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Hepatitis C: The New Epidemic

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This material is presented as a foundational overview, to assist the life care planner to learn about HCV and implications for life care planning practice.

Discovered in 1989, hepatitis C virus (HCV) has rapidly taken the forefront as a worldwide health issue. HCV has been labeled an instant epidemic, since it was spreading throughout various populations before identification. It is one of the most common causes of liver inflammation and a leading cause of liver transplantation. Approximately 4 million Americans have been infected with HCV, while 2.7 million have detectable virus in the blood (Bernstein, 2002).

According to the National Health and Nutrition Examination Survey study, the greatest prevalence of HCV is seen in the age group 44-59 years, with African Americans having the highest rate at 6.1%. Of those infected, 85% will develop chronic, active infection leading to various levels of liver inflammation and damage (as cited in Berger, 2000).

Risk Factors

Hepatitis C is transmitted parenterally (through injection into subcutaneous tissue, muscle or intravenously). Causes include intravenous drug use, blood transfusions before 1992, accidental needle sticks among health care workers, tattooing and body piercing. Other risk factors include kidney dialysis, intranasal cocaine use and sharing of household items. Perinatal transmission has been identified, although transmission through breast-feeding mothers infected with HCV has not been reported. Research continues regarding various other modes of transmission and controversy surrounds the question of sexual transmission (Bernstein, 2000).

The incubation period for HCV appears to be 6-7 weeks. An acute infection produces nonspecific symptoms in 25-35% of those infected, such as fatigue, weight loss, poor appetite, abdominal pain and depression. Most have no symptoms at all. Anti-HCV antibodies appear to be produced in 90% of patients by 12 weeks post infection and 85% of these will go on to develop chronic HCV infection. The discovery of HCV within an individual may occur upon analysis of blood work done during an insurance or work physical since consent to evaluate for HCV is not required.

The progression of hepatitis C is unknown (Berger, 2002). At this time, medical science cannot determine a date of onset, nor the impact of external/internal factors which lead to chronic disease. The certainty for those with HCV is chronic illness. These individuals continually shed virus into the bloodstream, which in turn results in viral liver inflammation. This

chronicity leads to elevated liver enzymes, detectable in the blood, and necrosis of the liver, detectable through biopsy. Some patients develop cirrhosis and of these, some may progress to hepatocellular carcinoma. End stage liver disease caused by HCV is the leading cause of liver transplantation (United Network for Organ Sharing – UNOS, 2001).

Treatment Issues

The primary goal of treatment for HCV is viral eradication. Successful achievement of treatment is defined as undetectable virus in the bloodstream six months after completion of antiviral therapy. Additional treatment goals include decreasing liver necrosis, halting disease progression, preventing hepatocellular carcinoma (HCC) and preventing transmission of the virus. Quality of life improvement is anticipated following therapy.

Antiviral therapy currently approved in the United States includes: interferon-alpha – 2a; interferon-alpha – 2b; interferon-alpha – con-1; pegylated interferon-alpha – 2b, combination interferon-alpha-2b with ribavirin. Pegylated interferon-alpha – 2b and ribavirin is approved, while pegylated interferon-alpha 2a in combination with ribavirin awaits approval. Pegylated interferon may be administered subcutaneously once weekly, with dosage based upon the individual's weight. Interferon alone requires subcutaneous injections three times weekly for 12-48 weeks. The decision to proceed with antiviral therapy is between the patient, family and provider (Berger, 2000). A strong support system is required throughout the therapy program.

One of the most significant treatment issues in HCV is the individual's willingness and ability to comply with the treatment regimen (Bernstein, 2000). Each individual who is diagnosed with HCV requires thorough patient education in order to make an informed decision about treatment options. It is critical that the individual and his/her support system understand the expected side effects of treatment and the need for commitment to completion of treatment.

Side effects impact the patient and family throughout therapy. Common side effects are nausea, vomiting, diarrhea, lack of appetite leading to weight loss, extreme fatigue, muscle pain, fever, chills, blood picture changes, sleep disturbance, depression, confusion, encephalopathy, skin changes and decreased pulmonary function. It is not uncommon to see changes in the teeth, resulting in loss of jawbone mass, loosening of teeth and repeated oral infections (Bernstein, 2002). Due to these severe expected side effects, it may be a difficult decision to move forward with treatment, knowing also, that side effects may not resolve with completed treatment.

Clearly, side effects prevent an individual from participating in work and many activities of daily living or activities important for quality of life. Treatment periods range from 24 weeks to 48 weeks and patients describe therapy as allowing "good days and bad days." A usual day was described by a patient as: "…waking and vomiting all night. Pain is indescribable and cannot be controlled. Anything I can take to really stop the pain would cause liver damage – so the doctor cannot even prescribe anything for pain. Every time I try to eat, nothing sounds good and nothing tastes good. If I didn't want a chance to live, I would never have done the therapy." (Personal communication, April 2002).

Another treatment decision is whether or not to proceed with a liver biopsy (Berger, 2000). Diagnosis of HCV infection is made by laboratory testing of liver enzymes and an enzyme-linked immuno-sorbant assay (ELISA), which detects antibodies against hepatitis C virus. Liver biopsies, however, clarify early fibrosis, the level of tissue damage and the presence of cirrhosis. This diagnostic information may guide the treatment protocol, but some

researchers believe the data obtained through biopsy may not add to information obtained through blood testing and clinical correlation of symptoms. Biopsy may not be of value if the decision to treat with antiviral medication has been established.

