

A Hepatitis C Support Group

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Hepatitis C infection can place a particularly taxing burden on veterans, who are more likely to have comorbidities that complicate or contraindicate treatment. These authors look at a VA medical center's attempt to ease this burden through a support group.

An estimated 3% of the world population has hepatitis C virus (HCV) infection, and the United States and Europe each have more than four million people infected.^{1,2} As the infection has a high chronicity rate (up to 85%),² and the rate of viral eradication with the standard treatment of pegylated interferon (INF) plus ribavirin remains inadequate, the infection is becoming a worldwide health care burden.

The burden to individual patients—who must cope not only with the liver problems that are associated with the disease but also with the number of harsh adverse effects and psychiatric complications that often accompany HCV treatment—is especially taxing. And veterans can expect an even lower treatment success rate than the general patient population as they are more likely to have disorders that complicate or contraindicate antiviral treatment.³⁻⁶

Although there is still a lack of direction regarding how best to treat patients with these treatment barriers,⁷ data suggest an interdisciplinary context is a safe place to start.⁸ Here at the Jesse Brown VA Medical Center (JBVAMC) in Chicago, IL,

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we developed an interdisciplinary team approach to HCV management. Within this integrative strategy, we identified a clear need for a support mechanism available to patients with chronic HCV infection. As such, the Hepatitis C Support Group was developed in 2002 to meet the emotional, educational, and social needs of these patients.

Very little research has examined the support group as a treatment modality in providing care for veterans with HCV. Studies have indicated that patients with the infection experience considerably reduced quality of life and more adverse psychological, emotional, cognitive, and social effects when they have poorer adaptive coping skills.^{9,10} Additionally, psychosocial factors have been found to be strong predictors of compromised health-related quality of life in veterans with HCV who are not undergoing antiviral clinical trials.¹¹

But has our HCV support group improved our patients' well-being by teaching them better adaptive coping skills and providing them with psychosocial assistance? Here, we examine this question by discussing the integrated HCV management strategy we have employed at our facility and the goals, set-up, and class content of the support group, as well as the characteristics of the group's attendees. We also offer some preliminary data on the support group's outcomes. First, however, we discuss

HCV and its current treatment (including adverse effects) and address the particular implications the infection and treatment have for the veteran population.

HCV AND ITS TREATMENT

About 3.2 million Americans now have chronic HCV.² End-stage liver disease secondary to HCV accounts for about 10,000 deaths per year and 30% of liver transplantations in U.S. adults, making it the major indication for this procedure.^{2,12} Within 20 to 30 years, about 10% to 15% of patients with chronic HCV will develop cirrhosis,¹³ which increases the risk of developing hepatocellular carcinoma to approximately 1% to 4% per year.¹⁴

Currently, the standard treatment for HCV consists of pegylated INF injections once weekly and ribavirin capsules twice daily, unless this combination therapy is contraindicated. The treatment usually lasts for one year, and its goals are eradicating the virus, slowing liver damage progression, and preventing end-stage liver disease. The treatment results in sustained virologic response or viral eradication only about half of the time, however, and this rate can be lower depending on a patient's race, initial viral load, and viral genotype.¹⁵

In one recent study, 80% of patients undergoing antiviral therapy for HCV described moderate to severe problems attributable to the

treatment.¹⁶ Some of the treatment's adverse effects—such as flulike symptoms, nausea, vomiting, fever, malaise, arthralgia, and fatigue—are systemic. Others are neurologic and include poor concentration, seizures, and disorientation. HCV treatment also can have hematologic effects, such as anemia and neutropenia, as well as endocrine and metabolic effects.¹⁷ Furthermore, it can induce, exacerbate, or cause relapse of depression and other psychiatric illnesses.^{18,19}

HCV AND VETERANS

The higher prevalence of HCV infection in the veteran population, as compared to the general population, makes the disease a major concern in the VA.²⁰ About 38,000 veterans were newly diagnosed with HCV in 2001, and about 180,000 received care for this diagnosis during 2002. Current annual VA expenditures for HCV care exceed \$100 million.²¹ In fact, the VA is becoming the largest provider of HCV health care. It is actively involved in screening veterans for risk factors, testing those who are at risk, and providing education regarding HCV and its treatment.

