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Introduction

Hepatitis C [HCV], a viral infection of the liver, is a growing public health threat to the people of Maine. Eighty-five percent of individuals exposed to the virus develop chronic infection with 20% ultimately developing cirrhosis. Hepatitis C contributes to 40% of chronic liver disease and is the leading indication for liver transplantation in American adults.

Almost four million Americans have evidence of infection with hepatitis C and 36,000 new cases are identified annually. An estimated 15,000 Maine residents have chronic hepatitis C, a prevalence of 1.3%. Because of the slow progression of the disease, most are unaware of their infection.

Hepatitis C is the most common bloodborne infection in the United States [U.S.]. It infects individuals of all ages, ethnic groups, and socioeconomic classes in urban and rural areas of Maine. The two major risk factors for hepatitis C among infected Maine residents are: a history of sharing needles for injection drug use (even once, even many years ago) or a history of receiving a transfusion of blood or blood products prior to 1992 (when more effective blood screening tests became available). Other risk factors for hepatitis C include: a history of accidental needle-stick or other blood exposures among health care workers, transmission from infected women to their newborn children (uncommon), a history of long-term kidney dialysis, the receipt of clotting factors for hemophilia (before 1987), or a history of sexual contact with an infected partner (also uncommon).

While hepatitis C virus has existed for the past fifty years or longer, it is only recently that its real impact has been recognized. During the 1970s and 1980s, epidemic transmission of this virus was occurring in the United States, but most of these infections were “silent”- asymptomatic and undiagnosed. Since the causative agent of hepatitis C was first identified during the early 1990s, it has become clear that a significant proportion of Americans are chronically infected, and that many of them are at risk of developing life-threatening disease complications during the next several decades.

Still, most infected persons have not been tested, and opportunities for preventive and therapeutic care are being lost. Of the estimated 15,000 persons infected with hepatitis C in Maine, fewer than 2,000 have been diagnosed.

Some hepatitis C issues are particularly challenging:

1. Prisons and jails throughout the United States have exceptionally high rates of infection and need to develop policies concerning diagnostic screening practices and the availability of drug therapy for prisoners with hepatitis C.
2. A growing number of persons diagnosed with HIV infection also suffer from hepatitis C. This combination of diseases poses very difficult problems for medical management.
3. Insurance programs (including Medicaid systems and HMO’s) are becoming increasingly burdened by the costs of HCV treatment and will be further challenged in the next 10-20 years by the costs of care for end-stage HCV-related liver disease.



4. In 2001, it is believed that the most common risk factor for newly acquired HCV infection is shared needle use among persons injecting heroin, methamphetamine, or other drugs. Because injection drug use appears to be increasing in some areas of Maine, this is an especially pressing concern.

An effective strategy for preventing illness, death, and disability related to hepatitis C is available. The strategy includes:

- Primary Prevention -- population-focused efforts designed to decrease new HCV infections by reducing the likelihood of transmission of the virus from one individual to another. Primary prevention measures might include strategies to decrease needle sharing, decrease the rates of needle-stick injuries among health care workers, and education to prevent transmission in household settings and through sexual contact.
- Secondary Prevention -- narrowly focused outreach to persons at high risk for HCV infection through targeted counseling and diagnostic testing. The purpose of secondary prevention is to identify cases of HCV infection and prevent the progression of HCV in those who are already infected. For persons who are at high risk for HCV infection this includes increasing awareness about testing options so that the status of infection becomes known; for those who are HCV-infected, this includes taking measures to prevent other types of damage to the liver (avoiding alcohol and certain medications, getting vaccinated against hepatitis A and hepatitis B) and ensuring access to drug therapy, if such treatment is determined to be appropriate in consultation with a medical specialist.

Efforts at both primary and secondary hepatitis C prevention in Maine have been difficult, in part, because of the lack of any organized statewide initiatives for HCV education, awareness, or care. Maine residents seeking HCV testing and counseling may find their options quite limited, especially if they lack health insurance. Persons needing medical treatment for hepatitis C are often faced with long distances to travel, and an uncoordinated system for complex medical care. At the present time there are no outreach programs or targeted screening efforts for high risk groups such as injection drug users. Gastroenterologists are often overwhelmed with the needs of a growing HCV-infected patient population, while primary care clinicians may feel inadequately trained or experienced to provide for the needs of their patients with hepatitis C.

In an effort to begin addressing some of these concerns, an informal coalition of Maine medical and social service providers, public health professionals, and patient advocates has been meeting for several years and recently organized the formal needs assessment that is summarized in this document.

What Maine has been doing to address hepatitis C

In 1997, the Maine Bureau of Health initiated mandatory case reporting of chronic HCV infection. In December, the Bureau convened the first quarterly meeting of the Maine Hepatitis C Working Group. This group included clinicians, patient advocates, and public health professionals interested in sharing information about HCV. Most of its efforts focused on the education of primary care physicians.

During 1999, in response to growing concern that a comprehensive approach to hepatitis C was needed, the Bureau of Health convened a subcommittee of the Working Group to develop a needs assessment in Maine.



This Needs Assessment Steering Committee ultimately included individual members of the HCV Working Group and other invited participants from the Department of Human Services [DHS] Bureau of Medical Services, the Maine Center for Public Health, the Department of Corrections, and the Department of Mental Health, Mental Retardation, and Substance Abuse Services.

After developing a plan for the needs assessment, financial assistance for the effort was obtained from the Maine Bureau of Health's Division of Disease Control, as well as Schering Oncology Biotech, Glaxo SmithKline Beecham, and Merck & Company¹ corporations. The Maine Center for Public Health served as the group's fiscal agent. In April 2000, Judy Storfjell, PhD, RN, a consultant with Lloyd Associates in Berrien Springs, MI, was retained to conduct the assessment.

Between May and September 2000, Dr. Storfjell gathered information about HCV in Maine from a variety of sources. She conducted focus groups with representatives from the Office of Substance Abuse, the Department of Corrections, AIDS service organizations, and a HCV community support group. All the groups were convenience samples created by the participating agencies. Dr. Storfjell also conducted twenty individual interviews with other informants who included representatives from Maine AIDS service organizations, HCV primary care providers, and hepatitis C patients from different areas of the state. Other components of the assessment included: a review of Maine hepatitis C epidemiologic surveillance data and HCV health care expenditure data; a review of the medical and public health literature; and phone interviews with public health officials from other states. Additional data was collected through two surveys: one, a sample of primary care health providers and gastroenterologists in Maine (conducted in collaboration with the Public Health Division, Department of Health and Human Services, City of Portland), and the other, a national survey of prison medical directors (conducted in collaboration with the Department of Corrections).

On November 9, 2000 the results of the needs assessment were presented to the Steering Committee and these findings were reviewed and discussed. Through a consensus-building process, the Committee developed six recommendations for addressing hepatitis C in Maine. These recommendations are presented in the final chapter of this report.

Outline of the report

Maine has arrived at a crucial juncture -- a crossroads -- in the hepatitis C epidemic in our state. This report seeks to give a full description of where we are and the choices before us as a state.

Chapter 1 includes an epidemiologic description of hepatitis C in Maine. It includes information on special HCV-related concerns and considerations regarding injection drug users, prison inmates, and persons with the dual diagnosis of HCV and HIV infections.

After briefly describing a model approach to a comprehensive system of HCV-related prevention and care, **Chapter 2** summarizes the current state of HCV-related prevention and care efforts in Maine. Included are the results of a statewide survey of primary health care providers and gastroenterologists, and a summary of HCV-related public health initiatives and prison programs in other states.

¹ While these corporations partially funded the needs assessment, they did not guide, review, or in any other way participate in the needs assessment process.



Chapter 3 provides a brief overview of the economic impact and costs associated with HCV infection. The final chapter, **Chapter 4**, summarizes key findings and presents the six recommendations for a Maine hepatitis C action plan from the HCV Infection Needs Assessment Steering Committee.

We thank you for your interest in hepatitis C infection in Maine and we hope you will join us in seeking solutions to its many challenges.

The Maine Hepatitis C Infection Needs Assessment Steering Committee

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² Organizations listed for identification purposes only.



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Chapter 1

The Epidemiology of HCV Infection in Maine

Hepatitis C is a particularly challenging disease because it is largely asymptomatic for the first 10-20 years of the infection. As a result, it is often unrecognized by patients and their physicians. In the absence of treatment, HCV will cause serious complications, and possibly death, in approximately 20% of infected persons (see Appendix A). This “silent infection” is a major public health concern because a significant number of those infected are not receiving medical attention for this condition and are losing opportunities for preventive and therapeutic management.

