



Hepatitis C: Are You Confused?

Issues Related to Patient Education

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More than 4 million Americans are infected with the hepatitis C virus. Although overshadowed by acquired immune deficiency syndrome, the hepatitis C epidemic is now recognized as a major health problem. Prevalence is estimated to be anywhere from 1.2% to 10% in specific populations. Nurses continue to express confusion in understanding the disease process; therefore, many opportunities are missed to counsel patients and families who may be at risk or who have hepatitis C. Many patient questions go unanswered because nurses mistakenly assume the medical provider will educate these patients and families. However, nurses have more contact with patients, and one of the nurse's roles is to provide health education. The Society of Gastroenterology Nurses and Associates and the Joint Commission on Accreditation of Healthcare Organizations agree it is the nurse's role to educate patients. Accurate hepatitis C virus information helps nurses guide patients and families in understanding this disease process.

The hepatitis C virus (HCV) is a blood-borne disease that attacks the liver. Many people do not know they are infected because there are no symptoms in the initial stages of the disease. However, hepatitis C can slowly progress to cirrhosis (scarring of the liver), liver cancer, or death (Alter, 1997).

Background

More than 4 million Americans (nearly 2% of the population) are infected with HCV. The U.S. Centers for Disease Control and Prevention (CDC) estimates the death toll from hepatitis C will triple during the next decade (<http://www.cdc.gov>), surpassing that associated with acquired immune deficiency syndrome (AIDS).

Hepatitis C virus is commonly referred to as the "silent epidemic." The laboratory test to identify individuals infected with HCV did not become available until 1990. Because individuals with HCV could not be identified or have disease diagnosed before that time, the HCV disease silently progressed for 20 to 30 years (Kim, 2002).

When testing became available in the early 1990s, the new laboratory test was not always accurate; some results were false positives or negatives. In those early years, many individuals merely received a letter in the mail from their blood bank informing them of their diagnosis of hepatitis C and stating their donated blood was rejected (Seefe, 2002). These individuals were advised in the letter to contact their primary medical provider. No written educational information explained the laboratory test result or informed these individuals specifically where to go to obtain additional medical evaluation and information. Not surprisingly, these patients and families experienced fear and confusion because of this lack of information or erroneous information.

Because of the stigma associated with AIDS, individuals in these early days were afraid to share their diagnosis with others for fear of being socially rejected. Many people associated hepatitis C virus with a contagious disease and attached a judgmental stigma related to alcohol or street drug use (National Institutes of Health [NIH], 2002).

Support for Patients With HCV

Because of the general lack of accurate information available with this new diagnosis of hepatitis C, the first liver support group for patients with HCV and their families began in 1991 (Veterans Affairs [VA], 2003). This was a grassroots effort started by two nurses who facilitated the group. The goal was to provide accurate HCV information to patients and families (Jessop, 2004) because no written

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information was available regarding this new disease. Individuals with newly diagnosed HCV needed to be educated regarding transmission issues and potential screening tests to evaluate their liver (Sylvestre, 2003).

Individuals with HCV were excluded from traditional liver groups unless they were listed for a liver transplant. During this early period, medical providers advised those with recently diagnosed HCV to return to the medical provider when their laboratory values showed liver damage, abnormal liver function, or when the patient experienced symptoms such as bleeding, edema, or increased fatigue. However, recent research results (Bacon, 2002) reveal liver disease may progress with no symptoms. Laboratory values used to evaluate liver function, such as alanine aminotransferase (ALT) and prothrombin time (PT), may actually appear within normal limits even though the hepatitis C virus is replicating and causing liver damage (Wright, 2002). Currently, the complications from HCV and advanced liver disease are becoming more evident in hospitals, clinics, and emergency rooms. More patients are presenting for treatment of HCV complications, including paracentesis, banding for esophageal varices, and management of portal hypertension (Wright).

Unfortunately, although there is an increase in patients with HCV, referral for HCV counseling and education is rarely initiated. Nurses interview patients daily as part of their role in assessing patients' knowledge, yet questions are seldom asked that focus on determining if a patient is at risk for HCV or has HCVCV. The nurse may be unfamiliar with or confused about ways to assist a patient or family exposed to HCV. Many nurses state they do not know what to ask patients regarding HCV. However, one aspect of nursing is the use of scientific principles to guide patient education (Manning, 2004), and nursing care of patients includes providing sources of education to those who have HCV. It is imperative the nurse caring for patients with HCV learns as much as possible about the disease and its complications so he/she can assume the role of patient educator.

