

Hepatitis C

A NURSING GUIDE



CANADIAN NURSES ASSOCIATION
ASSOCIATION DES INFIRMIÈRES ET INFIRMIERS DU CANADA

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I INTRODUCTION

The Canadian Nurses Association (CNA) believes professional nursing associations have the responsibility to encourage and support evidence-based nursing practices. In fulfilling this responsibility, *Hepatitis C: A Nursing Guide* has been published in 2002.

This guide is the first to be produced in Canada for Canadian nurses and other health professionals. The guide will provide a holistic approach to nursing care of clients with hepatitis C or clients at risk of developing hepatitis C.

Hepatitis C affects at least 0.8 per cent of the Canadian population, more than 240,000 people. Currently, a study of the economic impact of hepatitis C in Canada is underway. Health Canada anticipates that hepatitis C will become the leading cause of liver transplants, and the medical costs are expected to exceed those for HIV. Many of those who are infected with hepatitis C are not aware of their infection, because they may experience only mild symptoms, if any. More definable symptoms may begin to appear 20 to 30 years after the initial infection and can lead to severe complications like cirrhosis or cancer of the liver.

Hepatitis C: A Nursing Guide, funded by Health Canada's Hepatitis C Division, was written by nurses with the intention of making the guide accessible to anyone interested. The writers consulted expert nurses belonging to national associations and working in various care settings, including prisons, the streets, tertiary centres and the community. Hard copies of the guide can be requested through CNA. The guide is also available on CNA's web site www.cna-aiic.ca. The guide will be used as the basis for train-the-trainers workshops.

In closing, I would like to acknowledge the members of the advisory committee and the expert panel who worked with CNA to develop the focus of the content. The writers, Barbara LaPerrière and Jane Wilson, did an amazing job of listening to the group's comments, capturing the objectives of the working group and integrating all the comments into this guide.

Yours sincerely,



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II OVERVIEW

Hepatitis C is the most common cause of chronic liver disease in the western world. With more than three per cent of the world's population infected by hepatitis C, this disease has become a major public health challenge. The World Health Organization (WHO) has estimated there are more than 170 million people with chronic hepatitis, all carriers of the infection.

Why is hepatitis C so problematic? It stems from the fact that hepatitis C is a kind of public health iceberg: the majority of people who have hepatitis C have no symptoms and are not aware they are infected by the virus. At the same time, however, they are able to transmit it to others.

Hepatitis C represents a significant challenge to the health and well-being of Canadians and to the health care system. Hepatitis C infection becomes chronic in about 85 per cent of adults, but it can take several years before any symptoms of the disease appear. In Canada alone, it is estimated that 4,000 new cases are diagnosed each year. Many HCV infected people are in the 30 to 39 age group and may become affected by complications of the disease over the next 10 to 20 years. Cirrhosis of the liver, liver failure and deaths due to liver disease will increase dramatically.

While the modes of transmission of HCV are generally understood, there is still much that is not known about the disease. There is no vaccine. Prevention and control are absolutely key to halting the cycle of transmission.

Nurses have an important role to play in this challenge, in terms of assisting people with hepatitis C to live safely and in good health with this disease, as well as in working to reduce the risk of spreading hepatitis C.

This guide has been prepared to provide practical information to nurses, based on the best available information to date.

III INFORMATION ON HEPATITIS C

Epidemiology

Prior to 1989, when hepatitis C was first identified, it was known that there was some factor causing hepatitis among people who received blood transfusions or blood products. It was originally termed “non-A, non-B” hepatitis.

Today, we know that hepatitis C is an enveloped RNA virus, a member of the flaviviridae family. It constantly mutates, which is why it is able to evade the body’s immune system.

In fact, the hepatitis C virus is not one but several viruses, each of which differs slightly from the others in its genetic makeup. These “families” of the hepatitis C virus are classified as genotypes. Six major genotypes of HCV have been identified; differences exist within the genotypes too, so there are classifications for the subtypes, such as 1a, 1b, etc. The fact that there are several genotypes distributed throughout the world indicates that the hepatitis C virus has existed for many years.

The predominant type of hepatitis C in Canada is genotype 1, but all types have been seen in Canada. Genotypes appear to vary in pathogenicity and in how they respond to the antiviral therapy. Genotype 1b has been shown to have a significantly lower response to interferon treatment.

It is estimated that approximately 0.8 per cent of the population, or more than 240,000 people, are infected by hepatitis C.¹ The number of cases diagnosed has increased dramatically since 1992, partly due to improved awareness and recognition of the infection. According to the Population and Public Health Branch of Health Canada, the peak rate of HCV infection occurs in the 30 to 39 age group. The rates also “bulge” in the 40 to 59 age group, which may reflect infection acquired during the 1960s and 1970s.

Hepatitis C is a reportable disease in Canada.

Risk factors and HCV

High risk behaviour: The rate of HCV is higher among people who engage in certain high risk behaviours that can expose them to HCV-infected blood, primarily injection drug use.

Gender: The rate of HCV infection among males is twice that of females.

People with haemophilia: Prior to 1990 (when screening for HCV was instituted), the number of HCV infected patients among the transfused haemophilia population was near 95 per cent. According to the Canadian Haemophilia Society, 70 per cent of people with haemophilia are also infected with hepatitis C.

¹ There is no test available that can identify a “new” or “acute case” of hepatitis C. The tests can only tell you if the person has antibodies to the virus or if the virus is present in their blood. Therefore neither incidence nor prevalence is technically correct. It is why they will not be used in this document.

Aboriginal peoples: According to Health Canada, the rate of HCV among Canada's aboriginal peoples is seven times higher than the rate for non-aboriginal Canadian-born people.

Children: In the past, HCV was seen among children who were recipients of blood transfusions and blood products before today's screening techniques were used. At present, most new cases of HCV among children are a result of "vertical transmission," from the child's mother. In youth, new cases result from other behaviours involving contact with contaminated blood, such as injection drug use or body piercing, among adolescents.

Modes of transmission

The primary means of transmission of the hepatitis C virus is through blood, usually through some form of injection. The major group of people at risk for infection are those who share needles and other paraphernalia to use drugs.

See below for the sources of infection as listed by WHO. Nurses will want to remember that immigrants to Canada may have been exposed to risk from practices or procedures that are not usual within Canada.

Injection drug use: According to estimates from Health Canada, injection drug use accounts for 70 per cent of all prevalent HCV infections. There is the potential to become infected through the use of contaminated drug equipment, including straws, spoons and other devices employed in drug use, even without injection.

Workplace exposure: Canadian Needle Stick Surveillance data show that nurses reported more than half the number of needlestick injuries in Canada. The rate of HCV infection among health care and emergency services workers, due to exposure to infected blood or bodily fluids, is currently thought to be about that of, or perhaps slightly higher than, the general population, at one to two per cent. The actual number of cases may be higher due to under-reporting.

Blood transfusions: The risk of acquiring HCV from a blood transfusion or blood products is now very low, less than 1:500,000 units of blood donated. Organ transplantation also carried a risk for HCV prior to institution of the current HCV antibody screening techniques. Nurses should note that people may come to Canada having received blood or blood products in countries where blood is not screened for HCV.

Sexual contact: While the risk of acquiring HCV from an infected partner is low, there is evidence suggesting that individuals who engage in high-risk sexual behaviours may face a higher level of risk where no other risk factors have been reported. People with open genital lesions or who engage in sex during menstruation may increase their risk of acquiring HCV. HIV and herpes simplex II co-infections are also associated with sexual transmission of HCV. The rate of HCV among men who have sex with men (MSM) is similar to that for heterosexuals.

Mother-to-child: The risk of vertical transmission of HCV from mother to unborn child is less than eight per cent (Society of Obstetricians and Gynecologists of Canada, 2000). The following factors have been identified as increasing the risk of vertical transmission of HCV: HIV infection in the mother and a high maternal viral load. Currently, there is no evidence that breast milk is a means of transmitting the disease, however it is advised to avoid breastfeeding if the mother is HCV positive and has cracked/bleeding nipples.

Piercing/tattooing/acupuncture: Because of the possibility of exposure to infected blood where unsterile devices are used for tattooing, body piercing and acupuncture, this activity is considered to be a risk factor.

Nosocomial infection: Patients who are on long-term hemodialysis have a higher rate of HCV infection than the general population because of exposure to equipment in contact with blood. Concerns are being raised about other means of exposure to infection possibly through the reuse of single-use medical devices for diagnostic and treatment purposes.

Other: Household contact as from using shared articles such as toothbrushes or razors is a potential means of transmission because of the possibility of exposure to infected blood, but is uncommon. HCV is not spread through casual contact such as hugging or kissing.

About 10 per cent of people diagnosed with HCV appear to have no known risk factor.

Risk factors

People may be at risk for HCV if they:

- Engage in drug use, sharing inadequately cleaned or dirty needles, straws or other equipment that could be contaminated with infected blood;
- Have contact with contaminated equipment for the purpose of medical treatment, tattooing or body piercing;
- Have had a needlestick injury or mucous membrane exposure to blood or bodily fluids capable of transmitting HCV; or
- Were born to a mother who has hepatitis C.

Co-infection with HIV and hepatitis B

Hepatitis C occurs in 50 to 90 per cent of HIV-positive patients who have parenteral risk factors. As of 2000, it was estimated that more than 11,000 people in Canada are co-infected with HCV and HIV. Injection drug users and MSM are the two primary groups dually infected; people with hemophilia may also be co-infected. Progression to cirrhosis of the liver is more rapid among those who are coinfecting than those with hepatitis C alone (Canadian Association for Study of the Liver, 2000).

HCV is also seen as a co-infection with hepatitis B; the outcome tends to be more severe than for either virus alone. Usually, one infection is dominant and the other dormant, but occasionally, both diseases are active (Canadian Association for Study of the Liver, 2000).

Clinical features of hepatitis C

With acute hepatitis C, patients typically have no symptoms or exhibit only mild signs of any illness. Only 20 to 30 per cent of people infected with HCV exhibit symptoms. Symptoms might include jaundice, anorexia, malaise, dark urine, abdominal pain and fatigue.

There is a time lapse of six to seven weeks between the exposure to the virus and any symptoms that may result. Seroconversion, or the appearance of the HCV antibody in the blood, may take eight to nine weeks following exposure to the virus.

The majority of people with HCV (70 to 80 per cent) proceed to the chronic phase of the disease. Of these, 10 to 20 per cent develop cirrhosis of the liver, which can lead to liver failure and death, while one to five per cent develop hepatocellular cancer (HCC).

The course of chronic hepatitis C is slow and insidious, with most patients showing few physical signs of the disease during the first 20 years after infection. People may experience a progression from mild to moderate to severe hepatitis. People with chronic HCV are usually identified during blood screenings.