Each year in the United States, there are an estimated 36,000 new cases of hepatitis C, however, relatively few of these are diagnosed in their acute stages (Centers for Disease Control and Prevention [CDC], 1998). In Maine, there have been approximately 1,500 cases reported, however, estimates indicate there are likely to be at least 15,000 Maine residents with chronic HCV infection.

The Maine Bureau of Health has been monitoring the emerging HCV epidemic since the early 1990s when sporadic HCV positive cases were first reported. However, mandatory case reporting and expanded surveillance of chronic hepatitis C was not established until 1997. Under the 1997 reporting rules, all health care providers were required to confidentially report cases of hepatitis C to the Bureau and to complete follow-up questionnaires regarding demographics, risk, and clinical data for each patient. Through this effort a more comprehensive picture of the nature and extent of HCV infection in the state was obtained.

The results of these expanded surveillance efforts were reviewed and are summarized in this chapter. These data provide a fairly detailed picture of some characteristics of the HCV epidemic in Maine, including what has been derived from case report data on age, gender, transmission risks, and geographic distribution of diagnosed persons. In addition, limited data from a blinded HCV/HIV sero-prevalence study at three Maine STD clinics, data from Maine blood donors in 1994-1996, and Medicaid claims data regarding hepatitis C-related treatment during the 1997-99 period all describe hepatitis C prevalence in “snapshots” of very different populations. The chapter concludes with a discussion of how HCV impacts injection drug users, prison inmates, and HIV/HCV co-infected Mainers.

Hepatitis C Surveillance Data from the Bureau of Health

Since official case reporting was initiated in 1997, the Maine Bureau of Health has documented yearly increases in the numbers of Mainers diagnosed with hepatitis C. Most of the current documented cases are chronic hepatitis C infections that resulted from exposures at some time in the past, but that were only recently revealed through diagnostic testing. Individuals may have been tested for a variety of reasons, including:

- The development of late-stage liver disease with complications
- The presence of milder symptoms that led to diagnostic work-up
- The detection of elevated liver enzymes during routine examinations



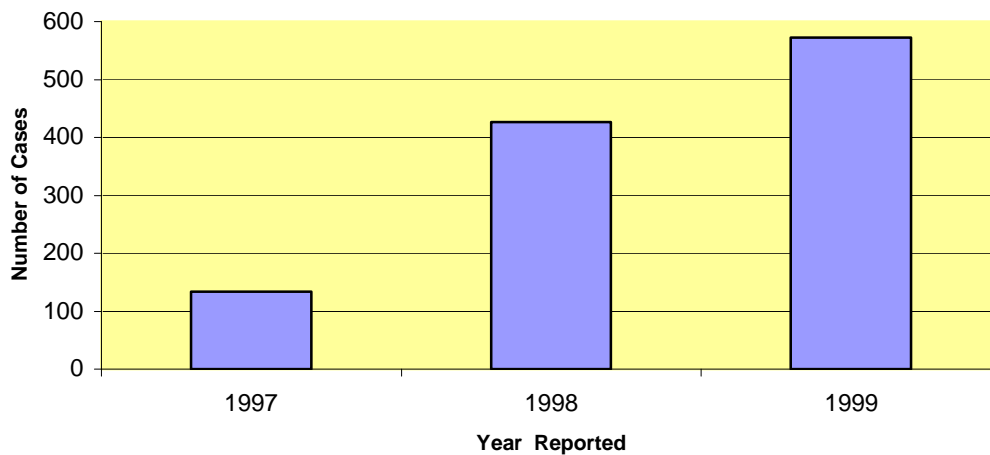
- A history of a risk factor for hepatitis that prompted the patient or his/her health professional to pursue testing for HCV infection.

Cases by Year of Report: Through 1999, there were more than 1,500 cases of hepatitis C reported to the Maine Bureau of Health. The majority of these cases (1,133) were documented between 1997 and 1999. **Figure 1** below demonstrates the steady increases in the numbers of reports received: 134 during 1997, 427 in 1998, and 572 during 1999. Again, most cases were chronic hepatitis C infections that were only recently revealed by testing.

Gender: Thirty-five percent of 1997-1999 cases were female and sixty-five percent were male.³

Figure 1

Maine Chronic HCV Cases Reported 1997-1999



Source: Maine Bureau of Health

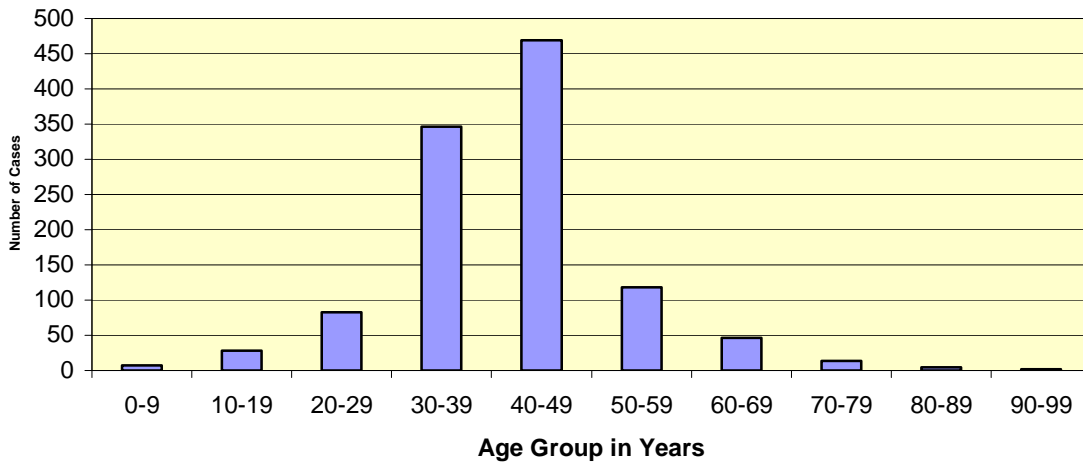
³Gender information was available for 1129 out of the 1133 cases.



Age distribution of HCV cases : The age distribution for the 1997-1999 HCV cases demonstrates that almost 70% of reported cases⁴ for whom age was available fall into the 30-49 year-old age group (**Figure 2**).

Figure 2

Maine Chronic HCV Reported Cases by Age at Report 1997-1999



Source: Maine Bureau of Health

Geographic distribution of Hepatitis C cases: **Table I** below summarizes the distribution of cases by county of residence, for persons reported with HCV infection during the 3-year period 1997-1999. Every county in the state is represented.

Note: this distribution is very likely influenced by differences in rates of HCV testing from one county to another. The true distribution of HCV infected individuals cannot be inferred from this data. Nonetheless, it provides some useful information about the statewide distribution of persons known to be HCV positive and may be useful in identifying areas that are most affected by hepatitis C and need comprehensive health care services.

⁴ Age was reported for 1118 out of 1133 cases identified

**Table I****Hepatitis C Infection Rates, 1997-99, by County of Residence**

<i>County</i>	<i>1999 Population*</i>	<i>HCV Cases, 97- 99</i>	<i>HCV Cases per 100,000</i>
Maine	1,253,040	912	73
Androscoggin	101,337	109	108
Aroostook	75,836	24	32
Cumberland	256,437	267	104
Franklin	28,797	8	28
Hancock	49,670	27	54
Kennebec	115,224	76	66
Knox	38,193	47	123
Lincoln	31,947	14	44
Oxford	54,288	22	41
Penobscot	144,432	91	63
Piscataquis	18,077	8	44
Sagadahoc	36,267	18	50
Somerset	52,630	22	42
Waldo	36,965	19	51
Washington	35,352	38	107
York	177,588	122	69

Source: Maine Bureau of Health

*U.S. Census, 2001 6666666666666666

Table I translates the 1997-1999 county numbers into rates to account for differences in population between the counties. When adjusted for population, 4 counties: Androscoggin, Cumberland, Knox, and Washington demonstrate higher rates than those for the state as a whole.

Androscoggin County and Cumberland County (and especially the Portland metropolitan area) have had high numbers of cases of HCV infection reported and high prevalence rates since the earliest surveillance reports were available. This reflects what is probably both a high burden of disease and an increased propensity by area physicians to test during the mid-1990s. The increased likelihood to test may have been influenced by the presence of specialists who were familiar with hepatitis C and were actively involved in hepatitis C education and treatment protocols. The high prevalence rate in Knox County is directly related to the presence of the State Prison at Thomaston. Most of the Knox HCV infections were diagnosed among inmates at that facility. In Washington County, the number of positive HCV test reports rose dramatically during 1999. Many of these cases were associated with a patient history of injection drug use, a problem that is reportedly expanding in downeast communities.