Treatment barriers for veterans

HCV treatment poses specific challenges to the veteran population. For one, there is a high frequency of substance use disorders (SUDs) in veterans with HCV. And intravenous drug use and alcohol use (which further accelerate liver damage) are leading HCV risk factors as well as complicating factors to treatment.³

Additionally, mental health disorders, such as depression and posttraumatic stress disorder, are common in the VA setting and can become very difficult obstacles to overcome before and during HCV treatment. Patients with a history of psychiatric disorders

are more likely than those without such disorders to experience adverse neuropsychiatric effects during treatment, and there is a higher likelihood that these patients will not receive adequate monitoring or follow-up.⁴ Significant, uncontrolled depression or other psychiatric disorders remain strong contraindications to HCV treatment with INF-alfa. Indeed, unstable psychiatric disorders and recent SUDs account for a large percentage of veterans with HCV being deemed ineligible for antiviral therapies.^{22,23}

Other comorbidities that are common in veterans—including uncontrolled seizures, diabetes mellitus, and hypertension—also can complicate or exclude patients from HCV treatment eligibility. Moreover, study findings suggest that only a small proportion of HCV-infected veterans are motivated to seek treatment.²⁴

AN INTERDISCIPLINARY APPROACH

Although clinicians are encouraged to increase the availability of treatment to patients with HCV who also have a comorbid psychiatric illness or SUD, there is apparently no consensus on how best to accomplish this goal.⁷ Data from the European treatment trials with INF monotherapy suggest that patients who have HCV and psychiatric disorders can be treated safely within an interdisciplinary treatment context.⁸ Whether these findings can be extrapolated to a veteran population remains unclear. Nevertheless, they highlight the fact that HCV management requires a high level of dedication to interdisciplinary efforts.²⁵

At the JBVAMC, our HCV team includes specialists from hepatology, pharmacy, psychiatry, and psychology. Once a patient is diagnosed with the infection, a hepatologist evaluates the patient, and, if appropriate, a

liver biopsy is performed. Given the high incidence of adverse psychiatric effects from HCV treatment, a psychiatrist is involved in screening each patient—regardless of psychiatric history—for any psychiatric disorder. If the patient is deemed eligible for antiviral therapy, it is begun right away. A pharmacist assists the patient with every aspect of therapy, from administration to adverse effects management and treatment monitoring.

Regardless of eligibility for treatment, every patient is referred to the support group. The team psychologist runs the group with the assistance of predoctoral psychology interns. In addition, the group is attended once monthly by the team pharmacist and once every six months by a hepatologist. The goals of the support group include encouraging patients to adhere to recommendations to abstain from substance use, to obtain necessary psychiatric care if this is indicated, to consider embarking on the antiviral treatment protocol, and to continue following up in the HCV clinic over time.

SUPPORT GROUP SET-UP

The support group is held at the same time and place as the HCV clinic. This arrangement not only facilitates patient attendance logistically but also allows for better quality of care, as different team members can stay in communication about each patient's condition and progress. In the beginning, the group was held weekly, but as the group has matured and the needs of the more regular attendees have changed, the meetings have been reduced to twice monthly. Since its inception, the support group has been open-ended, and new members can join at any time. Typically, five to eight patients attend the meetings in a small room adjacent to the gastrointestinal clinic.

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The psychologist and interns work with group members to identify their individual psychosocial needs. The small group size enables close follow-up and monitoring of each patient's educational and emotional needs inside a framework of facilitator-led support discussions and clinician-led class discussions.

The group as a support mechanism

One function of the support group is to assist patients who have initiated HCV treatment in dealing with potential emotional and physical adverse effects. As these effects can be much harsher than the disease itself, they eventually can lead to treatment nonadherence and premature discontinuation.

For patients who are experiencing particularly severe adverse effects, the group's primary goal is to provide encouragement. Patients who are more established in the group offer their advice in terms of how they got through their treatment days. These shared experiences also are valuable for patients who are not yet receiving antiviral treatment but are contemplating or are about to begin it.

For those patients who are currently considered ineligible for treatment, the support group provides assistance in regard to coping with any anxieties they feel about their condition and the ways it affects them socially.

The group as an educational tool

The psychologist and interns cover several important topics within the group setting, including communication with family and providers and leading a healthy lifestyle (Table 1). One major aspect of the group content is teaching coping skills to the patients. These skills include relax-

ation techniques and cognitive coping techniques, such as cognitive restructuring, behavioral goal setting, and meditation and visualization. The specific coping strategies that are taught help to ensure patients' emotional stability and maximize their chances of completing the treatment protocol.