Tests and diagnosis

As hepatitis C infection is usually asymptomatic, testing for HCV is done when physicians are treating patients for acute hepatitis (10 per cent), when investigating liver enzyme abnormalities (70 per cent), when there are symptoms present such as fatigue that could indicate liver disease (10 per cent) and when there is decompensating liver disease (10 per cent).

Diagnosis of hepatitis C is made based on the results of an enzyme immunoassay (EIA) that identifies anti-HCV-specific antibodies and the detection of HCV RNA through amplification tests such as polymerase chain reaction (PCR).

Essentially, there are two types of testing: qualitative tests provide a positive or negative result; quantitative tests give the viral concentration or viral load. Qualitative HCV-RNA testing is not necessary to make the diagnosis of hepatitis C in patients who are anti-HCV positive, but is indicated for those patients who are anti-HCV positive with persistently normal ALT (alanine aminotransferase) levels.

There are two limitations to diagnosis of HCV: first, the EIAs tend to be very sensitive and can result in false positive results, which need to be confirmed through further testing, such as recombinant immunoblot assay (RIBA). Second, the long lag time between initial infection and the appearance of anti-HCV antibodies means that the frequency of detecting HCV during the acute phase is low.

More recently, the development of nucleic acid amplification testing (NAT) has had a dramatic effect on the diagnostic process as a form of supplemental testing to exclude false positive results. NAT is positive one to two weeks after HCV infection. The test is used to confirm infection and to determine end of treatment response.

Interpretation of HCV Testing Results

ALT concentration	HCV RNA result	Interpretation
Normal	Positive	Patient is infected with undetectable liver disease.
Normal	Negative	False positive anti-HCV Spontaneous viral clearance False negative HCV RNA Dormant HCV infection
Elevated	Positive	Infected with active liver disease.
Elevated	Negative	False positive Spontaneous viral clearance False negative HCV RNA Dormant HCV infection; some other cause for liver disease

Source: Canadian Association for the Study of the Liver (CASL). (2000). *Management of Viral Hepatitis. Recommended Guidelines for Physicians.*

Current medical treatment

Interferon or a combination of interferon and ribavirin is used to treat hepatitis C.

Acute hepatitis C

Acute HCV infection is now identified primarily in people who have received an accidental needlestick injury. To detect infection, health care workers or others who have experienced a needlestick injury or other type of exposure should be tested for anti-HCV at the time of injury and after 12 weeks.

Early treatment of acute hepatitis C with interferon monotherapy may enhance the likelihood of response. The decision to treat the infection has to be balanced with the fact that as many as 15 per cent of people may spontaneously clear the virus. People with acute hepatitis C should be treated by a specialist with follow-up visits.

Chronic hepatitis C

Treatment is usually considered for patients who are between 18 and 70 years of age (some experts say 60) who have elevated ALT levels and inflammation or fibrosis of the liver demonstrated on biopsy. The major indication is that the ALT level is more than 1.5 times the upper normal limit. A liver biopsy is recommended to grade or stage the progression of disease; if the biopsy result shows a normal liver or minimal inflammation, treatment may not be necessary.

Other factors to be considered in the decision to treat HCV include the estimated probability of the patient developing cirrhosis and liver failure, and the presence of any other health conditions that may compete with the HCV for mortality. Contraindications for treatment include active alcohol or substance abuse; pregnancy or lack of contraception; or a predicted inability to follow a treatment regimen. Ideally, patients should abstain from alcohol while in treatment.

Currently, chronic hepatitis in children is not generally treated except in controlled trials.

Long-term studies demonstrate the effectiveness of anti-viral therapies. These therapies include standard interferon monotherapy, a combination of interferon and ribavirin, pegylated interferon monotherapy and a combination of pegylated interferon with ribavirin. A sustained response with a long-term viral clearance is achieved in 30 to 40 per cent of cases. (Combinations of pegylated interferon plus ribavirin are expected to be approved in Canada in late 2002.)

The treatment regimen most widely used is a combination of interferon alfa 2-b and the antiviral drug ribavirin. Interferon monotherapy is reserved for those patients who cannot tolerate ribavirin. Patients with advanced cirrhosis of the liver who might be at risk for decompensation and pregnant women should not receive anti-viral treatment.

Duration of treatment is determined by the virus genotype. For types 2 and 3, treatment is usually for 24 weeks; for all others, treatment is prescribed for 48 weeks, if a response to treatment has been seen at 24 weeks to increase rates of sustained virologic response.

The definition of successful treatment is when HCV-RNA becomes negative during therapy and remains negative six months after the treatment is completed. Repeated measurements of HCV-RNA using PCR assays in these “sustained responders” have now conclusively shown that 95 per cent of sustained responders remain virus-free for two, five, eight or more years, and are considered to be virus-free indefinitely, which many experts are now describing as “cured.”

If patients do not clear HCV-RNA after 24 weeks of treatment, they are not likely to become sustained responders.

Side effects of interferon alfa 2b/ribavirin therapy include flu-like symptoms, anemia, depression and alopecia. As well, aggression has been observed in patients undergoing treatment. Testing may also indicate changes in hemoglobin, thyroid function, uric acid levels, neutrophil counts and platelet counts (see “The Nurse and Hepatitis C” for more information on nursing management of treatment side effects).

Patients are increasingly interested in complementary or alternative remedies for HCV, particularly when there has been a failure to respond to anti-viral therapy. There are three groups: vitamins and minerals, herbs and homeopathic remedies. Nurses should ask patients if they are considering such remedies as not all preparations are safe for use during anti-viral therapy or for the compromised liver.

Prevention

Injection drug use is now the chief mode of transmission of HCV. Other modes of transmission include tattooing, body piercing with unsterile equipment, sexual, occupational, vertical (mother to child) and household transmission. Being infected with one genotype of HCV does not protect against another genotype.

Prevention efforts are best aimed at people who engage in high-risk behaviours, primarily those who inject drugs or use drug equipment that could be contaminated with infected blood. Health care professionals in all settings should question patients about injection drug use and high-risk sexual practices (see section “Special Considerations: Substance Use” for more information on harm reduction).

Injection Drug Use

Research shows the need to direct hepatitis C prevention strategies toward people who are just beginning to inject drugs or contemplating injection (Health Canada, 2000). Users of drugs that are not injected should be counselled on the danger of infection from equipment such as straws, which could be contaminated with infected blood.

Tattooing and Piercing

Anyone considering tattooing, body or ear piercing or acupuncture should be counselled to ensure that these practices are carried out with sterile equipment, preferably one-time-use equipment. This includes the ink used for tattoos. People should be counselled to observe that the practitioner also carries out other standard infection control measures such as hand-washing and cleaning of work surfaces.

Sexual transmission

The transmission of HCV from spouse to spouse is rare. However, contact with multiple partners and co-infection with HIV and herpes simplex II have been associated with increased risk for hepatitis C.

The following steps have been recommended:

- The infected person should inform sexual partners; testing should be offered to the partners.
- Use of a condom is advised in short-term sexual relationships.
- Infected women should avoid unprotected sex during menstruation as the virus may be present in menstrual blood.

Occupational exposure

Health care and emergency workers should all be trained in the risk and prevention of bloodborne infections, and should report any percutaneous or permucosal exposure to blood, or exposure through non-intact skin, to their employers. Although the risk of infection is relatively low, every effort should be made to make an early diagnosis and reduce the risk of nosocomial infection. Protocols for follow-up of such employees should be in place (see Readings and Other Resources, Occupational exposure and prevention/health care workers).

Recommendations have been made for health care workers who are infected with HCV (see “Special Considerations: Health care workers”).

Vertical transmission

Transmission of HCV from mother to child can occur at the time of birth. Delivery by caesarean section may not prevent transmission of HCV. Breast-feeding is considered safe as long as the nipples are not cracked and bleeding.

Household exposure

People with HCV should be advised not to share personal articles such as toothbrushes or razors because of the possibility they may be contaminated with small amounts of infected blood. People with HCV should also cover cuts and open sores on the skin. The nurse may also counsel them on how to manage accidental spills of blood (see Health Canada, 1998a for more information).

People infected with HCV should not donate blood, body organs, other tissue or semen.

Screening for HCV

Anyone who is concerned about the risk for HCV due to high-risk behaviour or other factors should be tested. Routine testing is recommended only for people who are engaged in high-risk behaviour, such as injection drug users or health care workers who may have been exposed.

Testing for hepatitis C

- Anyone who has injected drugs, even once.
- People with medical conditions who received clotting factor concentrates before 1990, were ever on long-term hemodialysis or have persistently abnormal ALT levels.
- People who received an organ transplant or a transfusion of blood or blood products before 1992.
- Health care or emergency workers who have had injuries from needlesticks or sharps.
- Children born to HCV-positive women.

IV LIVING WITH HEPATITIS C

Living with hepatitis C involves learning to live with the physical, emotional, social and financial consequences of the disease. Most people live with hepatitis C for many years without experiencing physical symptoms. Others have to deal with a variety of symptoms that range from mild to severe and that may come and go over time. Many people find the hardest part is learning to live with the emotional and social aspects of the disease. When the disease is first diagnosed, people need to deal with the emotional impact of learning they have a chronic illness that is potentially life threatening. They have to learn to deal with the uncertainty surrounding the progression of symptoms and the disease. They may be confronted with the social stigma associated with hepatitis C and the fear other people have of contracting the disease. Who to tell, when to tell and how to tell others about their infection becomes an issue.

People living with hepatitis C may be faced with financial concerns resulting from loss of income and cost of treatment. Drug therapy is expensive and may not be fully covered by provincial drug and treatment plans.

The following stories are personal accounts written by three people living with hepatitis C. The stories illustrate the far-reaching consequences of having the infection. The authors describe the challenges of living with a chronic illness for both themselves and their families. They reveal how, with support and education, they are learning to cope with the challenges.

Living with hepatitis C as a mother

I am a 39-year-old mother of three children. I have hepatitis C and contracted it by IV drug use in the late 1990s. I was diagnosed in 1996 after my then boyfriend told me he had hepatitis C. When we started to go out with each other, I had asked him if he was clean and his answer was yes, that he went for all the tests for sexual diseases, HIV and hepatitis – he was clean. We were together for a year, and he left. As he went out the door he informed me he had hepatitis C, and I should be tested for it. I was very angry with him, as he knew he had this disease, and he deliberately lied to me by saying he was clean.

I called my doctor the next day to make an appointment to get tested. A week later I received a call from his office – he wanted to see me the next day. I was very scared about what he was going to say. He told me I was positive for hepatitis C. All he could tell me was that there was no cure for this disease. He also told me to go home and live a normal life. When I got back from the doctor's office I started to cry. I thought, what will happen to my children? Where will they go? Who will look after them after I die? They hadn't told me how long I had to live. The doctor, at the time, didn't have information on this disease.

A friend of mine knew of a place I could call and get the support and all the information I needed to learn about this disease. I was introduced to someone from that hepatitis C support group. I was so happy I had a place to go and talk to someone that knew what to expect.

