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# Hepatitis C: Mental Health Issues

William Rowe, DSW, Jocelyn Rowe, MD, Leah Malowanec, BSW

## Hepatitis 'Non-A, Non-B'

When the hepatitis C virus (HCV) was identified in 1990, relatively little was known about the progression of the disease or the psychosocial implications of its diagnosis. If you were one of the Canadian blood donors who received a letter in 1990, informing you that hepatitis C had been identified in your blood and unfortunately no further donations could be accepted, there would have been a small note attached. The note would explain that the significance of this finding was unknown, but that you should see your doctor.

When your physicians contacted public health authorities and medical directors of blood collection agencies, they would have been advised that hepatitis C was not known to be the cause of any serious illness, so patients should be reassured.

But patients needed to know much more: What *was* hepatitis C? How did they get it? Should they start using condoms with their spouses of *12 years*? Would they become ill from this? What symptoms should they watch out for? Were there other tests they should have? Are there any treatments they should start? Were their children at risk?...

We did not *have*, and could not *obtain*, information regarding the medical implications of testing positive for the hepatitis C virus. We had little to guide us in our attempts to offer support. One woman commented, "Having hepatitis means that many things change, and a lot of them are invisible. Unlike having cancer or being hurt in an accident, most people do not

understand even a little bit about HCV and its effects." Patients and health professionals had very little information to work with.

## Wake-up call

We now know, of course, that the thousands of Canadians who have been diagnosed with HCV do have substantial and specific social service and mental health needs. We are better informed about what some of these needs are, and the nature of the responses and interventions that are necessary. What we do not yet sufficiently understand is to what degree effective social and mental health services are in place. To what degree do Canadians diagnosed with hepatitis C have adequate access to care and support? Public awareness relating to hepatitis C and mental health is still in its infancy. To what degree is public health policy responsive to the medical and mental health needs of Canadians diagnosed with hepatitis C?

## Difficult news

In the year 2000, we are well informed of the range of emotions experienced by persons diagnosed with HCV: shock, fear, denial, confusion, shame, regret, blame, suicidal ideation, and acute anxiety or anger.<sup>1</sup> These responses have been well described for persons coping with diagnoses of cancer, HIV, and other life-threatening illness. We know that with appropriate support, acute reactions can be anticipated and can evolve into adaptive coping strategies and support networks.<sup>2,3</sup> But persons isolated at and around the time of diagnosis of life-threatening illness can have much worse outcomes. The situation is intensified when there are pre-existing psychosocial stressors and health challenges.

Persons faced with health and social service providers who are unprepared and unavailable, experience much greater emotional suffering, more rapid progression of their disease, and earlier death. Their families and friends suffer greater devastation, and are less able to recover functioning (jobs, relationships) or well-being (physical or emotional) in the future. One woman remarked, "Looking back, I don't know how I functioned on a day to day basis. Every aspect of my life suffered. I was frightened, confused, guilty, incapacitated, and completely useless, unable to hardly take care of myself, let alone my house, or family."

Clearly these crises require specific and consistent response from health and social service providers.

## Acute responses

Persons receiving news of life-threatening illness will be overwhelmed. Typically, staggering quantities of information are offered, but people report "not hearing a word" after the doctor told them the diagnosis. People sometimes remember "nothing at all about what [they] did for the rest of the day." Ordinarily few of the details of complex explanation of medical implications and treatments are remembered the next day.

Ideally, physicians recognize the need for adequate preparation, background information and support, and engage the appropriate support personnel and services. Under the best circumstances, these services would be immediately accessible and available 24 hours per day. To what extent is this the case? Physicians have considerable experience in breaking bad news, but do not necessarily cope well with the task. We may not know how to make effective

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Correspondence: Dr. William Rowe, School of Social Work, McGill University, 3506 University Street, Montreal, QC H3A 2A7

use of limited time or have the additional training necessary to provide the intense specific support and intervention needed. Do social work professionals take the initiative to identify service and learning needs? Is there the will or the interest to develop and implement appropriate interventions and programs for patients and caregivers?

### Dealing with uncertainty

Physicians report that 'counselling' patients with hepatitis B or C viral infections is often the most difficult aspect of patient management.<sup>4</sup> Specific challenges identified are: the uncertainty surrounding the progression of symptoms and the disease; misinformation among medical professionals and the general public about HCV; physicians' time constraints, and the patient's distress at the time of diagnosis. Physicians note that "the patient's level of anxiety often impairs or even precludes their ability to understand and retain much of what has been said" by the diagnosing physician. Physician distress in the face of uncertainty and inadequate support can also be high.

Inadequate knowledge or support will prevent nursing, housekeeping, lab or dietary staff (to mention a few) from being able to provide consistent and appropriate care for patients with unusual diagnoses (as witnessed in previous years with cancer and HIV). It is therefore crucial that a broad base of health and social service professionals working in the area of public health and counselling be educated about HCV, and available for consultation and ongoing support for patients and care providers.

### Interferon: Mental health impact

Interferon is currently the only available treatment for HCV. As with many pharmacologic and immunologic manipulations, interferon can cause or exacerbate mental health problems.<sup>4</sup> There have been reports of severe depression, suicidal ideation, delirium, and manic depression induced by interferon.<sup>5</sup> Adverse psychiatric symptoms are the most common reason for discontinuing treatment and these side effects have been reported at both high and low doses.<sup>6</sup> One patient stated, "My constant compan-

ion was depression. The fog that I was in, caused by the medicine, kept me from seeing it clearly. I just thought that I was going insane!" People with a history of psychological instability or underlying psychiatric issues may be at greatest risk for problems associated with interferon.<sup>6</sup>

How consistently are patients/clients counselled about possibility of adverse psychiatric reactions? How closely are clients monitored? Physical, social and economic situations can deteriorate considerably before symptoms are recognized and treated. Self esteem and years of life can be lost in the process.

