Offers of Hepatitis C Care Do Not Lead to Treatment

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ABSTRACT *Since 2002, clinicians have been encouraged to offer chronic hepatitis C virus (HCV) treatment to patients with injection drug use histories. We conducted 69 baseline and 35 follow-up interviews between September 2002 and November 2004 with HCV patients who were treatment-naïve and receiving regular medical care at an HIV or methadone clinic in New York City at baseline. Of the 31 patients reinterviewed, 20 (65%) were offered treatment but only 2 (7%) were treated. Reasons for failure to be reinterviewed were loss to follow-up at the original site of care (30), death (6), and refusal to be reinterviewed (2). Whereas offers of HCV treatment may be increasing, there is a need to improve continuity of care, patient-provider communication, and patient education regarding HCV treatment options for treatment rates to improve.*

KEYWORDS *Health status, Hepatitis C treatment, HIV coinfection, Methadone maintenance treatment.*

INTRODUCTION

We report on offers and acceptance of hepatitis C virus (HCV) treatment among treatment-naïve HCV patients first interviewed at MMT and HIV clinics in New York City during a period soon after a 2002 NIH Consensus Conference report recommended offering HCV treatment to injection drug users.¹ We reinterviewed patients who remained in care approximately 18 months later.

METHODS

In a study of HCV treatment preferences,² HCV treatment-naïve patients ($n=69$) were recruited and interviewed at five different clinics in New York City. We used the SF-12 v.1,³ rating scales and standard gamble assessments to measure current health, the CES-D 10 to identify depressive symptoms,⁴ and the emotional/informational subscale of the Medical Outcomes Study to assess social support.⁵ At follow-up, patients ($n=31$) were asked if since the baseline interview they had (1) received a liver biopsy, (2) been offered HCV treatment, and (3) among those offered treatment, what they were told about possible side effects and if the treatment had been initiated. Reasons for not being offered or initiating treatment were asked by open-ended questions and responses were coded into 10 categories. Surveys were administered in English or Spanish.

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RESULTS

Patients were primarily African American (45%) and Latino (42%); 19 (61%) were male, 19 (61%) were receiving methadone, and 21 (68%) were HCV/HIV coinfectd. Figure 1 summarizes the disposition of the 69 patients interviewed at baseline. Six (9%) patients had died in the interval, two refused follow-up participation because of time constraints, and 30 were lost to follow-up or had moved out of the area. There were no significant differences in demographic characteristics, current health, depression symptoms, or social support recorded at baseline between those who were reinterviewed and those who were not reinterviewed, although there was a trend to less stable housing at baseline in the lost to follow-up group ($p=0.06$). Among those reinterviewed, mean current health, depression, and social support values were unchanged between baseline and follow-up interviews.

At follow-up, 65% of patients ($n=20$) reported that they had been offered HCV treatment. Two of the 20 accepted treatment and 18 declined: 10 cited personal reasons (no symptoms, fear of biopsy or side effects), 6 cited a provider reason (e.g., need for further evaluation), and 2 were awaiting medical evaluations to decide. Of the two who initiated treatment, one patient discontinued treatment early because of side effects and the other was still receiving treatment. HIV coinfectd patients were less likely to report having been offered treatment compared to HCV monoinfectd patients (55 vs. 91%, $p<0.05$) and Latinos were less likely to report having been offered treatment vs. non-Latinos (25 vs. 73%, $p<0.01$).

LTF= Lost to follow-up

F/U= Patients who received follow-up interview

Refused= Patients who were approached but refused follow-up interview

No/Reason Given= Provider did not give a reason for not offering treatment.

Causes of death were end-stage renal disease (2); HCV-related liver disease (1); other gastro-intestinal disease causes (1); and unknown (2).

FIGURE 1. Disposition of patients.

Of the 20 patients offered treatment, 13 recalled three or more side effects they might experience, four recalled being told about side effects but in less detail, and three reported that they were not told about any side effects associated with HCV treatment. Of the 11 patients who were not offered treatment, 5 reported that their doctors said that they did not yet need treatment and 1 was advised to defer treatment until he stabilized on a new regimen of HIV medications. The remaining five could not recall their provider giving a reason why treatment had not been offered.

DISCUSSION

Of those patients who remained in care, about two thirds were offered HCV treatment but very few patients initiated treatment. Some of the reasons given for refusing treatment may represent an informed consideration of the trade-offs between the benefits and adverse effects. However others reasons, such as absence of physical symptoms and fear of liver biopsy, appear to reflect insufficient understanding of HCV diagnosis and treatment. Many patients who had been offered treatment could not recall receiving a full explanation of HCV treatment side effects from their provider.

We also found that an important barrier to HCV treatment in this population is the lack of continued engagement in medical care at the same site. More than half were no longer in care at the same site after an average of 18 months. There was also a high mortality rate of 9%, indicating that another important barrier may be competing morbidities or advanced liver disease.

Our study is limited by its small sample size, which had been predetermined by our baseline survey objectives, and a high rate of loss to follow-up. It is also possible that patients who were reinterviewed did not adequately recall discussions with their provider about their illness or treatment options. Yet, even if inadequate recall existed, the patients' responses reflected their current understanding of their HCV treatment options. HCV patients who remain in MMT or HIV care are in regular and routine contact with their providers, who can keep them informed of their HCV health status and treatment options. Whereas offers of HCV treatment may be increasing, there is a need to improve continuity of care, patient-provider communication, and patient education regarding HCV treatment options for treatment rates to improve.

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