The class interventions are targeted toward enhancing self-efficacy and teaching the particular skills that can lead to the development of healthy behaviors and self-care. Since group members are at various stages of dealing with their condition, as well as various levels of psychiatric or chemical stability, the approach to assessment and intervention draws from the work of Prochaska and colleagues, who suggest using a "stages of change" approach to enhance behavioral change.²⁵ The clinician's task, therefore, is to identify the level of readiness for change and approach

the patient in a way that enhances readiness. This approach must be implemented within a group framework that challenges its members.

The psychologist and interns facilitate the involvement of new members, who often may feel overwhelmed by hearing about severe adverse effects from those members already receiving treatment. They work to normalize new group members' fears and anxieties while continuing to encourage realistic activity planning and finding effective outlets for support in their own environments.

Other topics of discussion for the group have included dealing with feelings of isolation that can result from a diagnosis that can be misunderstood by others. In this regard, members want to learn how to respond to others' concerns about the disease and how to feel more comfortable in social interactions with-

Table 1. Topics covered by various clinicians in the hepatitis C patient support group meetings

Topic	Psychologist	Clinical pharmacist	Hepatologist
Coping with chronic disease	X		
Information about latest treatment		X	X
Myths about herbal remedies		X	
Communication with family	X		
Coping with stigma and shame	X		
Healthy lifestyle	X		
Pros and cons of antiviral treatment	X	X	X
Communication with providers	X		
Coping with multiple medical illnesses	X		

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out the burden of intense feelings of shame or guilt.

The team pharmacist provides her expertise on HCV and its treatment options for attendees who have medically related questions. She also reinforces the topics covered by the psychologist. Her medical expertise dovetails nicely with the support aspects of the group. The hepatologist provides additional information about treatment during occasional visits with the group. In our experience, most of the educational needs of the support group come from those patients who know they have an HCV diagnosis and need assistance in deciding whether to embark on antiviral therapy or simply to allow the

clinic to monitor them through regular follow-up.

CHARACTERISTICS OF ATTENDEES

Institutional review board approval was obtained to review the computerized medical records of all patients who were referred to and attended at least one meeting of the HCV support group between its inception (January 2002) and March 2006.

A total of 125 patients attended the group over these four years, most of whom (97%) were male (Table 2). Of all attendees, 99 (79%) had attended one or two classes in a given year, and 26 (21%) had attended three or more in a given year (a fre-

quency that we defined as regular attendance).

Consistent with other reports on veterans with HCV,⁶ a large number of the support group attendees had psychiatric or SUD comorbidities. Specifically, 117 (94%) had a past or active history of SUD and 68 (54%) had a documented psychiatric diagnosis. Notably, the percentage of patients with a psychiatric diagnosis documented was much higher among regular compared with irregular attendees (88% versus 46%, respectively).

Of the patients who attended the support group, 40 (32%) were deemed ineligible to receive antiviral therapy—mostly because of psychiatric instability and active substance

Table 2. Characteristics of the hepatitis C support group patient population

Characteristic	No. (%) of regular attendees ^a (n = 26)	No. (%) of irregular attendees (n = 99)	No. (%) of total patients (n = 125)
Gender			
Male	24 (92)	97 (98)	121 (97)
Female	2 (8)	2 (2)	4 (3)
Ethnicity			
African American	18 (69)	87 (88)	105 (84)
White	7 (27)	9 (9)	16 (13)
Latino	1 (4)	2 (2)	3 (2)
Native American	–	1 (1)	1 (1)
Substance use disorders			
Past history	19 (73)	66 (67)	85 (68)
Active user	6 (23)	26 (26)	32 (27)
Never used	1 (4)	7 (7)	8 (6)
Psychiatric diagnosis			
Yes	23 (88)	45 (46)	68 (54)
No	3 (11)	54 (54)	57 (46)
HCV ^b treatment status			
Tried treatment but not successful	6 (23)	12 (12)	18 (14)
Tried treatment and successful	2 (8)	5 (5)	7 (6)
Monitor only	4 (15)	23 (23)	27 (22)
No follow up	4 (15)	25 (25)	29 (23)
Contraindicated	10 (38)	30 (30)	40 (32)
Other (treated by non-VA provider)	–	4 (4)	4 (3)

^aRegular attendees attended the support group at least three times in a given year. ^bHCV = hepatitis C virus.

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use. In addition, 27 (22%) of patients were offered treatment but chose to be monitored only—mostly due to concerns that treatment might worsen their psychiatric conditions. There were 18 patients (14%) who were treated unsuccessfully. Those patients who tried and responded successfully to treatment—seven (6%)—made up the smallest subgroup.