I told my children I had hepatitis C, and they had to be careful not to touch my toothbrush and my nail clippers. They couldn't understand what was going on at first, only that Mom was sick, and they had to be careful when I was bleeding and let me clean up my own cuts. They were not sure if they could get hepatitis C by hugging or kissing me. I told them that it was all right, and I had someone talk to them so they could understand things.

I have lost some jobs and had to learn to watch my money because I have to buy certain food that I wouldn't normally buy for myself. I have learned from the past not to mention that I have hepatitis C to anyone. I only inform the dentist or the nurses and technicians at the hospital. When I go for jobs, I will not tell them, because so many people don't understand hepatitis C and they don't understand that there is no chance they can get it from me unless it is blood-to-blood contact

I was referred to a gastroenterologist. He did some blood tests and a liver biopsy, and he decided to start me on treatment. Then the only available treatment was interferon. I couldn't do the whole six months because the side effects were too hard on me. I did stay on it for three months, and the treatment was still a success I went into remission for five years. Now I have come out of remission and am on Rebetron® (ribavirin). It is going very well so far. It's been three months since I started, and I feel much better than the first couple of months. They will decide in three more months if I can do the full 48 weeks. I hope so.

I have someone special in my life who does not have hepatitis C. He took the time to research the disease, and he still wanted a relationship with me. We have a wonderful relationship as a family, and we are making future plans for when the kids grow up and leave. It is nice to see that there are some people in this world who will take the time to see that we are not contagious to others under usual circumstances. There is still hope for everyone to have a normal relationship.

Some family members said I got what I deserved. I lost some friends and gained some very close friends. I never told my neighbours. Having hepatitis C has changed my life. Sometimes I feel it changed it for the worse, and sometimes I feel it changed me for the better. I do look at life differently now.

Living with hepatitis C as a person who injected drugs

I am a 51-year-old male with a history of substance use. I have been injecting drugs for the past 35 years. I started injecting drugs in Vancouver when I was 16 years of age. Heroin was my drug of choice. My first fix was in jail where I was taught by other inmates. Most of my early years were spent on Vancouver's downtown eastside.

My first connection with hepatitis was in 1976 when I was diagnosed with chronic hepatitis in correctional facilities. I was feeling sick at that time, got jaundice and was quarantined for nine days. For a while after that period, I would get jaundice and feel ill about every six months.

I was incarcerated several times over the years and was last released in 1981. I always made sure I had my own supplies and only shared occasionally when I was in jail. My injecting has slowed down over the past 10 years, and I haven't injected at all for the last year. I have also been on Methadone for the past several years.

In 1994 I was diagnosed with hepatitis C, and my doctor was unsure of how long I had it. For the last three years, I have felt very tired, some days exhausted from little activity, unable to work because of pain on my right side almost every day. Last year I saw the hepatologist, and at that time, he did not recommend I go on treatment. He said my blood work was not severe enough yet.

Every day is frustrating now. I haven't felt healthy for quite some time. I live on a limited income, and I manage a boarding house to help with my rent. My Methadone is also an added expense. My budget for food is limited, and it is hard to eat healthy on a limited budget. I take Vitamin C, exercise and drink plenty of water.

I get support from my friends who are also hepatitis C positive, and I also attend a support group for people with hepatitis C. I am quite open about my hepatitis C and am not afraid to talk about it. I have lost contact with a lot of my family. I do have a daughter that I talk with on occasion, and she knows I have Hepatitis C.

I try to keep myself as healthy as I can, and I do more on the days that I feel better. Basically, I take one day at a time and do the best I can with what I've got.

Living with hepatitis C as a nurse

My name is Debi Ripley. I am a 46-year-old mother of two teenaged children, and I am a non-practising nurse, although I am taking a nursing refresher course. I have hepatitis C and probably became infected in the late 1970s or early '80s. I wasn't diagnosed until 1995.

I have a few risk factors for hepatitis C: I was an operating room registered nurse for 15 years, and I received a blood transfusion after a caesarean section for my son in 1983.

I worked as a scrub and circulating nurse in operating rooms in my hometown of Moncton, New Brunswick, as well as Edmonton and Calgary, Alberta, and four different trauma hospitals in Riverside and Los Angeles, California. Many times I had been cut with dirty scalpels and suture needles.

Due to the progression of my disease, my specialist feels that I was first infected in the O.R., then re-infected by a tainted blood transfusion. All I know is that I have become progressively sicker since 1985 when I became pregnant with my second child.

Through the years my illness remained undiagnosed although I ran the gamut of symptoms – irritable bowel syndrome, pain in my right upper abdomen, constant aches in my joints, muscles and bones with an unexplained rheumatoid factor, headaches, decreased resistance to infections (in California I had meningitis, encephalitis and several bouts of pneumonia back at home), depression, insomnia, extreme fatigue and weight loss.

By the time I became too sick to work, I had lost my job in California and consequently lost my house, furniture, my husband and car and sold my personal possessions to come home. All the doctors I had seen for these vague but real symptoms came to the same conclusion: I was overly stressed and, as a woman, these symptoms were “all in my head” – psychosomatic.

In desperation, I was forced to accept social assistance, and finally, I consulted the family doctor in one last call for help. In the many blood tests, he discovered that my liver enzymes were more than double the high normal. A subsequent hepatitis C test proved positive.

I was relieved, devastated and puzzled all at the same time. Relieved to know that there was a name to this illness, yet devastated to think that I had a “terminal” disease and that there was a real possibility of losing my career. I was puzzled, because even being a nurse, I was not sure what hepatitis C was. I also had to face the probability that I unknowingly accidentally infected patients.

Knowing that I had a physical disease with a name helped to put everything else into perspective. I knew that I could research hepatitis C and learn how to cope with this potentially debilitating disease. And that is what I did.

My nursing training and instincts kicked in, and before long, even through two treatments plagued with many side effects, I formed a hepatitis C support/self-help group to help others infected/affected with hepatitis C, regardless of the source and to raise awareness in the Atlantic provinces.

What I have gone through goes a long way towards understanding others with any chronic illness. The emotions of the grieving process are the same as when one loses a loved one, but we are in the continual process of losing our health. Helping others gets our minds off ourselves and brings a personal satisfaction that we have made a difference in someone’s life.

Yes, I have lost everything to this disease, but I also gained so much more. Material possessions do not mean the world to me anymore – they are things that can come and go. I have learned the hard way to appreciate the so-called little things in life – a sunny day, laughing with my kids, my parents’ love, the peace and joy in my heart from my God and knowing that I am making at least a small difference in this world.

My passion and perfectionism for the challenges of the operating room has been replaced by my genuine devotion to helping people in all aspects of hepatitis C. The old adage still applies – once a nurse, always a nurse. I’m just in a different field.

“One thing that I do, forgetting those things that are behind and reaching forward to those things which are ahead...” Philippians 3:13

*[Excerpted from Canadian Journal of Public Health, 2000, 91(Supplement 1).
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Helping people live with hepatitis C

Stories like those told here can help nurses understand what clients consider most important in relation to their health. The nurse and client can begin to work in partnership to address the client's health related concerns from the client's starting point. In the client-nurse partnership, clients bring expertise on their bodies, how their bodies are responding to their illness and the social environment they live in with their disease. Nurses bring professional expertise. Information in the next section will assist nurses in building their expertise in the care of people living with hepatitis C and their families.

V THE NURSE AND HEPATITIS C

Nursing care of people with hepatitis C and their families requires a holistic approach through which nurses help their clients meet their physical, psychological, emotional, spiritual and socioeconomic needs. The holistic approach recognizes that multiple factors have an impact on people's health – factors such as income, education, housing and the environment, as well as the health care services they receive.

The care team

Many people who are living with hepatitis C and their families have complex care and treatment needs that can benefit from the knowledge and skills of an interdisciplinary team². Team members become active partners with the individual with hepatitis C and their families in decision-making and care planning.

The person with hepatitis

The person living with hepatitis C has the right to choose how he or she will participate in treatment and care decisions. Some will take a more active role than others. The nurse must respect people's right to exercise autonomy in decisions affecting them. This puts responsibility on the nurse to ensure that people living with hepatitis C have the information and tools needed to make informed decisions. Working in partnership in planning care provides an enriching experience for the person living with hepatitis C and all others involved in his or her care.

The family

Family means those who are closest to the person. It includes the family of origin or acquisition (parents, children, siblings, spouse) and the family of choice (anyone people choose to have close to them) (McAmmond, 1998). The person living with hepatitis C will decide how the family will be involved in his or her care.

The team

Composition of the care team will vary depending on the needs of the individual and his or her family. The team may have two or three health care providers who maintain consistency of care such as a primary care nurse or physician. The skills and knowledge of many health care providers may be necessary over the course of the person's illness, and they will participate on the team, as required. It is important for someone to assume the function of coordinating the team. The person with hepatitis C or another member of the team may assume this role. Frequently, the nurse takes on the role of case manager. Volunteers and informal care providers are often members of the team. Planning and implementing team building activities promotes more effective team functioning.

² Adapted from: Gimenez-Lambert et al., 1996

Context of care

Important concepts³ in nursing care for people with hepatitis C include health promotion, human rights, advocacy and empowerment, confidentiality and care across the continuum.

Health promotion

The goal of nurses' health promotion practice is to improve and maintain health. For many years, nurses assumed that providing their clients with information about how to change health-related behaviour would result in the desired change. They were often surprised when the expected change was not forthcoming. Most recently, nurse scholars have been exploring health promotion from a new perspective. A transformative approach to health promotion is "a collaborative process, one in which the health professional works with clients (defined as individuals, patients, families, communities and populations) to gain insights into social, organizational, political and personal patterns that strengthen or disrupt health and wholeness, and to take action toward improved health" (Young, 2002, p. 4).

In working with people with hepatitis C and their families, nurses can incorporate health-promoting patterns of interaction into their practice. One pattern is to understand the larger context within which the person with hepatitis C is situated. For example, some strategies for managing the disease might not be appropriate for people of limited financial means. One of the women, who told her story in the previous section, noted that she has to watch her money, because she has to buy particular foods that she normally wouldn't have purchased. Another health promoting pattern of interaction is engaging in flexible partnerships. According to persons who have chronic illnesses such as hepatitis C, effective partnerships with health care professionals are those that allow genuine sharing of authority and the exercise of expertise by both parties (Thorne, 2002).

Human rights

It is not known how much discrimination exists against people with hepatitis C. Nurses and other health care providers must respect the rights of people with hepatitis C regardless of how they were infected. There is often a stigma associated with hepatitis C for injection drug users who may be viewed as being personally responsible for their illness. Co-infection with HIV may increase the stigma and discrimination that people face. Everyone living with hepatitis C should have access to care and services regardless of gender, race, sexual orientation, lifestyle, place of residence or economic status.

