HCV health information. Finally, our study produced novel data about locus of control in contracting HCV, and about how the connection between substance use and HCV may influence patient motivation for treatment and recovery.

The qualitative interviews added the patient perspective to the development of an HCV self-management program that is currently being tested with results forthcoming. Future research should continue to explore the connections between substance use, mental health, and HCV infection, and find ways to address them simultaneously instead of individually. Because antiviral treatment is not successful for most HCV-infected individuals, more research should address the reduced quality of life that these people experience.

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APPENDIX A – QUALITATIVE INTERVIEW QUESTIONS

What other medical problems do you have besides hepatitis C?

When do you think you were first diagnosed with hepatitis C?

Do you know how you contracted or got HCV? Can you share that with us?

What was your psychological or emotional reaction to being diagnosed with hepatitis C? If they don't seem to respond, rephrase as "When you heard you had hepatitis C, how did you respond? How did it make you feel? What kinds of questions did you have? What concerns did you have?"

Overall, how has having hepatitis C impacted your life? How about on a day to day basis? are there problems/concerns/challenges that you have now that you didn't have before you knew about the hepatitis C?

How does it affect your health, or change things medically?

How does it affect other, non-medical parts of your life (like how you relate to others, to your family, things you do/don't do)?

What symptoms have you experienced from your hepatitis C? Are there symptoms you have that might be from hepatitis C or hepatitis C treatments, but you're not sure? Tell me about them. What kinds of things do you do to try to handle your symptoms when you get them?

How has your daily functioning changed since you got hepatitis C? Is it more limited? In what ways?

How has having hepatitis C impacted the lives of your family or friends? Do they know about it? What are their attitudes about it? Have any of them been tested for hepatitis C? Has hepatitis C changed the ways they act with you or you act with them?

What kind of things do you do yourself to help manage your hepatitis C?

Do you think patients should take an active role in helping manage their hepatitis C? What kind of things should an "expert patient" do?

What does "patient self-management" mean to you? What kind of things should be included in a self-management program designed to help patients with chronic HCV?