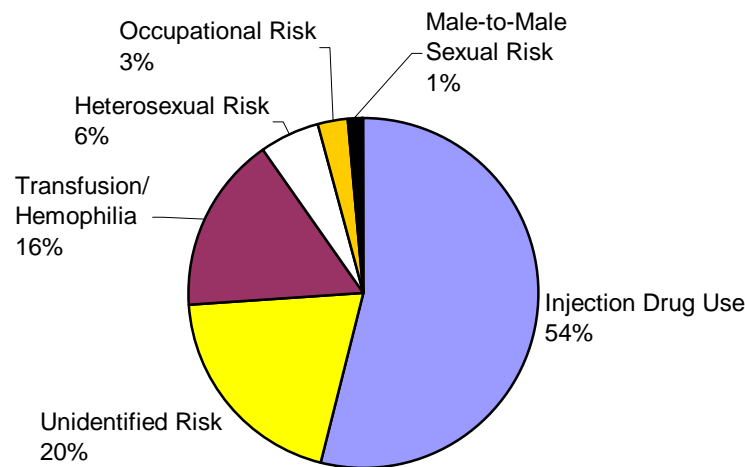


Whether the increase in positive tests reflects a growing burden of clinically apparent illnesses, an increased consciousness among physicians and patients about HCV infection, or some combination of both factors is not clear from these data.

Transmission Risks: **Figure 3** below illustrates the distribution of risk factors (elicited and reported by health care providers) for patients diagnosed with hepatitis C during 1997-1999. Data are listed only for those cases in which risk factor information was actually assessed by the clinician.

Figure 3

**Transmission Risk for Chronic HCV Cases Reported in
Maine 1997-1999**



Source: Maine Bureau of Health

Most striking is the high proportion of cases (54%) associated with a history of injection drug use (IDU). Anecdotal information from discussions with both patients and providers suggests that most of these IDU-associated cases had relatively brief histories of needle sharing, and for many, those experiences occurred in the remote past (primarily during the late 1960s, 1970s and 1980s). Most are persons who are not currently injecting drugs and might not identify themselves, even to their physicians, as former injection drug users. This is an important point for health care providers who may need to be very specific in their interviews with patients when eliciting hepatitis C risk factors in consideration of diagnostic screening.

Of the 16% of persons with blood product-associated hepatitis C, most were acquired through blood transfusions that occurred prior to the early 1990s. Relatively small proportions of the cases identified were exposed to HCV through occupational, heterosexual, or homosexual contact.



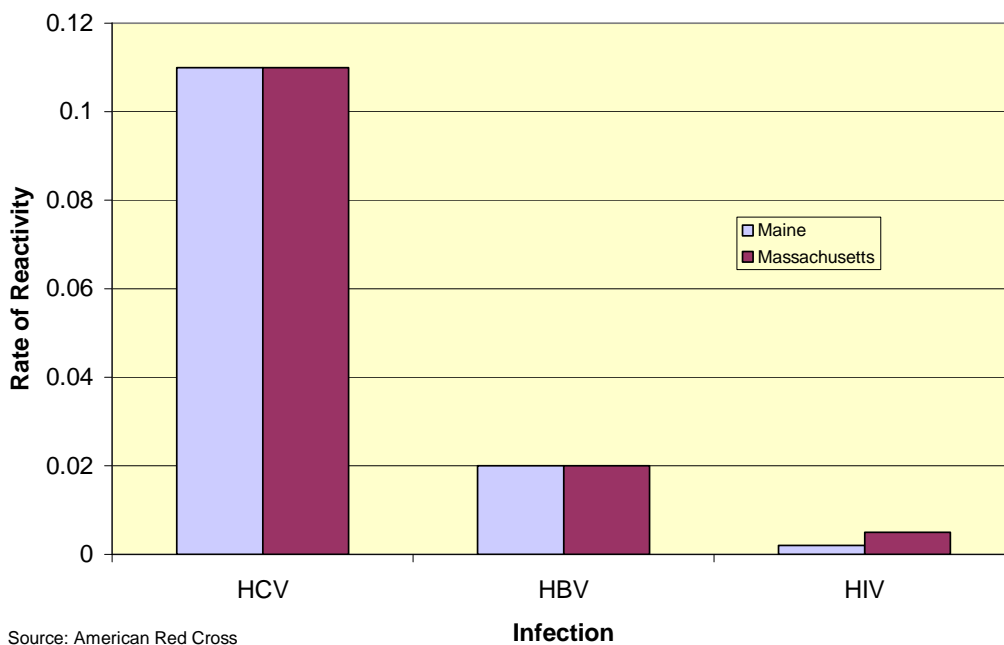
Blood Donors

Because blood donors are a “self-selected” population, from which persons at high risk for blood-borne infections are usually deferred, the rates of HCV positivity are lower than they are in the population at large. Since 1992, blood donors have been screened for HCV with highly sensitive tests to ensure that transfusion recipients are protected from infection. In addition, thorough risk-assessments conducted prior to donation help to reduce the chance of HCV entering the blood supply.

Figure 4 illustrates prevalence rates for HCV, hepatitis B virus (HBV), and HIV infections among units of blood from donor candidates in Maine and Massachusetts during the mid-1990s (Note: When any of these infections are identified in a unit of blood, the blood is destroyed and the donor is confidentially notified by the blood collection agency). While the rates for each of these three infections was quite low (the rate for Maine HCV infection was approximately 0.11% or 11 per 10,000 units), it is interesting to note the much higher rates for HCV infection relative to HIV and HBV infected blood from both states. Note also that HCV reactivity rates in Maine and Massachusetts are almost identical to each other.

Figure 4

**HCV, HBV and HIV Reactivity for Blood Donations
Maine and Massachusetts: 1994-1996**

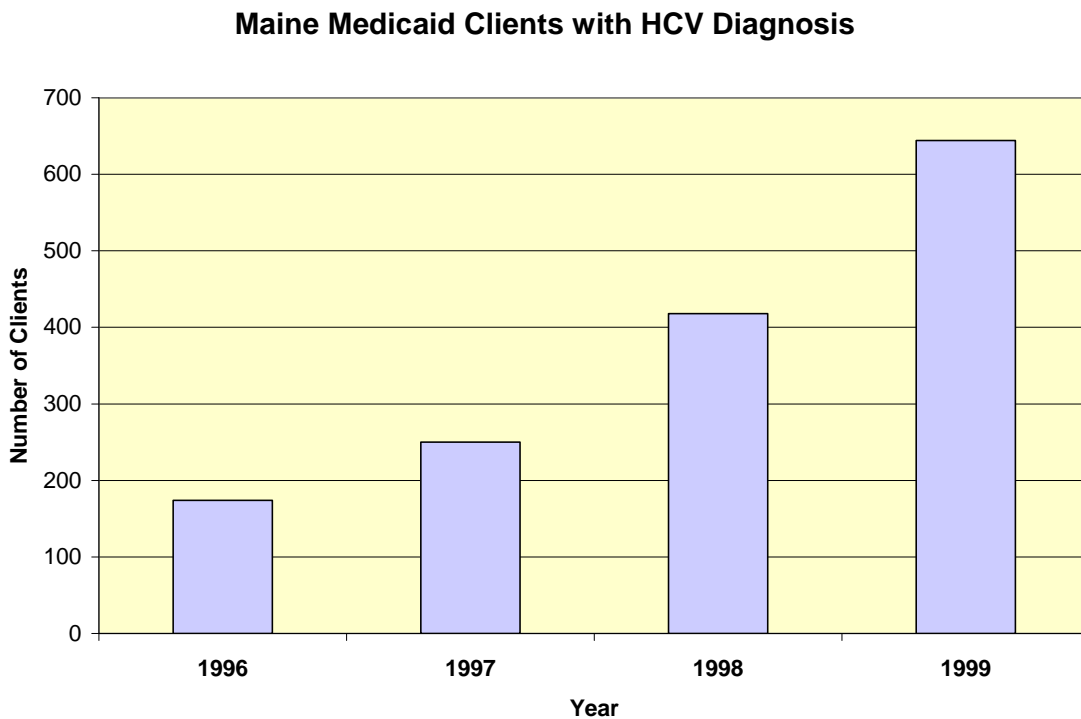




Maine Medicaid Clients

The Medicaid Management Decision Support System [MMDSS] provides a useful tool to follow hepatitis C diagnosis in Maine. Between 1996 and 1999, there was an almost 400 % increase in the number of Maine Medicaid clients with HCV diagnoses (see Figure 5). These patients included both persons with active liver disease who were undergoing drug therapy and also persons with asymptomatic infections, who came to diagnosis. The increase in diagnoses occurred for a variety of reasons including the evaluation of persons with symptoms directly related to HCV infections, abnormal liver function tests in asymptomatic persons receiving routine care, and an increased awareness among patients and doctors of the need to test persons with risks for hepatitis C. The increase in diagnoses of HCV infection among Medicaid eligible individuals parallels trends seen through HCV infection case reports. The economic implications of increasing HCV diagnoses and treatment among Maine Medicaid recipients are discussed in Chapter 3.

