Managing Chronic Hepatitis C in Primary-Care Settings: More Than Antiviral Therapy

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Millions of Americans have chronic hepatitis C, which can cause cirrhosis, liver failure, and liver cancer.[1,2] Most scientific literature and educational materials discuss antiviral medications as if they are the only treatment for hepatitis C. Although antiviral medications may eradicate hepatitis C virus (HCV) infection, overemphasis of anti-HCV medications by pharmaceutical manufacturers and patient and health-care provider interest in curing the infection have contributed to the failure to recognize the broader health needs of people with chronic hepatitis C. This article argues that (*1*) treatment of hepatitis C must be more broadly defined, (*2*) primary-care providers are the logical source of care for most people living with hepatitis C, and (*3*) increases are needed in both the capacity to deliver hepatitis C care and the funding for such care.

MILLIONS OF PEOPLE IN THE U.S. ARE LIVING WITH CHRONIC HEPATITIS C

The primary source of national estimates of HCV prevalence is the National Health and Nutrition Examination Survey (NHANES), which studies a representative sample of noninstitutionalized people in the United States.[3] Using NHANES data from 1999 through 2002, Armstrong et al. estimated that 4.1 million people (1.6% of the population aged 6 or older) have been infected with HCV at some time in their lives and 3.2 million people (1.3%) have evidence of chronic infection.[1] However, NHANES may substantially underestimate the extent of HCV infection in the U.S. because it does not include some large groups known to have high HCV prevalence, such as prisoners and people who are homeless.[2] Adding the groups excluded from NHANES, Edlin estimated that about 5 million people have been infected with HCV and about 4 million people have chronic hepatitis C.[2] Based on these estimates, three or four times as many Americans have chronic hepatitis C than the approximately 1 million Americans living with human immunodeficiency virus (HIV).[4] Only about half of people with chronic hepatitis C are estimated to be aware of their infection.[5]

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HEPATITIS C: A CHRONIC ILLNESS WITH MULTIPLE CLINICAL PRESENTATIONS

Chronic hepatitis C is often described as an asymptomatic infection that, after many years, causes morbidity and mortality in a fraction of infected individuals. In fact, well before severe liver damage occurs, many people with chronic hepatitis C have symptoms, disabilities, and diminished quality of life.[6–8] At all stages of chronic hepatitis C, the most common complaints of patients are fatigue, "brain fog" (i.e., difficulty with memory and concentration), and chronic pain (usually in muscles and joints without evidence of inflammation). Other conditions and symptoms include depression, nausea, and abdominal pain.[6–9] Many patients feel alienated from health-care providers because of HCV-related stigma and because some providers dismiss their symptoms as having no medical basis.[10,11]

UNCERTAINTIES ABOUT CHRONIC HEPATITIS C NATURAL HISTORY AND WHO NEEDS ANTIVIRAL TREATMENT

Our understanding of the natural history of chronic hepatitis C comes from two epidemiologic perspectives: studies of people infected by transfusions or other defined exposure and studies of patients seen for liver disease. These two perspectives give substantially different pictures of the natural history of chronic hepatitis C, with studies of people close to the time of infection portraying a much lower level of major complications (cirrhosis, hepatocellular carcinoma, and hepatitis C-related mortality) compared to studies of liver disease patients.[12,13] Unlike HIV infection, which eventually causes severe illness in essentially all people who are infected, many of the millions of people with chronic hepatitis C will live full lives with few consequences of their HCV infection.[12,13] Currently, we are unable to accurately identify the individuals who will develop progressive HCV disease and benefit from antiviral treatment. In addition, promising new antiviral medications currently being evaluated, such as protease and polymerase inhibitors, may in the future provide substantial clinical improvements compared to the currently recommended treatment with pegylated interferon and ribavirin.[14]

COMPREHENSIVE HEALTH CARE TO HELP PEOPLE UNDERSTAND, LIVE WITH, AND AVOID TRANSMITTING HCV INFECTION

Patients with chronic hepatitis C need information about HCV transmission and how to prevent it, the stage of their illness, symptoms, prevention of progression, and options for antiviral treatment. Health-care providers can help patients prevent complications and progression of chronic hepatitis C. First, people with chronic hepatitis C should, if susceptible, be vaccinated against hepatitis A and B. Second, providers should advise patients to abstain from or minimize alcohol use. Alcohol abuse and dependence are common co-occurring conditions in hepatitis C.[1] Screening for alcoholism and using brief interventions to reduce alcohol use are important skills for providers caring for patients with or at risk for HCV infection. Third, patients who inject illicit drugs are at risk of acquiring HIV infection and transmitting HCV to other drug users. They should be informed about substance abuse treatment; safer injection practices; and how to obtain harm-reduction services including access to sterile syringes. Fourth, because co-infection with HIV can speed up the progression of liver disease from HCV infection, patients should be tested for HIV and provided care if found to be infected. Finally, providers can help patients avoid common hepatotoxic medications.