Hepatitis C Virus Education

The first step in patient education regarding HCV is to assess and counsel those who might be at risk and who have not been tested (Alter, 2002). Accurate knowledge is essential. Counseling also should include reassuring information for the patient regarding management of the disease (Alter; VA, 2003). Education for patients with HCV also should include how to reduce the risk of transmission to others and prevention of other diseases for those who are at high risk for acquiring such diseases as human immunodeficiency virus (HIV) (Straits-Troster, 2003).

The NIH 2002 Consensus Conference on Hepatitis C established the current guidelines for the management of HCV (http://consensus.nih.gov/cons/116/091202116cdc_statement.htm). The statement recognized and encouraged patient education and support groups for those with newly diagnosed HCV, those undergoing therapy, and those recovering from addiction (NIH, 2002).

Hepatitis education is considered by many to be the physician's responsibility as part of the evaluation of the patient. However, patients with HCV have reported communication problems with their physicians (Zickmund, 2004). The nurse has more frequent contact with patients and thus should

assume the role of patient educator to facilitate referrals for testing, counseling, and education.

Diagnosis Confusion

The confusion about the diagnosis of hepatitis C is mainly attributable to the lack of education (Huber, 2001). Nurses have little knowledge about HCV and the functions of the liver. Educational guidelines should be established for nurses because accurate HCV and liver information will help nurses to guide patients and families to an understanding of the disease.

Nurses often ask patients if they have tuberculosis (TB), are HIV positive, or have been exposed to hepatitis (Alter, 2002). However, the patient with HCV is rarely asked by the nurse if he/she would like more information or a referral to a HCV nurse specialist or liver clinic. This is usually because the nurse does not have this information or does not know how to make a referral.

Nursing Education About HCV

As part of their teaching and assessment skills, nurses should be able to educate and counsel patients with HCV or those who are at risk for exposure to HCV. To do this, nurses need to know the functions and description of the liver, as well as risk factors and modes of transmission for HCV. Additional terminology related to HCV and the liver is highlighted in Table 1.

FUNCTIONS AND DESCRIPTION OF THE LIVER

The liver is the largest internal organ, weighing 3 pounds. It is located on the right side of the abdomen and is the only known internal organ that regenerates its cells. The liver performs more than 500 bodily functions, including digestion, metabolism and storage of nutrients, toxin filtration, and blood clotting factors (Society of Gastroenterology Nurses and Associates [SGNA], 2003).

RISK FACTORS AND MODES OF TRANSMISSION

Hepatitis C virus is transmitted primarily through blood (blood-borne virus), typically through sharing needles to inject drugs or, before 1992, receiving a blood product or transfusion. Before 1990, blood products were not adequately screened for the virus. Hepatitis C virus was also referred to as non-A, non-B hepatitis (Seefe, 2002).

Other risks for HCV blood exposure may include tattoos, body piercing (especially those done with a lack of sterile conditions), sharing of drug paraphernalia such as cotton balls to wipe the skin before use of intravenous drugs, or sharing straws for inhalation of nasal drugs (Alter, 2002). Individuals undergoing dialysis are also at risk because of their frequent exchange of blood (NIH, 2002). Sexual transmission is low; however, individuals with multiple partners are at higher risk (Terrault, 2002). The disease usually progresses to chronic hepatitis and may be fatal. No vaccine is available to prevent HCV (Hoofnagle, 2002).

Natural History or Progression of HCV

Natural progression of HCV varies with each individual. About 15% to 25% of patients may naturally clear the virus. This means that when their blood is tested, there is no detected or measurable amount of virus present (also called viral clearance) (Hoofnagle, 2002; Seefe, 2002).

TABLE 1

Glossary of Terms

Alanine aminotransferase (ALT): the enzyme released from damaged liver cells that is measured in the blood. A number elevated above normal range may indicate damaged liver cells (Bacon, 2002). Elevation can be due to added stress to the liver caused by toxins, alcohol, medications, or viruses. This number may fluctuate in individuals with detectable (viral load) hepatitis C virus (HCV); it may be normal or elevated (Bacon).