Figure 5



Source: Maine Bureau of Medical Services



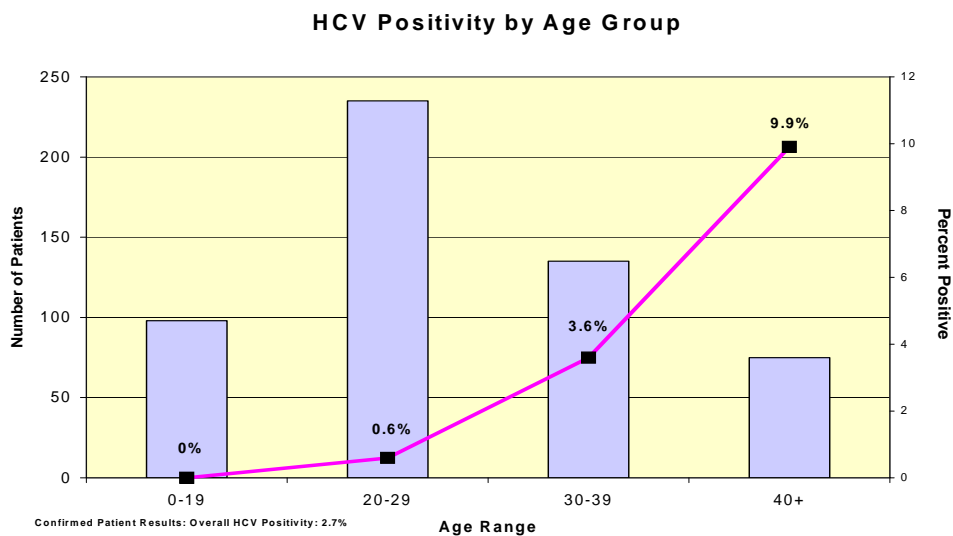
Blinded HCV/HIV Sero-Prevalence Study

While sexual transmission of hepatitis C does not occur frequently, national studies have indicated that persons with multiple sexual partners or with a history of sexually transmitted diseases, have higher rates of HCV infection than are seen in the population at large. Studies at a number of sexually transmitted disease (STD) clinics in cities outside of Maine have demonstrated higher rates than those that are estimated for the general population.

In Maine, public STD clinics are operated in Portland, Auburn, and Bangor. Each clinic serves clients who generally reside in the metropolitan area in which each clinic is located. During a six-month period, between September 1997 and April 1998, the Maine Bureau of Health conducted a “blinded” study to determine rates of HIV and HCV infection among clinic patients⁵.

Of 551 clients tested during the 6-month period, 15 people (2.7%) were confirmed HCV positive while only 0.5 percent were HIV positive. As shown in **Figure 6**, the prevalence of HCV among the 0-19 year-olds was 0%, among 20-29 year-olds the prevalence was 0.6%, and among 30-39 year-olds the prevalence was 3.6%. Among persons over age 40 (a relatively small proportion of all STD clinic patients) however, the rate was almost 10%.

Figure 6



⁵ In a blinded sero-prevalence study, blood samples routinely collected from patients for STD testing are retained after testing is completed. Identifying information is removed from the specimen, and assigned a number linked to basic demographic information (but not names). Results are for research only and cannot be linked to patient.



The overall rate of infection (2.7%) among clinic patients is approximately twice the rate estimated to occur in the general population. The HCV infection rates in patients age 30 and older coincide with higher rates of HCV infection found in the same age group in the population at large. This phenomenon can probably be linked to risks that persons in this age group (blood transfusions, injection drug use) experienced during the 1970s and 1980s.

These data may be most useful in focusing hepatitis C prevention education and diagnostic testing on this older group of clients. The findings underscore the need for resources to make HCV counseling and diagnostic testing widely available at STD clinical sites.

Populations of special concern: Injection drug users, prison inmates, HIV/HCV co-infected persons

With the reality of resource limitations, health and social service providers are faced with formidable difficulties in serving some groups at higher risk of acquiring hepatitis C, including injection drug users and prisoners. Another set of special challenges are presented by the needs of persons who are infected with both HIV and HCV. This state of co-infection may be very difficult to manage medically, increases the transmissibility of HCV infection, and is more likely to progress to severe disease.

Additionally, there is crossover among these populations, with many individuals falling into two or three of these categories. Injection drug users and prisoners typically have very limited financial resources and/or are dependent upon publicly-funded care and other services. Furthermore, persons in each of these populations are likely to come in contact with one or more service professionals (corrections staff, drug counselor, mental health provider, medical clinician) who may be in a position to educate or refer them appropriately, or perform HCV diagnostic testing. Hepatitis C educational efforts aimed at these professionals are especially important and serve the purposes of both primary and secondary prevention.

Injection drug users⁶

Injection drug use is frequently a chronic and relapsing condition due to the users' underlying addiction to the substance(s) they inject. Among injection drug users (IDUs), the shared use of syringes and related drug and site preparation materials (cotton, spoon, water) is quite common. Even a relatively few episodes of shared needle/other equipment use over short periods of time leads to a very high risk for blood-borne infections, including hepatitis C, hepatitis B (HBV), and HIV.

While HBV and HIV infections have been well-known as significant risks for IDUs since at least the early 1980s, HCV was not identified until the early 1990s. Currently, HCV infection rates among IDUs range from 60% to 80%, rates much higher than those for either HIV or HBV (Des Jarlais & Schuchat, 2001). The high prevalence of HCV infection among injection drug users increases the likelihood that their HCV-negative injecting partners, sexual partners, and unborn children are being exposed to HCV. As a result, needle sharing accounts for more acute HCV infections in the U.S. than any other type of exposure and accounts for more than 60% of all chronic HCV infections (ASTHO, 2000). HCV infection most often occurs early in an individual's drug injecting career, very often before she or he seeks help (Hagan, 1998).

⁶ Note: currently, data on injection drug use in Maine is not formally collected. Anecdotal evidence presented is taken from focus groups with health and social services providers in the state.



After 5 years of injecting, as many as 90% of users will be infected with HCV (National Institutes of Drug Abuse, 2000).

A recent study in Baltimore, MD, demonstrated that HCV infection is acquired very rapidly among IDUs, rising to 60% after only 2 years of experience with injecting. The relatively early onset of HCV among injection drug users presents a very brief "window of opportunity" to reach new users before they become HCV-infected. Thus, prevention of new infection among IDUs has been identified as a public health priority (Denis et al, 2000).

Injection drug users are faced with a myriad of challenges beyond drug use itself. Many suffer from a "dual diagnosis" of addiction and mental illness. Most are poly-substance abusers who use and abuse multiple substances including alcohol and other non-injected drugs. Serious medical complications may be more common among IDUs, as many access medical care only in urgent or emergency circumstances. Substance abuse providers in Maine report that their clients with IDU histories also face multiple economic and social problems, such as inadequate housing or homelessness and unemployment, due to their addictions. Many IDUs have a lack of knowledge of the risks posed to them by their unsafe needle use and sexual behaviors.

Currently, injection drug use in Maine is characterized by the use of prescription drugs such as OxyContin and Dilaudid in addition to heroin and methamphetamines. The purity of heroin has reportedly increased, is sold at a lower price than in previous years, and it is increasingly available in all areas of the state. In addition, new users are reported to be initiating their injection drug use at a younger age. Washington, Penobscot, and Hancock Counties have experienced recent increases in injection drug use.

Focus group participants from the Maine Office of Substance Abuse Services suggest that approximately 10% -20% of all substance abuse patients in Maine inject drugs⁷. Among methadone clinic patients, focus group participants estimate that 85% have HCV infection. This estimate mirrors anecdotal data from methadone treatment providers nationally, who generally estimate that 85 to 95% of their clients are testing positive for HCV (Alcohol and Drug Abuse Weekly, 1999).