Of the four female attendees (two of whom were regular attendees), one completed the course of INF-based treatment. The rest were deemed ineligible or opted to be monitored only due to concerns about worsening unstable depression.

As a group, the majority of regular attendees had the following characteristics: past SUD, stable psychiatric conditions, and either failed treatment (23%) or a treatment contraindication (38%).

MEASURING THE GROUP GOALS

Our data show that 100% of patients who regularly attended the support group for one year or more achieved the group goals of adhering to recommendations to abstain from substance use and to obtain necessary psychiatric care as indicated. Furthermore, 30% of these regular attendees (versus 17% of irregular attendees) chose to embark on antiviral treatment. Finally, 96% of the regular attendees followed up and kept appointments in the HCV clinic.

By contrast, for irregular attendees, 78% were contraindicated for treatment, chose to be monitored only, or had no further follow-up with the HCV clinic.

EVOLVING NEEDS

Consistent with other reports on support groups for patients with HCV,²⁷ our group's psychologist has observed that the needs of the attendees change

over time. The newer attendees' needs revolve around wanting information about the disease, to learn how to communicate with their significant other about the disease, to know when and how they may have gotten the infection, and to learn from others' experiences with treatment. By contrast, patients who have attended the group regularly for several years tend to be most interested in coping with the progression of liver disease and with multiple illnesses. A majority of these attendees have either completed antiviral treatment without success or have had to drop out of treatment following the development of complications or poorly tolerated adverse effects.

Despite their differing needs, our active, experienced attendees have indicated in group discussions and individual conversations with group leaders that they prefer to be included in the same group with the newer veterans. They indicate that part of their healing and coping with this chronic disease is to be able to advise the newer members, especially with regard to abstaining from substance use. They also discuss their shared and unique bond of camaraderie with other veterans.

GROUP MEMBER FEEDBACK

In order to evaluate the opinions, needs, satisfaction, and dissatisfaction of attendees to the support group, we developed a brief survey and began to use it in March 2005. We recognize and acknowledge that such a systematic means of evaluating member needs can point us in the right direction in terms of modifying and tailoring the group content. Group members are asked to complete the survey following each support group session. We ensure anonymity and encourage them to leave their responses in a suggestion box.

Of the 125 patients who had attended the group as of March 2006, 10 filled out the survey after a group meeting. An independent party contacted by telephone those patients who had not completed the survey after a support group session or had attended a group session before the survey was initiated. Through these efforts, another 31 survey responses were obtained, bringing the total number of respondents to 41—a response rate of 33%.

The feedback was mostly positive and serves as evidence of patient satisfaction. For example, 60% of the respondents strongly agreed that they learned new and useful information about HCV by attending the group, and 70% strongly agreed they have been able to use the information they learned in the group. The majority (85%) of the respondents strongly agreed that they would recommend the group to other veterans, and none said they would not recommend the group.

The respondents' answers to the question, "What aspect of this group did you like the most?" included: "talking to other veterans," "support from other veterans," and "knowledge by medical providers attending group." Their responses to the prompt, "If I could change anything about this group, it would be" included: "meet more often," "include more sessions with information from other professionals," and "obtain larger space."

It has been our experience that most of the attendees are open in sharing their likes and dislikes in the nonjudgmental context of the support group, particularly when the facilitators encourage such feedback. In fact, on a quarterly basis, one of our group sessions is devoted to eliciting such feedback from attendees. Such discussions fit in well with the spirit of

an open support group where members can discuss their opinions and are a natural part of the group process. Given this experience, we recommend that other group facilitators utilize a combination of systematic and more informal means of eliciting input about the group experience.

A CHALLENGING TREATMENT ENVIRONMENT

Data on other HCV support groups suggest that patients consider these groups to be “their most useful source of information” regarding this disease.²⁷ Overall, our findings show that most of our support group attendees use this group as a one- or a two-time informational and educational session, with fewer using it as an emotional support mechanism. Those patients who have continued to attend over time have a strong commitment to their health and well-being, are psychiatrically stable, and have a past history of substance addiction.

Even with the strong commitment to health on the part of these patients, we clinicians are faced with challenges in treating this population. For example, our group is attended by only a fraction of eligible patients—despite the high prevalence of HCV within our veteran catchment area (Figure). Of those who do attend, the majority (79%) have attended only once.