Advocacy and empowerment

Advocacy is an essential component of hepatitis C care, as people living with hepatitis C may experience discrimination, violations of their human rights and impediments in accessing health care. It is important for nurses to assume the role of advocate at both the individual and community level. Nurses can help to ensure that people living

³ Sources for this section: Gimenez-Lambert et al., 1996; Young & Hayes, 2002.

with hepatitis C are aware of and understand the choices available to them. In this way, people are empowered to make decisions and take actions for their health. At a broader level, nurses can work to advocate for policy changes that eliminate or reduce the barriers faced by people with hepatitis C.

Confidentiality

For people living with hepatitis C, breaches of confidentiality related to their health information can have serious consequences including stigmatization, isolation, job and housing loss and financial hardship. When nurses are faced with ethical dilemmas about maintaining confidentiality, they must work to protect the right of individuals to confidentiality and seek advice from experts in the field of human rights and ethics.

Care across the continuum

For most people, hepatitis C infection is a chronic illness that progresses over many years, at a different rate for each person. Continuity is an essential component of all care. Within a holistic framework, nurses engage in therapeutic relationships at every stage of the person's illness. For example, nurses help people deal with the emotional impact of diagnosis with hepatitis C. They explain diagnostic tests and help interpret results. They support people in making decisions about treatment and in managing symptoms related to the infection and side effects of therapy. Through interventions such as counselling, support and education, nurses work closely with individuals and their families to assist them in meeting their care needs in living with hepatitis C.

Helping clients learning to live with hepatitis C

For people living with hepatitis C and their families, knowledge may help them feel more in control of the disease. They can obtain information from a variety of sources including print and on-line material, support groups, educational programs, nurses and other health care providers. Given the explosion in the amount of material available, especially on the Internet, nurses should help people identify reputable sources of high quality health information.

People with hepatitis C generally want information about HCV infection including risk factors, modes of transmission, disease progression, treatment and side effects of treatment. Sometimes they want specific technical information such as techniques for giving themselves antiviral injections.

Nurses can offer people information about ways to maintain their health and minimize further damage to the liver such as:

- eating a well-balanced, low-fat, high fibre diet,⁴ unless advised to follow a special diet because of health problems;
- maintaining normal weight and avoiding obesity;

⁴ A standardized set of nutritional recommendations for people living with hepatitis C is not yet available.

- exercising regularly;
- avoiding intake of alcohol;
- trying to maintain normal work and recreational activities;
- checking with the physician before starting any new medicines, including over-the-counter medications and herbal or homeopathic preparations;
- seeking advice on getting immunized against hepatitis A and hepatitis B;
- being monitored regularly by a health care team.

Nurses can also help people living with hepatitis C to access sources of support. Individual support may come from family, friends and health care providers. Peer support is often available through meetings, support groups, telephone contacts and on-line chat groups. Nurses can help family and friends learn how to support someone living with hepatitis C.

Compensation has been approved by the federal government for all patients who have been infected with hepatitis C as a result of a blood transfusion, factor concentrates or infusion of any blood components between January 1986 and July 1990. The amount paid depends on a variety of factors including the severity of disease, whether treatment has been recommended or completed, and the loss of income. Several provinces have approved compensation for patients infected with hepatitis C having used blood, concentrates or blood components at any time in their life within these provinces. See Readings and Other Resources for sources of educational material for both people living with hepatitis C and health care providers and for the federal compensation claims co-coordinator's contact information.

Symptom management

One way nurses help people maintain and improve their health while living with hepatitis C is by supporting them in managing and monitoring the symptoms they experience. These may be symptoms associated with the virus itself or as a result of antiviral treatment.⁵

Acute hepatitis C

At the time of initial infection, most people experience no symptoms; only a third of people infected with the virus feel ill. They may experience flu-like symptoms such as nausea and vomiting, anorexia, fatigue, low fever and muscle aches that last two to twelve weeks. In some people, fatigue lasts longer. Ten per cent may have jaundice and dark-coloured urine.

⁵ Adapted from: Schering Canada, 2000, Gimenez-Lambert et al., 1996; Heathcote et al., 2001; Yim, 2001.

Chronic hepatitis C

By definition, hepatitis C is considered chronic when the virus remains in the body for more than six months. Some people live with hepatitis C for many years without experiencing any symptoms. Others report minor symptoms such as fatigue. Symptoms may come and go. The presence or absence of symptoms is not indicative of the degree of liver damage. Many symptoms are not specific to hepatitis C infection and may be experienced by people with other chronic health problems.

Common symptoms of chronic hepatitis C infection

fatigue	abdominal discomfort	nausea
anorexia	sleep disturbance	pruritis
depression		

(Source: Adapted from Heathcote et al., 2001)

Management of Commonly Reported Symptoms

The information that follows is presented to increase nurses' knowledge and understanding of symptoms people with hepatitis C may experience and possible ways to help clients manage their symptoms. It is not intended to reflect a prescriptive approach to patient care. From a health promotion perspective, nurses and patients work in partnership to address the health-related concerns of the client from the starting point of the client's agenda not the nurse's agenda.

Symptom	Characteristics	Management
Fatigue	<p>A common symptom</p> <p>Often described as a lack of energy, a feeling of weakness or sluggishness</p>	<p>Assess person's lifestyle and activity level.</p> <p>Promote self-care and self-awareness by having person document fatigue patterns, rest, nutrition, exercise and activity levels.</p> <p>Promote need for good nutrition, adequate rest and regular exercise (within the person's ability to tolerate activity).</p> <p>Teach energy conservation techniques.</p> <p>Encourage use of complementary therapies that promote relaxation.</p>
Abdominal discomfort	<p>Ranges from a dull ache to more severe "right upper quadrant pain"</p> <p>May be due to inflammation of the liver lining</p>	<p>Encourage person to monitor discomfort and report to physician.</p>
Nausea	<p>Generally mild with no vomiting</p>	<p>Encourage person to report persistent nausea or nausea with vomiting to physician.</p> <p>Monitor effects of anti-nausea drugs such as dimenhydrinate, if prescribed.</p> <p>Counsel person that such drugs can cause drowsiness and should not be taken if driving a vehicle. (See Anorexia for more suggestions)</p>
Anorexia	<p>Generally due to combination of factors such as fatigue, depression, pain and lack of sleep</p> <p>Occasionally causes weight loss</p>	<p>Encourage person to:</p> <ul style="list-style-type: none"> • eat small frequent meals instead of three large meals a day; and • stimulate appetite with regular exercise.
Sleep disturbance	<p>Having trouble falling asleep at night and waking up many times during normal sleeping hours</p>	<p>Counsel person to improve sleep routine by:</p> <ul style="list-style-type: none"> • reading, listening to music or having a warm drink before bed; • avoiding stimulants such as tea, coffee, smoking or excessive exercise before going to bed; and • using sedatives as a last resort. <p>Counsel person to avoid benzodiazepines such as lorazepam, diazepam and oxazepam.</p>

Symptom	Characteristics	Management
Pruritis	<p>Confined to parts of body (e.g., both legs) or may be generalized</p> <p>Usually no skin rash</p>	<p>Counsel person to:</p> <ul style="list-style-type: none"> • add baby oil to bathwater or use a good emollient lotion; • keep fingers nails short and wear thin gloves in bed to reduce surface damage to skin if scratching occurs during sleep; • wear light clothing of non-irritating material (e.g., avoid 100% wool); • consider using unscented laundry detergent; and • consult a physician for medication to relieve severe itching, if the severe itching persists.
Depression	<p>May be initial depression upon diagnosis from which most people recover</p> <p>May be manifested through symptoms such as lack of motivation, fatigue, loss of appetite and sleep disturbance</p> <p>For some people, depression may persist for an extended period of time</p>	<p>Consider the need for a psychosocial assessment, which may include history of interpersonal relationships, pre-existing mental illness, current distress, coping styles and resources, history of substance abuse and suicide risk.</p> <p>Encourage person to:</p> <ul style="list-style-type: none"> • develop a safety plan for coping with depression; and • seek professional help before the feeling becomes severe. <p>Monitor response to antidepressants if prescribed.</p>

Less commonly reported symptoms:

- dry eyes and mouth (Sicca syndrome)
- ulcer of the eye (Mooren's corneal ulcer)
- muscle and joint aches
- dizziness
- decreased memory
- decreased concentration
- rash (red blotches, most often on legs)
- blistering skin lesions

(Source: Heathcote et al., 2001)

If you have any question from your patients regarding the medical use of Marijuana, see Appendix 5.

Management of common side effects of drug treatment

The severity and type of side effects of treatment are different for each person. Side effects generally disappear quickly once the treatment is stopped. For some people, the dose of the medication may need to be adjusted; for others, therapy may have to be discontinued if the side effects become too severe. People on drug therapy should try to eat a well-balanced diet, drink plenty of water and exercise regularly. Nurses should encourage their clients to report any side effects of treatment so they can receive assistance in managing the side effects⁶ (see Appendix 1 for generally accepted drug treatments and dosages).

Symptom	Characteristics	Management
Flu-like symptoms such as muscle and joint aches, decreased appetite and nausea		<p>Counsel person to:</p> <ul style="list-style-type: none"> take interferon at bed time so that most of the side effects occur during sleep; take acetaminophen every 4-6 hours and/or prior to injecting interferon, if symptoms become severe; and to consult with physician about safe dosage levels of acetaminophen.
Muscle and joint aches		<p>Counsel person to:</p> <ul style="list-style-type: none"> exercise regularly; engage in recreational activities; and consider using complementary therapies such as massage therapy.
Decreased appetite and nausea	The person may experience a metallic taste in the mouth after the interferon injection	<p>Counsel person to:</p> <ul style="list-style-type: none"> eat regularly; try four to five small meals a day; and experiment with foods that may be easier to tolerate such as cold or bland foods.
Insomnia		<p>Counsel person to:</p> <ul style="list-style-type: none"> improve sleep routine by reading, listening to music or having a warm drink before bed; and avoid stimulants such as tea, coffee, smoking or excessive exercise before going to bed.
Dry, itchy skin		<p>Counsel person to:</p> <ul style="list-style-type: none"> Increase fluid intake (two to three litres per day) as soon as treatment starts; and * take fluids mostly during day to prevent interruption of sleep.

⁵ Sources of information for this section include: Heathcote et al., 2001; Yim, 2001.