Other reported side effects of the medication include fever, chills, anorexia, nausea, weight loss, myalgia, fatigue, hair loss, and cognitive problems.<sup>7</sup> These add further distress to the lives of people affected by HCV, as with any chronic illness. Increased use of interferon therapy is anticipated, thus more people will potentially be at risk of experiencing adverse psychiatric side effects.<sup>6</sup> Are we sufficiently prepared, educated, and motivated to provide adequate monitoring and supportive care? Whose job is it?

### Importance of support groups

The stigma attached to hepatitis C is similar to the early days of HIV. Support groups for people with HCV and their partners, friends and families are helpful in allaying fears and anxiety associated with the infection.<sup>7</sup> Some larger Canadian cities offer meetings, support groups, and telephone contacts, and there are several on-line chat groups accessible via the Internet. However, those who live in smaller cities or rural regions, or are without access to the Internet would benefit from contact with and support from others who are living with HCV. A person diagnosed with HCV who moved to a smaller city remarked, "When I came to this area, I found that services and support were virtually non-existent... there is a real need. After an article printed in our local paper on tainted blood came out with my phone number and intentions of starting a support group, I've had many people call me. Their stories all seem to be the same as mine... The information available is fairly outdated, confusing, and non-committal."

Issues relating to disclosure, the uncertainty of disease progression, and emotional factors may be best processed in a client-centered group format. "Having HCV has changed me. I fought this diagnosis initially – was angry and depressed. It took some time, but I no longer feel dirty, like I deserve this," commented one woman. Additionally, the opportunity to help and educate others about HCV may lead to a greater sense of well-being and improved mental health.

### Families, partners and friends

Families, partners and friends of those diagnosed with HCV may also benefit from support groups. Issues related to contraction of the disease, expectations of the HCV-positive person, and sex/intimate relationships may cause distress for those who are in close relationships with people diagnosed with HCV. The revelation that a loved one may have contracted HCV by engaging in risky behaviour (intravenous drug use, unprotected sex, etc.) can cause significant family and interpersonal upheaval. Addressing these issues in the context of a support group with a psycho-educational element may reduce some of the stress, anxiety, and uncertainty related to HCV.

### Socio-demographics

The socio-demographic characteristics of people infected with HCV differ from those who are not infected. A study detailing the health and socio-economic status of HCV-positive blood transfusion recipients in British Columbia revealed that those who were diagnosed with HCV were more likely to be male and unmarried than those not infected with HCV.<sup>8</sup> People who were HCV positive were also more likely to be unemployed, reported a lower household income, received more income from social assistance, and more frequently reported that they were unemployed due to illness or disability than the control group. One person noted, "When I learned that I had HCV, I had just graduated from college and I was too weak to look for work. All that hard work and now I was too sick to get a job."

Those diagnosed with HCV also made significantly more visits to their family physicians, other medical doctors, nurses, social workers, psychologists, and emer-

gency rooms. Further, they were more likely than those not infected with HCV to have spent money on alternative therapies, and were significantly more likely to have been refused insurance coverage. The implications of these demographic and socio-economic differences may be tremendous if they are not considered in treatment planning.

It is of great importance that services provided to those diagnosed with HCV be accessible, free of charge, and client-centered. Further research to determine the socio-economic profile of those infected with HCV nationally would be useful to expand our understanding of the treatment needs of Canadians.

### Drugs and alcohol

Within the population of people diagnosed with HCV, specific groups may have unique needs. People who are habituated to drugs or alcohol may need distinct mental health services. Drug or alcohol users who are diagnosed with HCV may wish to make significant lifestyle changes to promote health. They may experience mental health concerns as a result of their altered lifestyle. Alternative coping strategies must be introduced, and support must be given to maintain new methods of coping. The stigma associated with a diagnosis of HCV is often greater for substance users, as people who have used injection drugs are assumed to be personally responsible for contracting the illness. One person commented that "When I sat in my first support meeting, everyone focused on how they got HCV. Most of the people in the room were victims of blood transfusions. When it was my turn, I didn't say how I got it. I was too embarrassed... but I am

no less of a person because I contracted HCV through drug use." Injection drug use is associated with at least half of HCV infections in Canada,<sup>9</sup> and it is therefore important that health and social service providers are sensitive to the specific needs of this population.

### HIV co-infection

Those who are infected with both HIV and hepatitis C may need more intensive mental health support, in order to cope with the implications of dual diagnosis. "The prevalence of hepatitis C virus (HCV) and human immunodeficiency virus (HIV) co-infection ranges from nearly 30% to over 50%, depending on the population. HIV co-infection appears to worsen HCV infection, with studies showing more severe fibrosis, a higher frequency of cirrhosis, and increased deaths from liver disease."<sup>10</sup> This dual diagnosis may increase emotional stress for many people.

### Professional education

To work effectively with individuals diagnosed with HCV, professionals must have access to education that addresses both the disease and its mental health implications. A model for practice does not currently exist that integrates the essential elements of HCV and mental health issues. Designing an approach that is based on the practice model for people living with HIV/AIDS may be beneficial. Elements of education, harm reduction, prevention information, and a client-centered approach must be present in the model.

### Call for research

Further study is necessary to adequately assess the mental health needs of

Canadians who have been diagnosed with HCV. Specifically, research must be conducted to determine the extent to which Canadians infected with HCV are experiencing mental health problems, the severity of their symptoms, and how effectively existing services are meeting their unique needs. The uncertainty surrounding the progression of the disease and its psychosocial implications may negatively impact the health of Canadians, and it is therefore essential that these issues are addressed on the levels of practice, policy, and research.

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