Antibody to hepatitis C virus (ANTI-HCV): the antibody directed against HCV. Its presence in the blood often indicates HCV infection. This antibody has not been shown to protect against HCV.

Cirrhosis: excessive scarring of the liver tissue. When liver cells are stressed or damaged, they may initially regenerate. After a long period of time or because of too much stress (e.g., alcohol, viruses, or some drugs), liver cells become permanently damaged. They are not able to regenerate and scarring gradually develops in the liver. If the liver is heavily damaged (cirrhosis), it is no longer able to carry out its normal function or regenerate damaged cells (Wright, 2002).

There are degrees of cirrhosis depending on the amount of scar tissue.

a. Compensated cirrhosis is when the liver is scarred, but can still function.

b. Decompensated cirrhosis occurs when the liver has sustained so much damage, scar tissue may block the normal flow of blood through the liver. Complications include portal hypertension, varices, ascites, and kidney damage (Wright, 2002). Due to the lack of liver cells functioning properly and inability for blood to flow through the liver, individuals may need assessment for a liver transplantation. Patients with cirrhosis are also at risk for liver cancer (hepatocellular carcinoma) (El-Serag, 2002).

Genotype: the particular type of HCV that predominates in a person initially infected with HCV. There are six different genotypes of HCV. Each genotype also has subtypes (i.e., 1a, 1b, 2a, etc.) Different countries in the world will have a higher dominant or specific genotypes of HCV (Hoofnagle, 2002). An individual may also be infected with two different genotypes. The genotype cannot be measured if the virus is undetected by the viral load blood test. The genotype gives an individual more information as to an infected person's response to treatment. It does not mean worse liver damage. Genotype **1a** and **1b** are the most common and also the most resistant to treatment.

Hepatitis: "hepa" is Greek for liver; "itis" means inflammation or injury to the liver. Many agents can cause hepatitis (alcohol, drugs, fat, toxins, viruses) and lead to serious liver damage.

Hepatitis C: a virus that is present in blood and damages the liver

Hepatitis C virus ribonucleic acid (HCV RNA): a fragment of the HCV that can be detected using deoxyribonucleic acid (bDNA) assay and polymerase chain reaction (PCR) tests to determine the level of HCV present in the blood.

Hepatocellular carcinoma (HCC): a malignant tumor of the liver or liver cancer. When cirrhosis is present in the liver, there is a higher risk of liver cancer.

Interferon: a protein that is in the body to protect against infection. Many different cells, including liver cells, produce natural interferon. It can also be produced artificially through biotechnology and is used for therapy.

Liver: the largest organ in the body with over 500 functions including producing protein and bile, storing sugar, clotting blood, and breaking down and excreting toxins and medications.

Liver biopsy: the removal of a small piece of tissue from the liver using a special needle. The tissue is examined under the microscope to look for the presence of liver damage or inflammation.

Platelets: circulating cells derived from the bone marrow and essential for blood clotting. A low or high count may indicate liver damage.

Risk factors: certain behaviors such as injection drug use or blood transfusions, which can lead to infection with HCV.

Remission: partial or complete disappearance of the symptoms of a disease. Remission may happen independently or occur as a result of a medical treatment.

Viral load: measurement of the amount of a virus in a patient's blood. The test can quantitatively measure the amount of virus or qualitatively confirm exposure. One out of four individuals may naturally clear the virus after exposure (Pawlotsky, 2002); therefore, their viral test will be negative. This test is more sensitive and more accurate than the HCV antibody test (an individual will need a confirmatory viral test or viral load to determine the accuracy of the antibody test). The viral load is also the blood test used to determine if the individual has cleared the virus after treatment. The goal of treatment is to have negative or undetected viral load (VA, 2003).

Approximately 75% to 85% of patients experience chronic hepatitis from the virus (Hoofnagle); they do not clear the virus. The virus is replicating and measured in the blood by a specific detectable number (amount or viral load) or a qualitative (positive) exposure (Pawlotsky, 2002).

Each time the virus replicates it may damage the liver cells. Initial damage may not be seen for 20 to 25 years after the initial exposure. Usually an individual has no symptoms

during this period. Progressive damage may vary with each individual patient (Seefe, 2002).