People with chronic hepatitis C also need information about antiviral treatment options (currently pegylated interferon and ribavirin). In addition, they need help to determine: (*1*) their eligibility for antiviral treatment; (*2*) the urgency of treatment based on presence of liver fibrosis or other factors; (*3*) the likelihood of successful treatment (attaining sustained viral response [SVR]) based on factors such as having genotype 1 HCV infection or being African American, which are associated with lower response rates; and (*4*) whether they have contraindications to such treatment. Because of treatment side effects, patients receiving antiviral treatment require extra support and monitoring.

Ongoing care for patients who do not initiate antiviral treatment or for whom antiviral treatment is unsuccessful includes monitoring for signs of cirrhosis, liver failure, and hepatocellular carcinoma (in those with known or suspected cirrhosis);[15] managing symptoms; helping patients with hepatitis C-related disabilities obtain appropriate benefits;[16] referring appropriate patients to research studies; and, in advanced cases, referring eligible patients for liver transplantation evaluation, palliative treatment of cirrhosis, and end-of-life care.

Because many people with chronic hepatitis C are marginalized and stigmatized, support groups, chronic disease management approaches, and multidisciplinary care approaches can help improve care.[17,18] These approaches emphasize engagement and trust-building and include using peers and case management to provide comprehensive and culturally appropriate care.

Primary-care settings are well suited to providing care for people with chronic hepatitis C because primary care (*1*) is much more widely available than specialty care, (*2*) can create and sustain a long-term relationship between patients and care providers, and (*3*) provides comprehensive care that addresses a patient's physical, behavioral, and family/community needs.[19–22]

ANTIVIRAL HCV TREATMENT: AN IMPORTANT ASPECT OF HEPATITIS C CARE THAT IS POTENTIALLY LIFE-SAVING

Current antiviral treatment regimens can achieve SVR (i.e., reduction of HCV below detectable levels at six months after the end of treatment) in up to 50% of people with the most common genotype (type 1) and up to 80% of people with other genotypes (types 2 and 3).[23] Although HCV can be detected by more sensitive assays in some patients with SVR,[24] most patients who achieve SVR appear at very low risk of HCV infection relapse and may be thought to have achieved a clinical cure of the HCV infection.[25] However, many people with chronic hepatitis C do not receive antiviral medications because they (*1*) do not know they have HCV infection;[4,26] (*2*) cannot obtain care because of inadequate health insurance and/or trained providers are not available; (*3*) are considered, often mistakenly, ineligible for treatment because of continued alcohol use, unmanaged psychiatric illness, or failure to keep appointments;[27–30] or (*4*) although eligible, choose not to be treated because of concerns about cost, adverse effects, and/or preference to wait for improved antiviral treatment options. For example, at the Tom Waddell Health Center in San Francisco, only 52 (5%) of the 1,034 patients with chronic hepatitis C have received antiviral treatment (Tom Waddell Health Center, unpublished data, 2006).

Antiviral treatment is expensive and demanding for both patients and health-care providers. Quality of life during treatment with pegylated interferon and ribavirin almost invariably declines, with common severe adverse effects including anemia, depression, and flu-like symptoms.

DEMAND FOR SPECIALTY HEPATITIS C CARE OUTPACES AVAILABILITY

It is generally recognized that the number of gastroenterology, hepatology, and infectious disease specialists who are available to treat hepatitis C is insufficient to provide care for the millions of people with chronic hepatitis C. This is particularly true in some rural areas and prisons where there is a shortage of medical practitioners. For example, in New Mexico, where 32 of the 33 counties are listed as medically underserved and 14 are designated as health professional shortage locations, most hepatitis C specialists practice in the academic health center at the University of New Mexico in Albuquerque.[31] In addition, primary-care providers in training and in practice need additional training about chronic hepatitis C care.[20,22,32]