Symptom	Characteristics	Management
Hair loss	This is a common side effect and the loss is only temporary and not total. A hairpiece/wig is rarely required.	Encourage person to: <ul style="list-style-type: none"> • consider a shorter haircut; and • avoid perms and colour treatments.
Irritability		Introduce person to relaxation techniques. Counsel person to seek help if unable to control anger.
Depression	This is the most common symptom that causes people to stop interferon therapy.	Encourage person to: <ul style="list-style-type: none"> • deal with the flu-like symptoms as soon as they appear as they may increase the risk of depression; • seek professional help before the feeling becomes severe; • consider contacting a hepatitis C support group; and • monitor responses to antidepressants, if prescribed.
Shortness of breath (dyspnea)		Encourage person to report this symptom to the physician as the dose may need to be altered. Counsel the person to sit up slowly before standing up from a lying position, if he or she feels faint.
Diarrhea	The onset of loose stools is often noticed at the beginning of interferon treatment together with the flu-like symptoms. Diarrhea usually lasts for one or more months.	Counsel person to: <ul style="list-style-type: none"> • increase daily fluid intake to three litres to avoid dehydration; and • avoid milk and milk products and excessive amounts of fruit.
Mouth ulcers	Ulcers may develop in the mouth at any time during treatment and are more common when ribavirin is added to interferon.	Counsel person to: <ul style="list-style-type: none"> • eat soft fruits such as bananas, steamed vegetables and ground meat; • drink milk or milk shakes, if tolerated, as they are high in calories and protein; and • monitor weight: high-calorie/high-protein liquid or powdered dietary supplements may be prescribed by the physician, if required.

Special considerations

Substance Use

Sharing of substance use equipment or injection drug use is currently the main mode of transmission of hepatitis C virus in Canada. After five years of injecting drugs, as many as 90 per cent of users are infected with the hepatitis C virus (CLF National Hepatitis C Education Program, 2000). Injection drug users living with hepatitis C, like those living with HIV/AIDS, often have had a poor relationship with health care providers as a result of

- their unique life circumstances;
- discrimination related to injection drug use and hepatitis C; and
- lack of information available to caregivers about them and their lives (CPCA & BCHPCA, 1999).

In the last few years, more resources have been developed to help nurses learn to work with people who inject drugs (See Readings and Other Resources). Nurses may find the following statements from caregivers and users helpful as a basic set of principles to guide their practice.

- The goal is improvement in the person's health and quality of life – any improvement, no matter how small.
- Relate to the person as one human standing before another human.
- The person is the expert on their life. They know what they need. Listen to them. It's not about what the caregiver needs.
- Be flexible and creative. A solution is there if you can be open to it. Let the person guide and teach you.
- Appropriate, respectful care must never be denied just because a person uses drugs.
- Communicate, communicate, communicate – with the client and among caregivers. (*Source: McAmmond, 1998*)

Two specific guides for nurses are included as appendices. The first suggests strategies to guide the nurse in establishing a relationship of trust with the user and in fostering his or her autonomy (Appendix 2). The second tool is a guide for assessing substance use (Appendix 3). Many nurses are not comfortable discussing substance use with their clients. This assessment provides examples of questions that can be used as a basis for discussion. How the questions are used will vary with the person and his or her situation.

Prevention strategies

Nurses should provide injection drug users with information on how to reduce their risk of acquiring hepatitis C and transmitting the infection to others (see Information on Hepatitis C). The primary risk comes from injection with previously used needles

and syringes contaminated with the blood of another user. People who inject drugs are at an increased risk when they share other contaminated injecting equipment, such as spoons, or other drug paraphernalia, such as straws for snorting drugs.

HCV infection is acquired very rapidly after initiation into injection drug use. Nurses should include new injection drug users and those who are thinking about injecting in their prevention strategies (Health Canada, 1999).

Harm reduction

Some drug users decide to abstain from drugs, and nurses must support their self-care efforts. However, for others, total abstinence is not a realistic goal. Nursing interventions should then focus on encouraging behaviours and substance use practices that reduce the risk of hepatitis C and other infections such as HIV and hepatitis B. For example, the drug user could stop sharing equipment or change from injecting drugs to smoking, snorting or swallowing drugs. Most strategies to limit transmission of these viruses are based on a harm reduction model.

Harm reduction is a philosophy and an approach to care that minimizes harm from substance use and increases the health and quality of life of the person (McAmmond, 1998). A consistent caring relationship between the person who uses drugs and the nurse is needed to facilitate harm reduction. The following principles underlie the successful implementation of a harm reduction approach.

Harm reduction:

- recognizes the intrinsic value and dignity of all human beings;
- seeks to maximize social and health assistance, disease prevention and education while minimizing repressive and punitive measures;
- recognizes the right for comprehensive, non-judgmental medical and social services for the fulfillment of basic needs of all individuals and communities, including users, their loved ones and the communities affected by drug use;
- emphasizes the necessity for a comprehensive approach to drug use that addresses the isolation, survival needs and drug use of the user;
- does not judge licit and illicit drug use as good or bad, rather it looks at people's relationship to drugs and emphasizes the reduction of drug-related harm while encouraging safer drug use;
- recognizes the competency of users to make choices and changes in their lives;
- provides options in a non-judgmental, non-coercive way;
- demands that the individuals and communities affected by drug use be involved in the creation and implementation of harm reduction interventions;
- recognizes the diversity of users and drug use and the necessity for outreach and services reflecting every user's needs;

- expects accessible, non-judgmental drug treatment upon demand;
- supports legal syringe exchange, accessible sterile drug using and safer sex equipment;
- challenges current drug policy and its consequences, such as misrepresentations of drug users and misinformation about drug use.

(Source: American Harm Reduction Coalition cited in McAmmond, 1998)

The harm reduction model can give rise to value conflicts for nurses who may be concerned they are encouraging behaviours that are not health promoting. Learning more about harm reduction principles and discussing their concerns with their nursing colleagues and other health care providers may be helpful (Gimenez-Lambert et al., 1996).

Recent research has reported high rates of hepatitis C infection despite apparent widespread implementation of risk reduction strategies that appear to have been adequate to maintain a low or lower rate of HIV. This may be explained by the high percentage of injection drug users infected with hepatitis C. Another possible explanation is the high degree of infectivity and transmissibility of HCV per episode of blood contact compared to HIV. Further research is needed on how to modify existing programs or develop new ones that target elimination rather than reduction of HCV-risk related injection behaviours (Health Canada, 2001).

See Readings and Other Resources for selected sources of further information on principles of harm reduction, alternatives to injection and safe injection, other drug-related practices and methadone maintenance. Some specific harm reduction strategies are found in the section on hospice palliative care.

Other nursing interventions

This section has focused on interventions for developing relationships with people who inject drugs and on prevention strategies. In providing holistic care to injection drug users, nurses will incorporate into their practice, as appropriate, the broad range of interventions included in this guide (e.g., counselling, education and support). Nurses will find that much of the resource material developed to guide nurses in caring for injection drug users living with HIV/AIDS is applicable to the care of those with hepatitis C. For more information, see Appendices 2 and 3.

Hospice palliative care

Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with, or dying from, an advanced illness or are bereaved. This section focuses on palliative care for injection drug users with hepatitis C and takes a harm reduction approach⁷ (See previous section: Substance Use for information on harm reduction).

Many injection drug users with hepatitis C continue to use drugs. Nurses who provide palliative care from a harm reduction perspective respect the choices people make about substance use and help them to minimize harm to both themselves and those around them.

⁷ Sources for this section include: CPCA & BCHPCA, 1999; McAmmond, 1998; Paquin et al., 2001.

Many injection drug users with hepatitis C are co-infected with HIV. From working with people living with HIV/AIDS, we have learned that pain is usually undertreated in this population and especially in people who use substances. Undertreatment of pain may stem from health care providers' confusion about the legitimate use of controlled substances and fear of contributing to substance abuse or supporting addictive behaviour.

A comprehensive palliative care assessment for injection drug users includes a medical and health assessment that incorporates assessment of pain, a substance use assessment and a psychiatric assessment/history, if indicated. Understanding the client's substance use helps the nurse and the person receiving hospice palliative care to manage pain and other symptoms effectively and safely and to develop a realistic care plan that includes appropriate management of substance use and reduction of harm.

In providing palliative care for the person with hepatitis C, the nurse must be aware of the concept of total pain. Pain is not only a physical symptom. Total pain combines physical, emotional, social/familial, economic and spiritual factors. Key principles of pain management include:

- pain is what the client says hurts;
- medication must be given on a regular basis to maintain good pain control;
- other methods of pain relief such as relaxation, music therapy and massage therapy should be considered.

Harm reduction approaches in hospice palliative care could include:

- working toward safer injecting practices (e.g., use of clean needles, sterile procedure and vein management; finding safe locations to use – perhaps in an indoor location where sterile procedure is more likely and assault or theft less likely than in a back alley);
- working toward safer forms of use (e.g., smoking or snorting rather than injecting);
- use of drugs that are less physically harmful, less likely to result in disruptive or non-adaptive behaviour; and/or reduced levels and frequency of use;
- arranging safer, more stable housing and access to better nutrition, if the person is not already in a palliative care residential setting;
- ensuring the person is receiving all forms of income support for which he or she is eligible;
- linking the person with basic health care, as well as to specialized HCV care and other health and social services they might need;
- prescribing medications such as Methadone to replace other substances that may be associated with a greater risk of harm;
- working to help the person develop or strengthen their social support networks and their involvement in social, recreational or spiritual activities. Support groups (e.g., user groups, hepatitis C and HIV support groups) may be a useful option.

(Adapted from McAmmond, 1998)

Perinatal care

Women with hepatitis C do not need to avoid becoming pregnant, unless they are on antiviral therapy or such therapy is planned.⁸ However, in preconception discussions, nurses should inform women there is a risk of transmitting the infection to their babies. The risk of vertical transmission (mother to baby) is approximately 7.9 per cent. The risk increases up to 60 per cent if women are co-infected with HIV. Universal screening for hepatitis C before or during pregnancy is not currently recommended in Canada; however, women who are at risk for HCV infection should be offered testing.

Nurses should counsel women with hepatitis C who are taking ribavirin therapy not to become pregnant because ribavirin is a known teratogenic agent. The safety of interferon in pregnancy is uncertain. The partner of a male under ribavirin should receive the same counselling.

There are currently no documented measures for reducing transmission of HCV from mother to child. Nurses can counsel women about risk reduction including abstinence from alcohol, immunization against hepatitis A and B and, in the case of women who inject drugs, specific harm reduction strategies.

Women with hepatitis C and their fetuses are at no greater risk for obstetric or perinatal complications than other women. For most women, pregnancy does not appear to affect the course of their HCV infection.

There is no conclusive evidence of a relationship between transmission of the virus to the baby and mode of delivery. Women with hepatitis C can deliver vaginally unless there are obstetrical reasons for a cesarean delivery. Nurses need to observe standard precautions during delivery. Neither the mother nor the infant has to be placed in isolation.

Because of passive transfer of HCV antibodies, all infants of mothers with HCV will test positive for HCV at birth. Infants who are not infected with HCV should have cleared these antibodies by 12 to 15 months. Infants should be seen by a physician at three and six months, at which time they may be tested for HCV RNA; otherwise, testing should be done at 12 months. A negative result may help relieve parents' anxiety. If the results are positive, children should be referred to a specialist who will assess them for the presence of chronic liver disease. Hepatitis C seems to be mild in children; however, some children develop liver fibrosis rapidly over the years. More research is needed on the possible progression of the disease as children grow older.