Since the prevalence of HCV is high in injection drug users and awareness of the infection is low, it is likely HCV is being transmitted to others in expanding cycles of infection. Increasing access to effective drug prevention and treatment programs statewide is critical to the prevention of new cases of hepatitis C infection in Maine. For those individuals who will not or cannot stop using drugs, access to intermediate "harm reduction" services such as needle exchanges has proven to be effective in decreasing rates of HCV and HIV (Hope et al, 2001). In 1993 and again in 1997, the Maine legislature took a national lead in this effort by removing the prescription requirement for syringe purchase and decriminalizing the possession of 10 or fewer hypodermic apparatuses. In addition, the legislature authorized the Bureau of Health to certify Needle Exchange Programs. The first such program was initiated during 1999 in Portland and at least one other program is planned.

⁷ It is difficult to gauge the full extent and nature of those most affected and at risk for HCV via injection drug use in Maine. Currently, no statewide estimates of absolute numbers of current IDUs nor demographic information such as race, gender, age, ethnicity, or sexual orientation is available.



Prison inmates

1.4 million people with HCV infection pass through U.S. correctional systems each year, representing an infection rate that is nine times greater among inmates than in the general population (Positive Populations, 2000). Studies conducted in California, Virginia, Connecticut, Maryland, and Texas state correctional systems report HCV infection rates ranging from 29-42 % -- ten to twenty times the 2% infection rate among the general U.S. population (ASTHO, 2000).

The high HCV infection prevalence among prisoners in the U.S. most likely reflects the high rate of current or historical illicit substance use among those that are sent to prison. Eighty percent of the nearly 2 million inmates in the U.S. have used illegal drugs, nearly twice the 48% of the general population who have done so (Varghese, 1999). In addition, 80% of all inmates are implicated in crimes linked to drug and alcohol abuse (ASTHO, 2000). Fully one-quarter of state prison inmates in the U.S. have a history of injection drug use.

Incarcerated persons may also be at risk of contracting HCV infection after they enter penal institutions. This is related to the high rate of risky behavior(s) in a population that has a high concentration of HCV infected individuals. The risky behaviors include injection drug use and shared use of needle/preparation equipment- sharing. Tattooing and body piercing with contaminated makeshift materials is also unsafe, as is the sharing of razors, nail clippers and other personal hygiene or grooming equipment. Complicating the risk of HCV transmission is HIV co-infection and a host of other diseases. Currently, 80% of inmates with HIV infection in the U.S. are believed to be co-infected with HCV -- resulting in a disproportionate number of co-infected persons living in correctional institutions (Positive Populations, 2000). Knowledge about HCV infection is low and those who are at high risk for hepatitis C often have not been tested prior to prison admission.

Even though inmates may have significant HCV risk factors, most correctional facilities do not routinely screen for hepatitis C. The Maine Department of Corrections [DOC] does not collect HCV prevalence data. DOC tests only the inmates who are symptomatic, have diagnostic markers such as elevated liver enzyme levels, or have requested testing.

DOC estimates that 85-90% of the inmates have abused drugs and/or alcohol and recognizes the possibility that routine screening might reveal a high HCV prevalence. A recent study commissioned by Maine's Office of Substance Abuse Services found that 8.5% of the 1,240 inmates surveyed reported a history of some form of heroin use. The 2000 Maine DOC census was 1,680 inmates, with 767 annual new admissions in the 8 adult facilities around the state. If the range of HCV infection prevalence rates reported by other states are applied to Maine (ranging from a low of 4.4% to a high of 42%), between 70 and 700 of Maine's current prison population may have HCV infection.

HIV/HCV Co-Infected

In 1999, the U.S. Public Health Service called HCV infection the "newest opportunistic infection of HIV." Currently, 400,000 persons, or 40% of Americans living with HIV infection are chronically infected with hepatitis C infection and it is their number one killer (Haller, 2000). According to some projections, the number of deaths from liver disease among HIV infected people are expected to increase (Waldrep, Summers & Chiliade, 2000). The implications of this co-infection are significant chiefly because co-



infection accelerates the progression of HCV disease and leads to higher rates of liver damage and liver failure. With improved therapies, HIV infected patients are living longer and are more likely to suffer and die from complications related to HCV. The plight of those dually infected is often complicated by a health care delivery system that is fragmented and poorly prepared to address these two complicated chronic and potentially life-threatening infections.

Although HCV does not accelerate HIV disease, it does cause liver damage that may prevent the use of anti-HIV drugs (ASTHO, 2000). HIV antiretroviral therapy is particularly toxic to the already weakened liver, making therapy particularly challenging. On the other hand, HCV therapies may lower CD-4 counts which are vital in preventing opportunistic infections associated with HIV. Because protocols for treating HIV/HCV co-infection are still being formulated, each patient's medication regime must be reviewed individually.

Currently, there are an estimated 950-1300 people in Maine who are HIV positive. Some AIDS service organization staff estimate that 25% of their clients are HCV positive and many arrive at the organization already infected. A public health practitioner in Portland estimates that 80-85% of the clients seen at the Ryan White Title III clinic are HIV/HCV co-infected. These anecdotal reports are in sharp contrast to Maine Medicaid data through 1999 which indicates that only 5% of Medicaid clients with HIV are co-infected with HCV.

Chapter Summary

The number of recognized and diagnosed chronic HCV cases in Maine has dramatically increased since 1997, revealing a "silent epidemic" that has existed in Maine for many years. Diagnosed individuals include a wide spectrum, ranging from persons dying of end-stage liver disease to otherwise healthy persons with asymptomatic infection. Aggregate Medicaid data indicate that the numbers of recognized and diagnosed cases are also increasing and that the associated costs, now and during the next twenty years, will be substantial. Those most affected are people in the "prime of their lives" (30-49 years old). Many of these persons have remote histories of injection drug use, but have long since stopped injection of illicit drugs. Many others were infected during the past 30 years through blood transfusions. HCV has touched every county in the state and is quickly emerging as a major public health issue.

While Maine has a considerably more detailed epidemiologic profile of hepatitis C than most other states, additional resources for data gathering, analysis, and dissemination to health professionals and policymakers are needed to achieve a level of understanding of HCV infection in Maine that will maximize prevention and care efforts. Particular attention needs to be paid to a more detailed understanding of HCV infection in specific populations within Maine, including injection drug users, prisoners, and those infected with both HIV and HCV.



Chapter 2

Current Status of Hepatitis C Infection Prevention and Care in Maine

Overview

The challenges posed by the HCV epidemic in Maine are many and complex. They include:

- No fewer than 15,000 Mainers are currently infected and reside in every county in the state;
- 9 out of 10 of those infected with HCV in Maine are currently unaware of their infection;
- 8 out of 10 of those infected will go on to develop liver disease, including some who will develop cancer or complete liver failure as a result of HCV infection;
- Transmission of HCV continues in Maine at an unknown rate, particularly among those currently injecting drugs; and,
- Knowledge of HCV diagnosis and management is not widely disseminated among Maine health and human services professionals.

All of these HCV-specific challenges are further complicated by problems common to the entire health and social services system in Maine, particularly inadequate access to health care. Inadequate access to health care may be caused by lack of insurance, under-insurance, low income, and/or inadequate supply and distribution of health professionals across the state (Governor's Year 2000 Blue Ribbon Commission on Health Care, 2000). To meet these challenges, Maine requires a comprehensive, coordinated system of prevention and care for those living with HCV infection. At the time of this assessment no such system exists.

This section of the **Maine HCV Infection Needs Assessment** describes the components necessary for the construction of a comprehensive, coordinated system of HCV prevention and care and the extent to which each service exists in Maine. A description of the current and planned systems of prevention and care in other states is included for comparison purposes. The section concludes with a discussion of HCV prevention and service needs of Maine's prison population and an overview of HCV programs in prisons across the county.

Components of a System of Prevention and Care

Disease prevention, medical care, behavioral health, social support, and system coordination services are the five key components of a comprehensive, coordinated system of HCV prevention and care. Brief descriptions of each component and an assessment of the current status of that component in Maine are provided below.

1) Disease Prevention

Two levels of disease prevention services are needed:



- *Primary prevention*, or population-based, outreach and education that seeks to prevent new HCV infections by decreasing or eliminating behavior(s) that increase risk of exposure to HCV; and,
- *Secondary prevention*, or early detection of infection in persons who are already infected so that measures may be taken to prevent progression of disease. Such efforts include focused outreach to counsel and test persons at high risk and assist them in taking measures to prevent disease progression and prevent transmission to others.

At the time of this assessment, no HCV prevention services -- primary or secondary -- are being delivered in a coordinated, sustained manner across the state. Individual interviews and focus groups with substance abuse treatment providers and HIV care and prevention providers indicate that a few agencies have taken the initiative to begin providing HCV risk reduction and prevention education to participants in their programs. Expanding the number and scope of Maine's needle exchange programs, along with other HCV risk reduction education targeting injection drug users should be the highest priority for primary prevention of HCV infection.