CHRONIC HEPATITIS C DISPROPORTIONATELY AFFECTS PEOPLE WHO ARE STIGMATIZED AND HAVE LIMITED ACCESS TO HEALTH CARE

Many people with chronic hepatitis C are marginalized and stigmatized; for example, prisoners, homeless people, present or former injection drug users, and immigrants from countries with high HCV prevalence associated with widespread needle and syringe reuse in medical and household settings (e.g., Egypt and Bolivia).[33] In the U.S., many people with chronic hepatitis C live in poverty and have limited access to health care because they are uninsured, underinsured, or lack other support for health care.[34] The limited access creates substantial barriers to receiving care for chronic hepatitis C.[34] For example, sexually transmitted disease clinics that screen clients for HCV have experienced considerable difficulty finding medical evaluation and care for people with positive HCV screening test results that did not have health insurance or other support for health care. The difficulty finding care has, for some, raised doubts about the merits of HCV screening.[35–38]

Financial obstacles to care for chronic hepatitis C have prompted a variety of responses to increase access to and availability of affordable care. For example, federal funding improves access to hepatitis C care for some qualified veterans and people living with HIV. Veterans have access to health care through the Department of Veterans Affairs (VA) health system; those with limited financial resources can receive comprehensive care at little or no cost. Because of the 1998 National Hepatitis C Program, which mandated a variety of hepatitis C services including treatment, the VA treats more people with hepatitis C than any other health organization in the United States.[39] An integrated, co-management model of care for veterans diagnosed with chronic hepatitis C has been developed by providers working through the Northwest Hepatitis C Resource Center and includes psychiatric and substance abuse screening and treatment as an integral part of care.[40]

In addition, some people who are co-infected with HCV and HIV have access to care through the Ryan

White CARE Act.[41] In many states, the Ryan White CARE Act covers care for chronic hepatitis C. For example, the Alameda County Medical Center in Oakland, California, has a co-infection clinic where HIV primary-care clinicians and staff also provide HCV care and treatment to co-infected patients.[42]

A number of innovative, small-scale models have improved access to care for chronic hepatitis C for people with little or no health insurance. Hepatitis C care has been incorporated into health-care services for the homeless at the Tom Waddell Health Center in San Francisco.[43] In Maryland, in 2000, a tax-exempt corporation (Frederick County Hepatitis Clinic, Inc.) was created to attract donations to help fund care for people with chronic hepatitis C. As of 2005, the Frederick County clinic had provided care to more than 1,000 people with chronic hepatitis C.[44]

Another innovative and promising model for overcoming the shortage of trained care providers and economic barriers is Project Extension for Community Healthcare Outcomes (ECHO) in New Mexico. Project ECHO uses an innovative distance-learning system that allows academic medical center specialists to work with primary-care providers in rural areas and prisons. Through Project ECHO, the specialists have helped primary-care providers manage specific patients and increase their ability to care for people with chronic hepatitis C.[31]

CONCLUSION

Although antiviral treatment for chronic hepatitis C can reduce HCV transmission, symptoms, and mortality, it is currently useful and successful in a minority of those who are infected. Chronic hepatitis C requires long-term care to reduce transmission, reduce disability, decrease progression to cirrhosis and hepatocellular carcinoma, provide education and support to patients, and improve quality of life. It is important to increase provider skills and willingness to screen for substance abuse, to deliver brief interventions to help reduce alcohol abuse, and to help patients obtain substance abuse treatment. For these reasons, we should recognize that antiviral treatment is only one element of comprehensive care for patients with chronic hepatitis C and that primary care is the most appropriate setting for most people living with chronic hepatitis C.

Major barriers exist in delivering primary care to people with chronic hepatitis C. These barriers affect those who are currently in need and are likely to be worse in the future because of progressive illness of the cohort infected in the 1970s.[45] These barriers will also affect the large number of people with chronic hepatitis C who will be identified through expanding HCV screening in private and public health settings, as recommended by the Centers for Disease Control and Prevention. The number of providers trained and available to provide care for people with chronic hepatitis C, especially patients without health insurance, does not meet current needs. Federal funding supports care for many veterans and people co-infected with HIV, and some local efforts have expanded the availability of HCV care. Even so, many people with chronic hepatitis C do not have access to the care they need. To meet these and future needs in the United States, more primary-care clinicians must be trained to provide care for people with chronic hepatitis C, and funding for long-term care of people with chronic hepatitis C must be increased. Policy makers should consider creating systems for chronic hepatitis C provider training and care reimbursement modeled on the successful HIV programs of the AIDS Education and Training Centers[46] and the Ryan White CARE Act.[41]

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