Some researchers have detected HCV RNA and anti-HCV antibodies in colostrum and breast milk. However, to date no cases of transmission of the virus through breastfeeding have been documented. Women with hepatitis C can breastfeed their babies. If their nipples are cracked or bleeding, they should suspend breastfeeding until the nipples are healed. Nurses can help women with breastfeeding techniques to prevent cracked or bleeding nipples.

⁸ Sources of information in this section include: CDC on-line course, 2001; CLF National Hepatitis C Education Program, 2000; Boucher & Gruslin, 2000.

Health care workers

Nurses and other health care workers are at risk for occupational exposure to HCV; however, they do not need to be screened routinely for hepatitis C.⁹

Nurses must familiarize themselves with and adopt preventive strategies. The primary means of preventing transmission through occupational exposure is to follow infection control precautions that assume that the blood and other body fluids from all clients are potentially infected. These precautions include: routinely using barriers such as gloves and/or goggles when contact with blood or body fluids is expected; immediately washing hands and other skin surfaces that have come in contact with blood or body fluids; and carefully handling and disposing of sharp instruments.

Nurses need to be aware of current recommendations for the management and follow-up of health care workers who have had a potential occupational exposure to HCV. Health Canada (1997a) has published recommendations for: immediate post-exposure activities, evaluating a significant exposure, counselling health care workers following a significant exposure, testing the source and the health care workers after informed consent, post-exposure prophylaxis for the health care workers and post-exposure counselling recommendations (see Reading and Other Resources). At the present time, there is no effective post-exposure prophylaxis against HCV.

There is much controversy about whether health care workers infected with hepatitis C should continue working. There is no legal restriction to prevent a nurse with hepatitis C infection from working in nursing in Canada. There may be modifications to work practices or work restrictions for health care workers with significant dermatitis and for health care workers who perform exposure-prone procedures and are infected with HCV (Health Canada, 2002).

There have been anecdotal reports suggesting that nurses with hepatitis C, like their colleagues with HIV, may encounter difficulty with employers who are aware of their HCV-positive status. Nurses may need to access legal counsel to assess the implications for protection of confidentiality and continuation of work.

In general, nurses with hepatitis C are not required to disclose their HCV-positive status to their patients or co-workers. However, they have a personal and ethical responsibility not to endanger their clients. In exercising their responsibility, nurses should:

- properly use routine practices for preventing transmission of infection in health care settings and make use of available infection control technology;
- seek advice on assessing the level of risk of transmission related to exposure prone procedures and determine whether they can continue to participate in this aspect of patient care;
- report a potential exposure to a patient to ensure the patient receives the proper follow-up care;
- agree to voluntary HCV testing if they engage in high-risk behaviours.

⁹ Sources of information in this section include: CDC on-line course, 2001; CLF National Hepatitis C Education Program, 2000; Boucher & Gruslin, 2000.

For more details, consult Readings and Other Resources under occupational exposure and prevention/health care worker.

Nurses are encouraged to refer to CNA's *Code of Ethics for Registered Nurses* (1997), which is scheduled for revision in 2002, for guidance on ethical issues.

Hepatitis C in federal correctional facilities

Although the rate of HCV in all Canadian correctional settings is unknown, hepatitis C infection is a major concern. One study states that 30 to 40 per cent of federal offenders have hepatitis C. This represents a dramatic rise over the past decade (McVie, 2001). Almost 70 per cent of offenders admitted to federal custody have some level of substance abuse problem requiring intervention. Problems of substance abuse are disproportionately represented among aboriginal and female offenders.

Prison inmates are known to engage in high risk behaviours. Injection drug use and sexual activity are not uncommon in prisons.

Nurses who work in correctional settings face many of the same issues as those working in community clinical settings. A protocol has been developed to manage the care of HCV-positive inmates, *Technical Annex on the Management and Treatment of Hepatitis C Virus in Correctional Service of Canada*. The annex is currently undergoing revision with more consideration being given to follow-up in the community and community involvement in education within the institutions.

Harm reduction programs that have been implemented in federal prisons include:

- a national methadone treatment program;
- provision of condoms, lubricants, dental dams and bleach;
- educational programming about infectious diseases and high risk behaviours awareness (e.g., Reception Awareness Program, Peer Education Counselling, Choosing Health in Prison);
- preparation and distribution of educational pamphlets (*Hepatitis C – Inside the Walls and Going Home Healthy*) and comic books (*From Darkness to Light* for women offenders and *Red Alert* for male offenders).

Transplantation

Hepatitis C is the most common reason for liver transplantation in Canada.¹⁰ Fortunately, only a small number of people with hepatitis C develop liver disease that is severe enough to require transplantation. A main indication for liver transplant is the onset of liver failure. The signs of liver failure may include ascites, jaundice, mental confusion and bleeding from the rupture of esophageal varices.

The overall success rate of the surgery is high; however, in almost all cases, the transplanted liver becomes infected with hepatitis C. The transplanted liver can continue to function well for many years even if infected with hepatitis C, thereby extending

¹⁰ Sources for this section include: Heathcote et al., 2001; CLF National Hepatitis C Education Program, 2000)

the person's life. Monotherapy with interferon may not work, and the combination with ribavirin is generally poorly tolerated.

People being considered for transplantation need to go through an extensive screening program. Nurses can support people facing this process by providing them with information and assisting them in making decisions about treatment options. See Reading and Other Resources, Transplantation.

Mental health issues

At the present time, little is known about the extent to which people infected with hepatitis C experience mental health problems or how serious their symptoms are. We also do not know how effectively existing services are meeting their unique needs.¹¹

Persons diagnosed with HCV experience a range of emotions including shock, fear, denial, confusion, shame, regret, blame, suicidal ideation, acute anxiety and anger. Uncertainty about the progression of symptoms and the disease may also cause emotional distress. Nurses can help people with hepatitis C and their families develop effective coping strategies and support networks.

Injection drug use and high-risk sexual behaviour with multiple partners are common in the mental health community. As part of harm reduction planning, nurses need to work with the mental health community to provide services and education toward prevention. This would include needle exchange programs, providing condoms, risk reduction for people living on the street and for those in psychiatric facilities, community living facilities, halfway houses, etc.

People with a history of psychological instability or underlying psychiatric issues may be at risk for problems associated with interferon such as severe depression, suicidal ideation, delirium and manic depression. Nurses should counsel their clients with a history of psychiatric problems about the possibility of adverse psychiatric reactions and monitor their responses to the medication. People co-infected with HIV may experience increased emotional stress and may require more intensive mental health support.

Hemodialysis

The rate of HCV infection in people on long-term dialysis is estimated at 20 to 50 per cent in North America.¹² People on chronic dialysis are thought to have an increased risk of acquiring HCV infection from blood products transfusion or nosocomial (hospital-acquired) transmission in hemodialysis units. As the length of time people spend on dialysis increases, the likelihood of HCV infection increases with an estimated risk of 10 per cent per year. The risk of acquiring HCV infection on long-term hemodialysis is expected to decrease because of the screening of blood products for HCV. The risk of acquiring HCV through nosocomial transmission (for example, failure to use routine precautions) is not clear.

¹¹ Sources of information for this section include: Rowe, Rowe, & Malowaniec, 2000.

¹² Source of information for this section: Yim, 2001.

The current standard of treatment using interferon and ribavirin is not indicated for people on long-term hemodialysis. Because ribavirin causes hemolysis that does not get cleared in hemodialysis, there will be a build-up of hemolysis. Therapy with interferon alone is possible but is poorly tolerated by people receiving hemodialysis. Dose reduction is frequently required.

Nurses should counsel people on hemodialysis (as with all patients with impaired renal function) to avoid non-steroidal anti-inflammatory drugs, including aspirin, and benzodiazepine type of sedatives such as lorazepam and diazepam, which may promote encephalopathy in an individual with cirrhosis.

To reduce nosocomial transmission of HCV, nurses need to be familiar with the policies and procedures for hemodialysis units. See Readings and Other Resources, Hemodialysis for more information.

Hemophilia

Hemophilia refers to two X - linked genetic disorders characterized by absence of one of two important clotting proteins, factor VIII (hemophilia A) or factor IX (hemophilia B). Normal clotting involves a complex series of reactions that start as soon as bleeding occurs. Where there is an absence or deficiency of either factor VIII clotting protein or factor IX clotting protein, clotting is delayed. Bleeding may continue until treatment is administered. Treatment consists of replacing the missing protein in the form of clotting factor concentrates. Some of these concentrates are now produced by genetic engineering, with albumin added to some of the factor VIII concentrates for stabilization of the factor VIII protein. No human material is used in the manufacturing of Factor IX concentrates.

Prior to 1994, all concentrates were made from human plasma, and before screening for hepatitis C was introduced in July of 1990, the concentrates were heavily contaminated with the hepatitis C virus. The rate of hepatitis C infection in patients with hemophilia who were treated with concentrates prior to 1990 is approximately 95 per cent. The rate is less in patients treated with whole plasma and cryoprecipitate. All patients treated with any blood component prior to 1990 should be tested for hepatitis C. Testing for HCV-RNA done in the past three years shows that approximately 15 per cent of patients have spontaneously cleared the virus.

Monitoring of people with hemophilia who have hepatitis C is essential. In this way, they will have access to timely therapeutic and prophylactic measures to delay or prevent progression of hepatitis and its complications. Safety is a key issue for patients with hemophilia. Treatments with the potential to exacerbate bleeding or procedures that may cause bleeding must always be assessed very carefully as to the risk versus the benefit for the patient. The patient's medical records should carry a prominent sign stating that he/she has a bleeding disorder.

There is much controversy in the hemophilia population about the need and risk of a liver biopsy. Most hepatologists will insist on a liver biopsy before suggesting treatment. Many patients who have chosen to have the liver biopsy done have been reassured that where there is minimal damage to their liver they have a choice of waiting

for treatment at a later time. Treatment modalities are changing and the hope is for a treatment with few side effects. Where the biopsy shows fibrosis and treatment is more urgent, patients are more prepared to embark on a course of treatment knowing that they have a good chance of clearing the virus for life.

Treatment with interferon and ribavirin does not provoke bleeding, but anemia secondary to blood loss may be exacerbated, as ribavirin itself is associated with development of anemia. The muscle pain associated with interferon can be misconstrued for a bleed, or alternatively, a bleed may be misconstrued as a side effect of the drug. Muscle weakness can develop as a result of inactivity due to fatigue. This may place the patient at risk for falls which may cause bleeding. It is vital that care providers of people with hemophilia are informed when they start treatment and that good communication between caregivers continues throughout the course of treatment.

Children with hemophilia who were born after 1991 and who have been treated with factor concentrate should not be infected with hepatitis C. Children treated prior to 1990 for bleeding episodes with factor concentrate should be tested for hepatitis C.

Treatment for hepatitis C in children is quite controversial and very little information appears in the literature. As with all patients, monitoring of liver function is vital and treatment must be tailored to each child. The psychosocial care of these young people also requires attention. Parents and siblings will need information and reassurance about the child's condition. There may be issues in the school with teachers and other pupils. Information should be sought from the child's hemophilia treatment team, always respecting the right of the child to confidentiality.