A no-charge HCV infection counseling and testing program -- modeled on and integrated with Maine's successful HIV counseling and testing program -- would be an effective secondary prevention strategy. This program would include two separate risk assessment and risk reduction counseling sessions for each individual tested. Pre-test counseling would provide individualized HCV infection risk assessment and education. Post-test counseling would provide a means to assure that HCV-infected individuals are referred for medical treatment, mental health or substance abuse treatment, and are informed about precautionary measures to prevent the spread of infection. Post-test counseling for the HCV negative would provide in-depth education about behavior changes that may reduce the likelihood of their contracting HCV in the future.

At the time of this assessment, there is no HCV counseling and testing program in Maine. Counseling and testing instead take place on a case-by-case basis in a few clinics in Portland, in a number of substance abuse treatment facilities, and primary health care offices⁸ around the state. In order for someone to receive testing, he/she has to actively seek out care of some sort and either present symptoms of liver disease, or specifically request the test.

Feedback from focus groups of HCV-infected Mainers and interviews with medical specialists providing care to people with HCV infection indicate many of those currently providing testing have limited time to counsel patients adequately. This leaves patients without consultation on their illness, how to prevent the spread of the infection, and without resources or referrals to HCV specialists or ancillary support services. If they are HCV negative, they are left without consultation on how to prevent infection in the future.

⁸ Another option for testing includes an FDA approved home test kit called Home Access, but this does not allow for face to face counseling.



2) Medical Care

The purpose of HCV treatment and care is to delay the progression of the infection and, if possible, eliminate it altogether. The treatment is complex and challenging for both the providers and patients. Medical management standards of care have been established by a National Institute of Health Consensus Conference (NIH, 1997). For those that meet the medical criteria, the most effective current treatment for HCV is a combination of alpha- interferon and ribavirin. For about 30 % of cases, this treatment combination reduces HCV viral loads to undetectable levels. Recent studies show that new formulations of the drug regimen increase the success rate to about half of those treated. The side effects of the treatment are significant. If a patient is using alcohol, drugs, or has a history of depression, cirrhosis, pregnancy, AIDS, or is under 18 or over 65, he or she may not be eligible for treatment (CDC, 1998; NIH, 1997). Even if patients are eligible for treatment they may be reluctant to initiate treatment because of a lack of HCV symptoms and fear of the side effects that are likely to have a dramatic effect on quality of life.

Currently, medical management of those infected with hepatitis C in Maine is provided both by primary care providers and gastroenterologists. As part of the **Maine HCV Infection Needs Assessment**, a sample of primary care health professionals and gastroenterologists were surveyed regarding their knowledge, attitudes, beliefs, and practices for managing people with HCV infection. A brief summary of the survey results follows in order to provide information regarding the current status and future capacity of Maine's medical care providers to manage the growing numbers of those with HCV infection⁹.

In September 2000, the survey was mailed to a random sample of 417 Maine primary care providers (physicians, nurse practitioners, and physician assistants) drawn from lists provided by the Maine Board of Nursing and Maine Board of Licensure in Medicine. Two hundred and five surveys were returned (response rate 49%) and 145 of these surveys were used for the analysis. The survey was also sent to all 37 gastroenterologists practicing in Maine. Twenty surveys were returned from this group of specialists (response rate 54%).

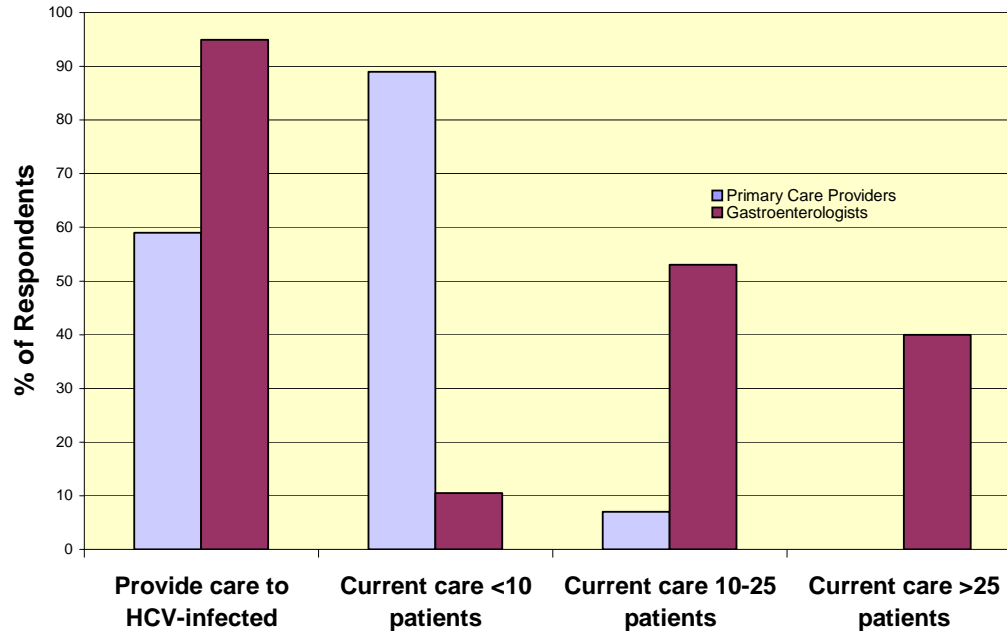
As illustrated in **Figure 7**, the number of HCV-infected patients that are being cared for at present differed greatly between the two groups: more than half (59%) of primary care practitioners [PCP] surveyed reported that they had provided care for HCV-infected patients while nearly all (95%) of the gastroenterologists [GI] had provided such care. Nearly all (87%) of the PCPs reported they had fewer than ten current patients while over half (53%) of the GI specialists are caring for between ten and twenty-five patients. Over one-third (37%) of GI currently manage twenty-six or more HCV-infected individuals.

⁹ A detailed report of the surveys summarized here is available from Paul Kuehnert, Director, Division of Disease Control, Maine Bureau of Health, 11 State House Station, Augusta, Me 04333-0011. A copy of the survey instrument can be found in Appendix C (PCP) and Appendix D (GI).



Figure 7

Comparison of Primary Care and Specialty Medical Care Providers' Experience with Hep C Patients



Source: Maine Bureau of Health

Both groups of medical providers reported their current practices regarding screening patients for HCV infection related risk behaviors. In each group, nearly all (92% of PCPs and 100% of GIs) indicated they would screen patients with a history of injection drug use. Only three-quarters (78%) of the PCP respondents indicated they would screen patients with a history of receiving blood products prior to 1992 while all of the GIs would perform screening on those with such a history. Only 72% of the specialists indicated they would screen sex partners of HCV infected individuals who reported unprotected sex, while 85% of the PCPs would screen these individuals.

The survey also asked a series of ten questions related to knowledge of HCV transmission, natural history, diagnostic testing, and medical treatment. Nearly half (46%) of the PCP respondents answered fewer than 7 of these questions correctly while most (95%) GI specialists answered 8 or more of the 10 questions correctly.

In summary, a small number of medical specialists and gastroenterologists are currently caring for the majority of HCV-infected Mainers. Primary care practitioners have had limited experience providing medical management to persons with HCV infection. There is a need for continuing education for primary care providers around indications for HCV screening, proper follow-up, and medical management. In



addition, a significant minority of gastroenterologists are currently managing substantial caseloads of patients with HCV infection. Attention needs to be paid to assuring adequate access to specialist consultation and care for the HCV-infected around the state. There may be a role for a more clearly defined system of expert HCV medical management consultation services accessible by phone for primary care professionals providing care to HCV infected patients, similar to the AIDS Consultation Service provided by Maine Medical Center.

3) Behavioral Health Services

The third component of a comprehensive, coordinated system of prevention and care for HCV infection is behavioral health services, including both mental health services and substance abuse treatment. Focus groups and interviews conducted with medical providers, substance abuse treatment providers, HIV/AIDS community service agencies and people living with HCV infection addressed current needs for and availability of behavioral health services for the HCV infected.

Two particular needs were identified. First, depression is a very common side effect of the current pharmacological treatment of HCV infection and the full range of therapeutic interventions are needed. Secondly, due to the large number of current or former injection drug users in the population of those infected with HCV, the demand for substance abuse treatment services is expected to increase.

A widely held belief among those interviewed was that, with few exceptions, behavioral health professionals in Maine are currently unprepared to respond to the emerging demand for their services from HCV-infected community members. The development and delivery of HCV-specific continuing education programs geared to these professionals is the necessary first step in assuring that Maine's mental health and substance abuse treatment agencies can meet the demands that will be placed on them by the HCV epidemic.