Age is a factor when considering HCV therapies. Interferon is not FDA approved for persons under 18. HCV patients who are over 60 are carefully analyzed for potential benefit due to the side effects of interferon therapy and the risks associated with comorbidities. One study suggested a patient age 20 would gain 3.1 years of life expectancy with interferon treatment, while a 70-year old may gain only 22 days (Bennet, Inoue, Beck, 1997).

Cost Effective Treatment

Due to the epidemic expansion of HCV in the United States, the annual estimated cost for treatment of HCV infection is $5.6 BILLION (Bernstein, 2002). Questions revolve around who to treat, when to treat and the length of treatment. Currently, the most cost-effective strategy for HCV treatment appears to be genotype testing. Genotype testing identifies the genetic makeup of the virus, which in turn generates the potential to predict therapeutic outcomes. Genotype testing offers the promise of development of medication specific to the virus genome.

Mass screening for hepatitis C has been shown not to be cost efficient. However, risk factor identification, prior to screening, may mitigate poor cost efficiency in mass screening efforts. Some researchers believe that mass screening of high-risk populations may offer educational opportunities to decrease the spread of the disease.

Once a diagnosis of HCV is made, treatment options must be considered. It is estimated that 40% of HCV patients diagnosed are candidates for antiviral therapy and various research reports conclude that therapy should be initiated immediately (NIH, 2000). Currently, treatment length is based upon the genotype of the virus.

Cost concerns for treatment present a reality in today's managed health care environment. Bennet and Koff have researched various treatment models and have demonstrated costs for producing one year of increased life expectancy from $500-$62,000. Variables include age, response to treatment and progression of the disease. Current cost estimates for interferon alone are $6,250 to $12,500 and costs for all supplies and medical care for 24-48 weeks of therapy exceed $12,000-$30,000. This cost can escalate with complications and need for paid care providers.

Comments

Hepatitis C infection is an increasingly common diagnosis in those who received blood products, health care workers and intravenous drug users. Transmission is primarily parenteral and infection can be diagnosed within three to six months after exposure. More than 80% of those diagnosed with HCV will develop a chronic infection which can progress to active hepatitis, cirrhosis or hepatocellular carcinoma. Hepatitis C cannot be cured and treatment with current therapies produce less than a 50% response rate after 12-18 months of treatment. The cost for treatment and complexity of patient needs for those with HCV creates a need for life care planning for these patients.

Resources

1. American Gastroenterological Association
   7910 Woodmont Avenue, Seventh Floor
   Bethesda, MD 20814
   301-654-2055
   www.gastro.org

2. American Liver Foundation
   1425 Pomptom Avenue
   Cedar Grove, NJ 07009
   800-GO-LIVER (800-465-4837)
   888-4HEP-ABC
   www.liverfoundation.org

3. CDC Hepatitis Resource Center
   www.cdc.gov/ncidod/diseases/hepatitis/resource/index.htm

4. Centers for Disease Control and Prevention
   1600 Clifton Road
   Atlanta, GA 30333
   404-639-3311
   888-4-HEP-CDC
   www.cdc.gov

5. Chronic Hepatitis C:
   Current Disease Management
   www.niddk.nih.gov/health/digest/pubs/chrnhepc/chrnhepc.htm

6. Common Laboratory Tests for Liver Disease
   cpmcnet.columbia.edu/dept/gi/labtests.html

7. Customizing Treatment for Patients with HCV
   www.projectsinknowledge.com/HCVDSS/index.html

8. Facts Regarding Hepatitis C
   www.hopkins-id.edu/diseases/hepatitis/hcv_faq.html

9. Hep C Connection
   www.hepc-connection.org

10. Hepatitis C
    www.emedicine.com/emerg/topic244.htm

11. Hepatitis C
    www.hep-help.com

12. Hepatitis C
www.MayoClinic.com/home?id=5.1.1.8.9

13. Hepatitis C: An Update
www.fda.gov/fdac/features/2001/401_hepc.html

14. Hepatitis C Fact Sheet
www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm

15. Hepatitis C Outreach Project
P. O. Box 248
Vancouver, WA 98666
888-968-4267
www.hcop.org

16. Hepatitis Foundation International
30 Sunrise Terrace
Cedar Grove, NJ 07009-1423
800-891-0707
www.hepfi.org

17. Hepatitis Research Foundation
www.hcrf.org

18. National Institute of Allergy and Infectious Diseases
31 Center Drive MSC 2520
Bethesda, MD 20892-2520
301-496-7051
www.nida.nih.gov

19. National Institute of Health Consensus Statement
odp.od.nih.gov/consensus/cons/116/116cdc_intro.htm

20. United Network for Organ Sharing
www.unos.org

21. What You Should Know About Hepatitis C
www.niaid.nih.gov/dmid/hepatitis/hepcfacts.htm

22. World Health Organization
Avenue Appia 20
1211 Geneva 27
Switzerland
(+00 41 22) 791 21 11
www.who.int

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