There are 26 comprehensive hemophilia programs in Canada. The Canadian Hemophilia Society (CHS) is an excellent source of information and provides support for people with hemophilia. See Readings and Other Resources for more information.

The nursing care and symptom management discussed in the guide pertain to the hemophilia population with special precautions needed for situations where bleeding is a risk. For further information on care of people with hemophilia, see Appendix 4.

Aboriginal Population

The fact that in the majority of instances the sharing of injection drug paraphernalia transmits HCV, accounting for approximately 70 per cent of the 240,000 estimated cases in Canada, is significant. This is especially interesting in light of the fact that HIV infection by Injection Drug Use (IDU) is rising in the Aboriginal population. Before 1989, 6.3 per cent of HIV infection was linked to IDU increasing to 25.4 per cent from 1989-93 and to 51.2 per cent during 1994-98 (Health Canada, 1999). In addition, AIDS is more prevalent in the younger Aboriginal population – 29.3 per cent are less than 30 years of age, compared to 17.6 per cent of cases in the mainstream population under 30 years. As well, AIDS is found more frequently in the entire female population, with 17.5 per cent of Aboriginal cases being female, compared to 6.4 per cent female cases in the non-Aboriginal, mainstream population (Health Canada, 1999).

According to recent HIV/AIDS data (1993-98) obtained from B.C., Alberta and Saskatchewan, Aboriginal people make up 15 per cent, 26 per cent and 30 per cent, respectively, of the newly diagnosed positive cases and, most notably, IDU and heterosexual behaviours were the most commonly identified risk factors (Health Canada, 1999). The proportion of new HIV-positive tests between IDU and heterosexual exposure differ significantly and were rated as follows: 73 per cent and 13 per cent for B.C.; 60 per cent and 13 per cent for Alberta and 83 per cent and 8 per cent in Saskatchewan, with infection as a result of IDU ranking considerably higher in all three provinces (Health Canada, 1999).

The rates of HCV infection among Aboriginal populations are far greater than for the non-Aboriginal population in general. According to Health Canada, the prevalence of HCV among Canada's Aboriginal peoples is seven times higher than the rate for non-Aboriginal Canadian-born people.

To begin to meet the needs of Aboriginal persons infected with hepatitis C, nurses should be familiar with aboriginal specific aspects such as culture, etc.

VI GLOSSARY OF TERMS

Acute hepatitis	Inflammation of the liver that resolves within six months of the onset
ALT	Alanine aminotransferase, a liver enzyme
Antibody	Proteins produced by the body in response to new proteins (antigens) that the body has not seen previously
Antigen	A protein, often part of a virus, recognized by the body as being new
Anti-HCV	Antibody to HCV that develops in response to HCV infection
Chronic HCV	Persistent infection with HCV, identified by HCV RNA 6 months after acute infection
Cirrhosis	Extensive scarring of the liver, due to viral infections, alcohol abuse, medications etc.
Decompensated liver disease	Liver disease that has reached a stage where the liver can no longer function normally
EIA	Enzyme immunoassay
Fibrosis	Scarring of the liver, less severe than cirrhosis
HBV	Hepatitis B virus
HCC	Hepatocellular carcinoma, or liver cancer
HCV	Hepatitis C virus
HCV-RNA	The genetic material of the virus that coordinates viral reproduction and protein synthesis
HIV	Human immunodeficiency virus
IDU	Injection drug user
Incidence	The rate of occurrence of new infections in a population over a given period of time
Mortality	Death rate
MSM	Men who have sex with men

NAT	Nucleic Acid Amplification Test (diagnostic test)
Pegylation	Protection or stabilization of a protein so that it disintegrates more slowly than normal; in this context, applies to new generation of interferon
Prevalence	The number of cases present in a population at a given time
Qualitative RT-PCR for HCV RNA	Test to identify HCV RNA by amplification of viral genetic sequences
Qualitative assays for HCV RNA	Test to identify HCV RNA viral load or concentration by amplification of viral genetic sequences
RIBA™	Recombinant immunoblot assay
RNA	Ribonucleic acid
RT-PCR	Reverse transcriptase polymerase chain reaction
Supplemental anti-HCV test	Additional test (e.g., RIBA) used to identify positive anti-HCV result obtained by EIA
Sustained responder	Person who is HCV-RNA-negative six months after completion of treatment
Vertical transmission	Transmission of an infection from mother to child at birth
Viral load	The amount of virus present

VII READINGS AND OTHER RESOURCES

Hepatitis C

Health Canada

Hepatitis C: Get the facts

Hepatitis C Division

2nd Floor, 400 Cooper Street

Ottawa, ON K1A 0K9

Postal Locator 4602A

Fax: (613) 941-9813

E-mail: hepc@hc-sc.gc.ca

Web site: www.healthcanada.ca/hepc

Centers for Disease Control (US)

Hepatitis C: What clinicians and other health care professionals need to know, an on-line course offered by the Centers for Disease Control at www.cdc.gov/ncidod/diseases/hepatitis/c_training/edu

Canadian Liver Foundation

2235 Sheppard Avenue East, Suite 1500

Toronto, ON M2J 5B5

Tel: 1-800-563-5483

Web site: www.liver.ca

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Hepatitis C: Canadian Perspectives. (2000). *Canadian Journal of Public Health*, 91(Supplement 1).

Proceedings of the First Canadian Conference on Hepatitis C. (2001). Available at: <http://www.hepc1conf.ca>

Compensation

Hepatitis C Claims Centre

PO Box 2370

Station D

Ottawa, ON K1P 5W5

Tel: 1-877-434-0944

Fax: (613) 569-1763

E-mail: www.hepc8690.ca

Manitoba

MHCAP

Manitoba Health

4036 – 300 Carlton Street

Winnipeg, MB R3B 3M9

In Winnipeg: (204) 788-6339

Toll-Free: 1-866-357-0196

Ontario

Ministry of Health and Long-Term Care

Ontario Hepatitis C Assistance Plan (OHCAP)

c/o 77 Wellesley Street West

Toronto, ON M7A 1N3

Toll free: 1-877-222-4977

Quebec

For information:

In Québec City: (418) 646-4636

In Montréal: (514) 864-3411

Elsewhere in Quebec: 1-800-561-9749

The Nurse and the Context of Care

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Harm reduction

Canadian Centre on Substance Abuse

75 Albert Street, Suite 300
Ottawa, ON K1P 5E7
Tel: (613) 235-4048
Fax: (613) 235-8101
Web site: www.ccsa.ca

Canadian Harm Reduction Coalition

666 Spadina Avenue, Suite 1904
Toronto, ON M5S 2H8
Tel : (416) 928-0279 or 1-800-728-1293
Fax : (416) 966-9512
Web site: www.canadianharmreduction.com

Centre for Addiction and Mental Health

33 Russell Street
Toronto, ON M5S 2S1
Tel : (416) 535-8501
Web site: www.camh.net

Perinatal

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IX APPENDICES

Appendix 1: Antiviral Therapy for Chronic Hepatitis C

1. Current licensed antiviral therapy for chronic hepatitis C

Drug	Brand name	Suggested dose	Possible result
Interferon alfa-2b + ribavirin	Rebetron	Interferon alfa-2b: 3 million units 3x weekly SC for 24-48 weeks Ribavirin: 1000-1200 mg/day PO for 24-48 weeks	Sustained response in 41%
Peginterferon alfa-2b + ribavirin	Pegetron	Peginterferon alfa-2b: 1.5 mcg/kg body weight once weekly for 48 weeks Ribavirin: 800-1200mg/day	Sustained response in 61%
Peginterferon alfa-2b monotherapy in the presence of contra-indications for ribavirin	PEG-Intron	Body-weight dependent, based on 1.0 mcg/kg body weight once weekly for 48 weeks	Sustained response in 25%

2. Other

Peginterferon alfa-2a + ribavirin Will become available early 2003

Note: Therapies will change as medical research advances.

Source: Colina Yim (June 3, 2002).

Appendix 2: Intervention Strategies for Establishing Trust and Autonomy with People Living With Substance Use

- Explain purpose of intervention
 - focus on the health determinants of clients
- Explain confidentiality
 - obtain consent
 - discuss all possible disclosures
- Remove stigma associated with hepatitis C infection
 - don't stigmatize – don't sanitize e.g., “anybody can get hepatitis C and everyone is important”
- Establish credibility
 - never distort or withhold information
- Maintain a non-judgmental attitude
 - avoid “should”
 - respect differences in values and risk tolerance
- Encourage client participation
 - ask open-ended questions
 - teach self-assessment
 - provide choices and options
 - encourage the client to set personally relevant goals
- Use non-threatening/non-invasive approaches
 - avoid overly technical or sensational language
 - respect personal and group boundaries
 - pay attention to how the word “you” is used
 - do not require self-disclosure
- Be supportive
 - avoid aggressive confrontation
 - respect the defense strategies used by the person

- Be sensitive to cultural differences
 - consider ethnic background, age, gender, sexual orientation, socioeconomic status, and regional identification
 - consider beliefs and values about risk-taking, decision making and personal control
 - consider attitudes towards sexuality, pregnancy, childbirth, parenting and other relevant issues

- Share responsibility
 - for defining the problem
 - for identifying relevant options
 - for decision making and planning

Adapted from: Meijer, L. (1990). *AIDS curriculum for substance abuse counsellors*. Seattle, WA: University of Washington AIDS Education and Training Center Program, H15-H19.

Appendix 3: Substance Use Assessment

Current Use:

What drugs have you been using in the last few days and weeks?

How much?

How (e.g., smoking, fixing, injection sites, snorting, popping, etc.)?

How long at the current level of use?

When are you most likely to use?

What do you feel like when you use?

How does it help you?

What problems does it cause?

Previous Use:

What was your use like before that (i.e., before the above period)?

If use has changed lately, why is that?

Drug Treatment:

What's the longest you've gone without using?

How did you accomplish it?

Any detox attempts? Tell me about it.

Any treatment programs? If answer is yes: Which ones? How did it work for you?

Social Situation:

Are you in a relationship?

Does your partner use?

Are you in touch with your family?

Do your friends use?

Do you have friends who don't use?

Have you been involved with the law? Jail time?

What are the biggest hassles right now in your life?

What are the good parts of your life?

(Source: McAmmond, 1998, p.19)

Appendix 4: Hemophilia and Hepatitis C: Further Information

Invasive Procedures (e.g., liver biopsy)

Prior to all invasive procedures patients should have a complete blood count (CBC), an international normalized ratio (PT INR) and an activated partial thromboplastin time (APTT), as well as their Factor VIII or Factor IX level. Where it is not practical to get a factor level, the APTT may be used to monitor the response to the infused factor concentrate VIII or IX.