4) Social Support Services

Not unlike other groups of people living with chronic and debilitating conditions, people with HCV infection have a variety of needs that fall into the category of social support, such as: consumer-led support groups, transportation, housing, advocacy and support in obtaining entitlements, and assistance in coordinating needed medical and behavioral health services. Individuals who were interviewed and focus groups conducted for the needs assessment with medical providers, substance abuse treatment providers, HIV/AIDS community service agencies, and people living with HCV infection were queried regarding current needs for and availability of these social support services for the HCV-infected.

With the exception of active consumer-led focus groups in Lewiston-Auburn, Portland, and Bangor, none of the array of support services needed by persons with HCV infection are provided on any formal, program-level basis by agencies in the state. Many of those interviewed noted the similarity in need for social support services between the HCV-infected and those infected with HIV, as well as the fact that some individuals may be co-infected. Many of those interviewed suggested that the network of community-based HIV service organizations around the state might be a ready resource for developing the needed network of social support services around the state for people with HCV infection if adequate human and financial resources were made available.



5) Assessment, Coordination and Evaluation Services

Assessment of the epidemiological dimensions and dynamics of HCV infection in Maine, planning to meet the human needs that result from the epidemic, and evaluation of the effectiveness of prevention and care services are all activities that make up the final key component of a comprehensive system of HCV prevention and care. At the time of this assessment, senior staff from programs within the Maine Bureau of Health's Division of Disease Control have collaborated to provide and/or coordinate HCV chronic infection surveillance, needs assessment and planning activities. In September 2000, a two-year commitment was secured from the Centers for Disease Control and Prevention [CDC] for one public health prevention specialist for these efforts. Further development of a comprehensive, coordinated system of HCV prevention and care will require additional resources in order to assure the effective use of all resources brought to bear on the HCV epidemic.

Responses to HCV by Other States

To gain perspective on Maine's response to the emerging HCV epidemic and to identify possible models of comprehensive efforts by others, a telephone survey of eleven state and two city health departments¹⁰ was conducted in October, 2000. Summary information regarding HCV initiatives from three additional states, three counties and one city¹¹ was obtained from staff with the CDC. HCV initiatives in these states are comprised of a variety of activities. The depth and breadth of these activities are dependent upon their respective policymakers' perception of the importance of the problem. At the time of this assessment, no federal funding program focused exclusively on HCV prevention or care has been developed. As a result, these state and local HCV initiatives are largely dependent upon non-federal funding.¹²

In general, the state and local HCV initiatives are made up of one or more of the following activities:

- Special HCV surveillance projects
- Targeted HCV counseling and testing
- HCV education, including general public education as well as efforts targeting health professionals and those at highest risk
- Specialist consultation and other support for primary health care providers
- Provision of medical care for the indigent and uninsured
- Needle exchange programs
- Provision of hepatitis A and B vaccines to those infected with hepatitis C
- Social support programs, including peer-led support groups and case management.

Table II below provides a brief description of different HCV program approaches in six states.

¹⁰ The states were: CO, FL, MA, MI, MT, NM, OH, OK, OR, TX, and WA. The cities included: Austin, TX and New York City.

¹¹ The states included: IL, RI, and VA; the counties: San Diego and San Francisco, CA and Erie, NY; and the city of Houston, TX.

¹² A modest viral hepatitis integration demonstration project was initiated by the Centers for Disease Control and Prevention in the summer of 2000. Fifteen projects were funded for an average of \$106,600 each. All of these projects are included in the summary presented here.

**Table II Summary of Hepatitis C Initiatives of Select States, December, 2000**

State/County	Setting for integrated services	Major activities
Florida	Statewide	<ul style="list-style-type: none"> • Hepatitis hotline in conjunction with Home Access • Public awareness campaign to market hotline • Hepatitis C CD ROM for health professional training • Developed educational materials for AIDS service organizations • Intranet based surveillance system for hepatitis
Illinois	STD/HIV clinics Drug treatment centers Jails and juvenile detention centers Gay bars/MSM support groups Needle exchange programs	<ul style="list-style-type: none"> • Offer HBV and HCV testing to IDUs • Offer hepatitis A and B vaccines to men who have sex with men and IDUs
Massachusetts	Competitive bid process in progress, will vary in geographic location and type	<ul style="list-style-type: none"> • Integrate HCV services into 3 sites • Adapt existing training/education materials to local use • Provide training to providers
Montana	Community clinic Yellowstone county	<ul style="list-style-type: none"> • Target Yellowstone county for education, awareness campaign to address hepatitis among IDU, providers in drug treatment, corrections, and HIV CTS for education • Offer HAV, HBV, and HCV screening and hepatitis A and B vaccine services
New Mexico	Statewide	<ul style="list-style-type: none"> • Held statewide consensus conference of health/social services providers to establish priorities and protocols for screening and treatment • Providing software support for HCV clinical records for providers • Expanding basic health cost payments involving public and private insurers
Texas	STD clinic State	<ul style="list-style-type: none"> • Full HCV testing services • Public awareness campaign • HCV testing in 20 sites • Developed and distribute treatment protocols • Statewide hotline



Populations of Special Concern for Prevention and Care: Prisoners

A focus group made up of Maine Department of Corrections (DOC) staff and health services contractors was conducted to identify current DOC practices and concerns regarding HCV infection in Maine's state prisons. Currently HCV education and testing are not routine or universal. DOC tests inmates on a case-by-case basis depending on symptoms and diagnostic markers. Focus group participants did not believe there would be objections to implementing a more formalized screening program if they have the proper protocols and adequate funding.

A major barrier to routine, voluntary HCV screening identified by the group was the fact that DOC must provide medical treatment for any prisoner's medical condition. An additional concern with HCV treatment in particular was the length of the treatment schedule in relation to the inmates' sentences. While most HCV treatment may extend over a year, a prisoner may be released due to completion of sentence or parole before treatment is completed. This presents questions involving possible delay of treatment until after release or, if treatment was initiated in prison, how it would be completed and who would assure continuity of care.

On the other hand, focus group members expressed concerns about moral, ethical and legal liability issues of DOC not screening for HCV and not treating HCV infected inmates. In the two to five years that an average inmate may reside in prison, medical treatment and consultation have the potential to slow the progression of HCV infection. If the inmate remains untreated, serious complications may result.

Other concerns voiced by the focus group included the need for a comprehensive program that addresses all of the issues related to HCV treatment. Many prisoners addicted to alcohol or other drugs will need treatment services. Many prisoners will likely need mental health services for problems that are exacerbated by HCV treatment.

As a part of the **Maine HCV Infection Needs Assessment** process, the Maine DOC and Bureau of Health collaborated on the development of a national survey of state prison medical directors regarding their prisons' HCV policies and practices¹³. The results of this survey are summarized below.

Thirty five of the fifty medical directors responded to the survey (response rate 70%). Twenty of the thirty-five states (57%) reported that they were currently providing HCV tests for prisoners and two additional states reported that they had provided testing in the past but no longer did so. HCV screening tests were *not* provided *universally nor are they required* of prisoners by any state that responded. HCV tests are provided based upon:

- History of high risk behavior
- Medical indications or
- Prisoner request.

¹³ A detailed report of the surveys summarized here is available from Paul Kuehnert, Director, Division of Disease Control, Maine Bureau of Health, 11 State House Station, Augusta, Me 04333-0011. A copy of the survey instrument is found in Appendix B.



Those states that are currently testing or have tested inmates at their facilities reported a HCV prevalence ranging from 4.4% to 33%. The vast majority of the states doing testing (85%) provide voluntary pre- and post-test counseling to the prisoners. One state provides only post-test counseling and one other state requires prisoners to receive HCV counseling.

Costs for testing per inmate were reported as ranging from \$5-\$160, depending on the tests used for screening and confirmation. Funding for testing comes from general health care appropriations, grants, and legislative appropriations.

Two thirds (65%) of the states that are testing have developed treatment protocols and guidelines for managing HCV infection in their facilities. In those states, combination therapy of alpha interferon and ribavirin is widely used and immunizations for hepatitis A and B are provided. A variety of HCV-specific educational materials and prevention programs are offered to all prisoners in twenty-three states (66%) and another nine (25%) are planning to begin prevention efforts.