Risk Behavior Reduction

Individuals with HCV are advised not to share toothbrushes, shaving razors, or personal manicure items because blood from these items may transmit the HCV virus to others (NIH, 2002). Behaviors such as unprotected sex or sharing

of syringes and other drug paraphernalia may put an individual at higher risk for other viruses, such as HIV and hepatitis B virus (HBV) (Alter, 2002; Sylvestre, 2003).

To decrease the transmission of HCV and other viruses to others, individuals should be counseled on avoiding these risk behaviors. Individuals actively using intravenous drugs also should be referred to a needle exchange program (Sylvestre, 2003).

The Importance of Follow-up With a Medical Provider

Although individuals may not yet have symptoms related to HCV, it is important to rule out other liver diseases or comorbid conditions, including hypertension and diabetes, which can contribute to liver problems (Wright, 2002). A provider can order laboratory tests related to the liver, interpret these test results, and provide medical advice.

Process of Referral to a Support Group

Nurses need to obtain a list of approved liver disease support groups in their area and be ready to offer the information to patients with HCV and their families (Jessop, 2004). Lists are available via the Internet through such organizations as the American Liver Foundation (<http://www.liverfoundation.org>). Patients with other chronic diseases (cancer, organ transplantation, etc.) have demonstrated the value of ongoing education and support for a patient to accept a new diagnosis.

Lifestyle Changes

A patient's perception of the HCV diagnosis is important to accepting recommended lifestyle changes (Fontana, 2004). Researchers have found patients with HCV may be able to slow down the workload of the liver and decrease the risk of cirrhosis and liver cancer (El-Serag, 2002). The following lifestyle changes are known to be helpful.

ALCOHOL AVOIDANCE

Daily (more than 3 drinks/day) alcohol ingestion may actually increase the rate of replication of HCV (Monto, 2004). The liver cells are stressed from the virus and alcohol, increasing the risk of scarring of the liver tissue. This may increase the damage to the liver and shorten the natural history or length of time when damage may appear (Monto, 2002).

HEALTHY DIET

Patients with HCV should avoid fatty food and lose weight, if needed. Fat interferes with the normal function of the liver cell. When the liver cell cannot function or can no longer regenerate, additional damage may lead to permanent scarring of the liver (steatosis) (Monto, 2002). Steatosis is graded during a liver biopsy to assess the degree of damage (scarring) to the liver.

Vaccinations for Hepatitis A and B

If an individual is not already immune for hepatitis A and B, he or she should be vaccinated for protection from those viruses. A patient with HCV may not be able to tolerate hepatitis A or B exposure because the added infection may add too much stress for the liver to recover (NIH, 2002).

Management of Over-the-Counter Drugs

Many over-the-counter drugs are filtered through the liver and may cause damage to an already poorly functioning liver in the individual with HCV (SGNA, 2003). It is important for patients to discuss their medications and dosages, such as use of Tylenol or nonsteroidal anti-inflammatory drugs (NSAIDs) and herbal or vitamin supplements, with their medical provider (NIH, 2002). For example, it is recommended a patient with HCV not exceed 2 grams of Tylenol per day because of the increased stress on the liver.

Conclusions

Each individual presents with different risk factors related to HCV. The progression of the disease and potential liver damage also are different for each person. Research demonstrates early intervention may decrease or slow the virus, thus decreasing possible liver damage, and lead to earlier and more effective treatment options (Bacon, 2002). Treatments such as use of interferon to stop the replication of the HCV virus are more readily available today than 5 years ago (VA, 2003). Interferon may actually be more effective before advanced scarring or damage has occurred in the liver (Wright, 2002). It is imperative nurses assess their patients for the virus and refer them for early treatment evaluation (VA, 2003).

Unlike earlier years, medical providers today are more aware and educated regarding HCV. Community forums are educating the public about HCV and providing information and education that is needed to ease the confusion about this disease (American Liver Foundation [ALF], 2005). Through enhanced education, nurses can counsel their patients about this complex disease. They can identify those who are at risk for HCV and refer them for appropriate testing (Alter, 2002).

As educators, nurses can convey accurate information to patients with HCV and their families and help decrease transmission to others. The goal of HCV education is to help patients decrease the workload of the liver through a healthy lifestyle and prevent the disease from progressing to cirrhosis or cancer. Nurses with knowledge of HCV resources can effectively refer individuals for medical evaluation and community support groups.

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