Studies show that a liver biopsy can be safely done by the transjugular route in patients who have a good response to factor VIII or factor IX concentrate. Detailed instructions from a hematologist knowledgeable in the care of patients with hemophilia must be obtained well ahead of a scheduled biopsy. The hemophilia nurse or other designated person will make arrangements for the administration of the factor concentrate. Careful monitoring and specific written guidelines are given to the patient by the nurse who is experienced in hemophilia care.

Radiologists, hepatologists or gastroenterologists planning a liver biopsy for a patient with hemophilia must consult with the patient's hematologist for the specific guidelines. Where a patient has an inhibitor to the factor concentrate, careful consideration must be given to the absolute benefit of doing a liver biopsy.

An inhibitor is an antibody formed against the deficient clotting protein that is used to treat bleeding episodes in patients with hemophilia. This complication of treatment occurs in approximately 25 per cent of treated patients with hemophilia A and approximately 2 per cent of patients with hemophilia B. This antibody will inhibit the therapeutic effect of the factor clotting concentrate. There are alternative treatments, but their efficacy is less predictable than is specific replacement therapy.

Factor concentrate is given one hour prior to the procedure (the half-life of factor VIII is 8 to 12 hours, and of factor IX is 12 to 16 hours). The level of factor VIII or IX should be raised to 75-100 per cent of normal. Follow up treatment is administered at 12 hours post-procedure and daily for a further three days. Most patients self treat, but in the case of patients who are not trained to self infuse, arrangements will be made for the follow up treatment to be done in the community or at the hospital clinic. Patients are advised to report any sign of bleeding, abdominal pain, nausea or vomiting.

Factor concentrate replacement will also be necessary prior to invasive procedures such as paracentesis, TIPS insertion, etc.

Esophageal varices

The development of esophageal varices is a serious complication of liver disease. It is important to make the diagnosis before bleeding occurs. Hemophilia nurses spend a lot of time with their patients discussing the importance of careful monitoring of blood testing results and the importance of checking for complications of hepatitis C such as esophageal varices.

Factor concentrate, raising the level of the missing clotting protein to at least 50 per cent of normal should be given prior to the oesophagogastroduodenoscopy (OGD). One dose is usually sufficient for the procedure. If varices are present, the patient is at risk for bleeding so it will be necessary for the patient to discuss replacement therapy on a regular basis as a prophylaxis. If banding is done, the hematologist should be notified. Patients will need to take a proton pump inhibitor to prevent bleeding when the scarring occurs.

Cirrhosis

Cirrhosis of the liver with all its attendant complications raises warning flags for this group of patients. As the PT and INR increase, it will be important to know which other clotting factor proteins are being affected. Bleeding may occur due to decreased levels of other clotting proteins, as well as decreased platelet count as the patients' condition deteriorates. It may be necessary to maintain the patient on regular prophylaxis, replacing the missing clotting protein on a regular basis. It will be important for the care providers to consult with the hemophilia treatment team.

Immunization

All patients in hemophilia programs who were born after 1983 should have been vaccinated against hepatitis B. Patients treated before that time have most likely been exposed to hepatitis B through the concentrates and are immune for life, except in about three per cent of patients who remain carriers of the virus. More recently, nurses and physicians have advised all patients to be vaccinated against hepatitis A. There have been reports of serious complications with hepatitis A in the presence of hepatitis C

Injections

When administering IM injection to patients with hemophilia, a 25 gauge 1" needle should be used, no larger. The preferred site is the deltoid region where good pressure can be maintained for five to seven minutes. With this technique, bleeding should not occur and factor concentrate is generally not needed.

Where the patient has marked thrombocytopenia (less than 50,000 platelets), and severe hemophilia (<0.02 u/ml of the clotting protein), it may be necessary to replace the missing clotting protein to a level of 30 per cent to prevent a muscle hematoma. The hepatitis A vaccination has a 25 gauge 1" needle attached to the pre-mixed solution; this is the ideal size. This same technique can be used for all other vaccinations. Injections by the subcutaneous route using a 25 gauge 7/8" can be safely given, again applying pressure for five minutes.

The following information on safety features can be copied and added to the patient's chart:

THIS PATIENT HAS A BLEEDING DISORDER.
PLEASE:

- INTRAMUSCULAR INJECTIONS TO BE GIVEN USING ONLY A 25 GAUGE 1" NEEDLE INTO THE DELTOID REGION. PRESSURE TO BE MAINTAINED FOR 5 TO 7 MINUTES.
- VENIPUNCTURE TO BE PERFORMED USING A 23 GAUGE BUTTERFLY. APPLY DIRECT PRESSURE TO THE SITE.
- NO ARTERIAL BLOOD GASES
- NO ASPIRIN CONTAINING DRUGS
- NO INVASIVE PROCEDURES WITHOUT FIRST CONSULTING THE HEMATOLOGIST

Appendix 5: Marijuana for Medical Purposes: Information at a Glance for Palliative Home Care Practitioners

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Introduction to the new Health Canada Regulations

The new Health Canada *Marihuana*¹⁵ *Medical Access Regulations* (Health Canada (2001) are effective July 30, 2001. The regulatory approach centres on the process of providing access to marijuana for medical purposes while it is being researched as a potential medicine. **Marijuana still remains an illegal drug in Canada.**

The new regulations contain two main components:

- Authorization to possess
- Licence to produce.

The regulations protect certain patients with chronic or terminal illnesses against marijuana-related prosecution. Such patients may apply for permission to grow, possess and use marijuana to relieve symptoms including pain, nausea and poor appetite (Fayerman, 2001).

This document will focus on how an individual can apply for an “authorization to possess marijuana for medical purposes.” It includes other relevant information that may guide palliative home care practitioners in responding to questions from clients.

Authorization to possess

Criteria

- Individuals ordinarily resident in Canada.
- Individuals living with a prognosis of a life span of less than 12 months; or
- individuals **suffering from specific symptoms** associated with some serious medical conditions such as multiple sclerosis, spinal cord injury or disease, cancer, HIV infection/AIDS, severe forms of arthritis and epilepsy; or
- individuals who have been advised by two medical specialists to use marijuana.

Application process for eligible individual (Health Canada 2001)

- Get an application form on the Health Canada web site www.hc-sc.gc.ca or by calling Health Canada’s Office of Cannabis Medical Access at (613) 954-6540.

¹³ *It should be noted that “marihuana” is spelled with an “h” in the Controlled Drugs and Substances Act and its Regulations, as well as in the Marihuana Medical Access Regulations. “Marijuana” is the other common spelling. Either spelling is acceptable but when referring to the Canadian legislation marihuana has to be spelled with an “h”.*

- Have the medical declaration section of the form completed by a medical practitioner (family physician) if living with terminal illnesses. If not, the medical declaration has to be signed by one or two specialists.
- Attach two (2) current passport sized photographs certified by a medical practitioner or a specialist. The photographs will be used for an identification card to be issued by Health Canada. No personal medical information will be indicated on the card.
- Mail the application form to Health Canada for approval by the Minister. Application from individuals with terminal conditions will be given priority for processing.

Other relevant information

- The physician completing the application form has to indicate the daily dosage of dried marijuana (in grams), the form and route of administration recommended and the period for which the use of marijuana is recommended (Health Canada, 2001).
- The authorization to possess expires 12 months after its date of issue unless the physician in the application form specifies a shorter period.
- Hospitals, hospices and correctional institutions have their own regulations and policies governing the use or access to drugs for medical use. These will determine whether marijuana may be used and under what conditions.
- Canada Customs and Revenue Agency Regulations do not permit an individual to import or export marijuana for medical or any other purpose. Existing provisions under the Controlled Drugs and Substances Act continue to apply as before, prohibiting any person from importing or exporting marijuana. Although individuals who hold an authorization to possess marijuana may attempt to take marijuana out of the country, this activity remains illegal.
- Health Canada seeks continuous feedback on the regulations and medicinal marijuana. A survey form can be completed at the following address: http://www.hc-sc.gc.ca/english/magazine/2000_08/marijuana.htm

What is marijuana?

Marijuana is the common name of *Cannabis sativa*, a plant that contains more than 400 chemicals. What is commonly referred to as marijuana (“grass”, “pot”, “weed”) in North America is usually made up of crushed cannabis leaves, flowers and often twigs. Like most plants, marijuana is a variable and complex mixture of biologically active compounds. THC (delta-9 tetrahydrocannabinol) is the main psychoactive constituent in marijuana. When marijuana is smoked, THC is absorbed from the lungs into the bloodstream within minutes (Health Canada, 1999).

What is the potential therapeutic efficacy of marijuana (Health Canada, 1998)?

Much of the evidence of the potential therapeutic efficacy of smoked marijuana is anecdotal. Marijuana has been claimed to have the following beneficial effects:

- Relief of nausea and vomiting associated with cancer and HIV/AIDS therapies;

- Stimulation of appetite and weight gain in Wasting Syndrome in AIDS and cancer;
- Relief of muscle pain and spasms in Multiple Sclerosis; and
- Reduction of the frequency of epileptic seizures.

What are the potential health effects of marijuana (Health Canada, 1998)?

The potential health effects associated with the use of marijuana for medical purposes have not been adequately researched. Listed below are the main known health effects from smoking marijuana:

- Physical and psychological dependence (Australian Drug Foundation, 1998): there is clinical and epidemiological evidence that some marijuana users experience dependency. Abrupt termination of marijuana can produce a mild withdrawal syndrome. Symptoms include sleep disturbance, irritability, loss of appetite and consequent weight loss, nervousness, anxiety, sweating and upset stomach. Sometimes chills, increased body temperature and tremors occur. The withdrawal syndrome usually lasts for less than a week, although sleep disturbance may persist for a longer period.
- Psychomotor skills: Marijuana reduces the ability to perform tasks requiring concentration and coordination such as driving a car.
- Respiratory: Marijuana causes some lung damage similar to that caused by tobacco smoke. Users may need to be cautioned to avoid, for example, smoking marijuana in public places near children or any place where others might be exposed to the second-hand smoke without prior consent.
- Cardiovascular: Marijuana increases heart rate and blood pressure.
- Immune system: The complete effects of Marijuana remain unknown, but the substance may have an effect on the immune system.

Approved pharmaceutical drugs related to marijuana (Health Canada, 2001)

Drugs are approved for sale in Canada under the Food and Drug Act Regulations. The approval process generally includes controls respecting the safety, efficacy and quality of products. Marijuana has not been reviewed for safety and effectiveness and has not been approved for sale as a drug in Canada.

Within the full set of approved pharmaceutical treatments, there are two commercially available drugs related to marijuana:

- MARINOL[®], which contains chemically synthesized THC; and
- CESAMET[®], a synthetic cannabinoid.

In Canada, both drugs are approved for the treatment or management of severe nausea and vomiting associated with cancer chemotherapy and may be prescribed by physicians. MARINOL[®] has also been approved for the treatment of anorexia associated with weight loss in people living with AIDS. Both drugs are taken orally.

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