There are multiple factors that could account for the low attendance rate. Both transportation and financial issues are cited as problematic to more regular attendance.²⁸ Fear of stigma and confidentiality concerns have both been identified as potential barriers to attendance through formal surveys in studies of support groups for patients with HCV in the general population.²⁸ Other researchers cite lack of interest or motivation to receive treatment

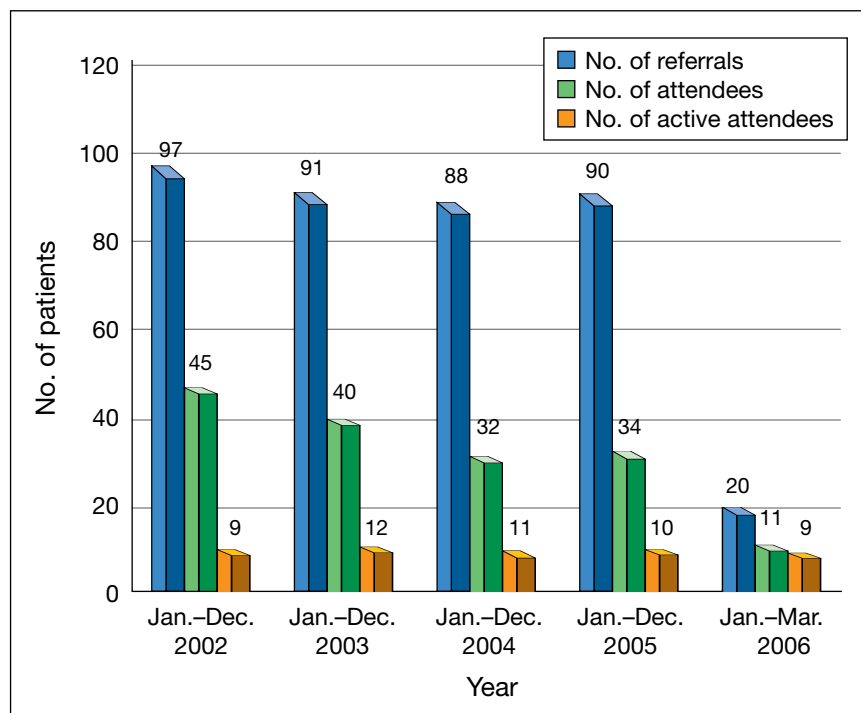


Figure. Patients referred to and attending the hepatitis C patient support group between January 2002 and March 2006.

for a disease that is, by and large, asymptomatic.¹⁶ This is likely mediated through beliefs about illness and one’s own perceived vulnerability and is reflected in the often-stated comments of patients, “I’ve had [HCV] for years and I’m still fine.” The fact that most patients are contraindicated for treatment or simply do not follow up with further testing once they learn of the diagnosis, along with the grim facts on treatment success rates, also lead to lowered rates of support group attendance.

Another treatment challenge is addressing the needs of our female veterans with HCV. It has been difficult to sustain the membership of those women who have attended the group. Only 3% of attendees have been women, and only half of these have attended the group regularly. The reasons have been varied and include relocation to other states, full-time

college attendance, and active substance abuse. Multiple roles as caregivers to children and elderly parents and work and school responsibilities were the primary reasons given by female attendees for lack of regular follow through with group attendance.

Our team has increased active outreach efforts in the past year, including informing the primary care providers more routinely about the availability of the support group to all patients with HCV. A monthly calendar listing the dates, times, and location of group meetings is distributed regularly to primary care providers. In addition, we have a volunteer who contacts the patients with HCV who are scheduled to have clinic meetings with the pharmacy specialist or to attend upcoming classes. This volunteer reminds patients of the group meeting times and mails them flyers about the meetings.

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FUTURE DIRECTIONS

A drawback of our current evaluation is that we cannot compare our support group findings with those of patients who did not attend the support group but who did decide to embark on antiviral treatment. This is an area for future research within this patient population and one that will necessitate obtaining further institutional review board approval in order to address it adequately.

The generalizability of our observations is limited, given the significant range of heterogeneity within the veteran population and in differing geographic regions—where patients represent a different mix of ethnic and psychosocial issues. The JBVAMC serves a predominantly urban patient population and, as such, our observations are likely more consistent with other urban VA facilities. It would be constructive to facilitate communication among providers of support group services for patients with HCV in different VA facilities in order to compare and contrast their experiences in hopes of finding trends, similarities, and unique experiences. Studying these experiences can help to improve the quality of delivered services to this challenging patient population. ●

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