Chapter Summary

Currently, there are no coordinated, ongoing efforts in Maine to raise public awareness of HCV infection, prevent new cases, encourage testing for those at risk, provide counseling or testing services, nor provide educational and support services for primary health care and other behavioral and social service professionals. To the extent such services are available, they are provided by single agencies or voluntary groups of concerned consumers and professionals, at the expense of each agency or group. In addition, it is likely that substantial numbers of inmates in Maine's state prison system are infected with HCV and are without the means to get tested, diagnosed or treated.



Chapter 3

Economic Impact and Cost of Care for HCV Infection

The economic impact of hepatitis C may be gauged in two basic ways: The first is defined by the burden of disease, and includes such costs as medical care and the loss of productive work time for patients and families. The second is defined by the costs of prevention activities. The following summaries address the burden of disease:

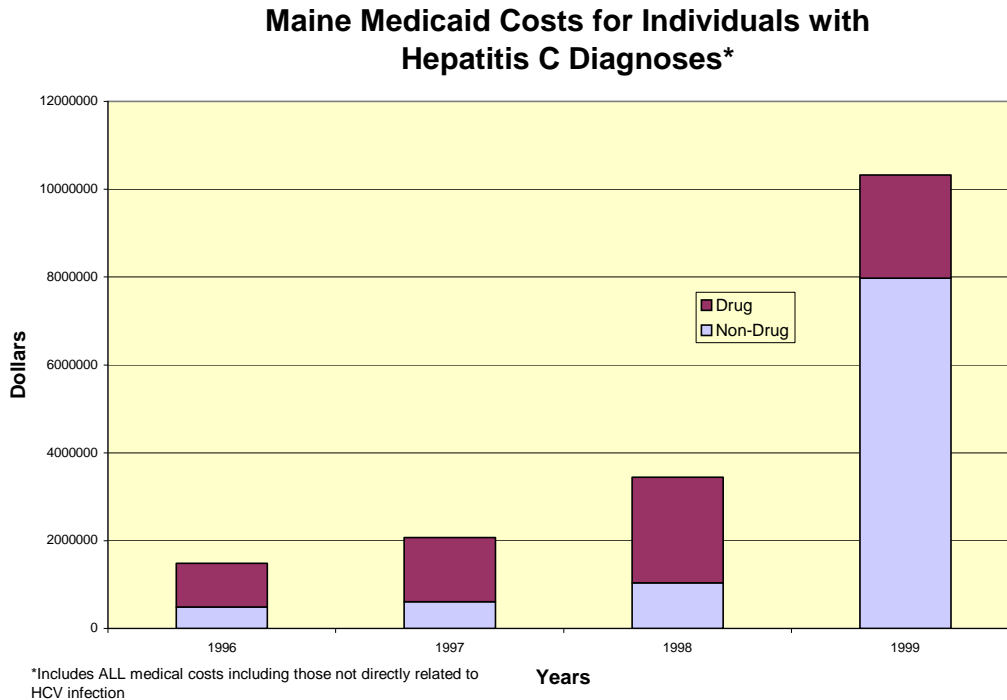
- According to the Centers for Disease Control and Prevention, all costs (medical and work) associated with acute and chronic hepatitis C currently exceed \$600 million annually (1998). Because the number of cases of hepatitis C needing medical care is expected to double or triple in the next 10-20 years, projections of medical costs for the future have been made by a number of researchers.
- According to a [Markov] computer simulation (Wong, et al, 2000) direct medical costs (not charges) will range from \$6.5 to \$13.6 billion during the period 2010-2019. Social costs such as lost productivity will equal \$54.2 billion from decompensated cirrhosis and \$21.3 billion from hepatocellular carcinoma (liver cancer).
- An actuarial model by Milliman and Robertson (funded by Schering Plough) suggests greater than \$15 billion per year in medical costs in 2000 increasing to > \$26 billion by 2021 (all medical care). The study also postulated that curative treatment would pay for itself in 10 years. For example, \$1 spent on combination therapy might result in about \$4 of medical cost savings. However, disability losses associated with hepatitis C will cost employers \$4-5 billion if patients do not receive treatment (Dulworth, Patel, & Pyenson, 2000).

One recent study suggested that average savings of \$400 to \$3,500 over a patient lifetime would result after 6 months of interferon therapy (DeGroot & Bick, 2000).

Insight into some Maine-specific hepatitis C costs may be obtained from data obtained from the Maine Medicaid Decision Support System and illustrated in **Figure 8** below.



Figure 8:



Source: Maine Bureau of Medical Services

Maine Medicaid costs (drug and non-drug) for individuals with HCV diagnoses increased substantially from 1996-1999. In 1999, Medicaid made payments of \$10.3 million for 644 HCV-positive patients, an average of \$16,000 per client. In late 2000, the projected cost for the Year 2000 was \$12.8 million based on expenditures for the first 6 months of the year. It should be noted that these expenditures represent costs for ALL medical needs of persons with hepatitis C diagnoses.

It is also important to consider the costs for prevention. A comprehensive hepatitis C prevention program will include primary and secondary prevention efforts:

- Primary Prevention:** Costs associated with primary prevention (preventing uninfected individuals from acquiring HCV) would result from efforts to raise public awareness using television, radio, and newspapers, and the production and distribution of Maine-specific brochures. In addition, focused campaigns to prevent needle-sharing will help to prevent the most frequent cause of new infections.
- Secondary Prevention:** Secondary prevention involves efforts to identify persons already infected so that measures to prevent disease and deaths can be applied. This would include targeted outreach efforts to offer diagnostic testing and associated counseling to those at highest risk of having HCV infection, and efforts to assure access for HCV-infected persons to appropriate care



(assistance with transportation costs to reach needed specialist care, for example) and ancillary services including substance abuse treatment and hepatitis C support groups to help patients comply with health promotion measures. At this time, efforts to make reasonable estimates of these costs are underway.

Chapter Summary

Maine's Medicaid costs for care to patients with hepatitis C infection already exceed \$10 million annually. Costs to other Maine insurers and to the health care system for the care of the uninsured with HCV have not been quantified to date, nor are reliable estimates available for the level of funding needed to initiate and sustain a statewide primary and secondary HCV prevention initiative. Dedicated assessment and planning resources are needed to address these issues in a comprehensive manner in order to contain the projected mushrooming of HCV medical costs in Maine.



Chapter 4

Conclusions and Recommendations

Hepatitis C viral infection is a serious blood-borne chronic disease that is rapidly reaching the point of crisis across the country. Because of the latency period and lack of symptoms, many people are completely unaware that they are infected. As Maine's population ages, more and more cases of clinical disease due to chronic HCV infection will arise.

Key findings of the Maine HCV Infection needs assessment include the following:

- Fewer than 1 in 10 Mainers infected with HCV know that they have this life-threatening infection;
- Little is going on in Maine to raise public awareness of HCV and prevent new infections;
- Screening tests for HCV are not readily made available or accessible to those at highest risk for the infection;
- Once tested and found to be infected with HCV, a typical Mainer must find his or her own medical treatment and support resources;
- Medical expenditures for HCV treatment have skyrocketed in the past three years, with the state's Medicaid program spending in excess of \$10 million in 1999.
- Injection drug users, prison inmates, and HIV/HCV co-infected individuals are all groups of Mainers that, at present, are disproportionately affected by HCV and are particularly vulnerable to serious complications of the infection.

Based on these findings, the Maine HCV Infection Needs Assessment Steering Committee recommends the rapid implementation of a comprehensive strategy to prevent and treat hepatitis C infection in Maine. The strategy must include statewide efforts coordinated by the Maine Bureau of Health to immediately address the following six priorities:

- 1. Increase public awareness of hepatitis C.** A wide variety of media should be used to convey clear, accurate messages about HCV infection to members of the general public, policymakers, and health and human services professionals.

- 2. Develop and implement an accessible hepatitis C counseling and testing program, which targets those at risk and builds on the existing HIV counseling and testing infrastructure.** This can be achieved by education and training of current HIV/STD prevention staff, substance abuse treatment counselors, and prison health staff; providing funding for HCV screening and follow-up tests through the Health and Environmental Testing Laboratory; and providing access to free counseling and testing for those at highest risk.

- 3. Stop the spread of hepatitis C infection through community outreach prevention programs.** Community-based health and social service agencies with proven health education track records ,



particularly with the marginalized in our society, should be funded in a coordinated, statewide HCV prevention initiative.

4. Improve the quality of care for persons with HCV infection by providing state-of-the-art continuing education programs and expert consulting services to physicians and other health and social service professionals. An initiative modeled on the AIDS Consultation Service at Maine Medical Center should be established through an inclusive, public-private partnership.

5. Develop and ensure access to an affordable, comprehensive system of care for people with HCV including, at a minimum, medical, mental health, and substance abuse treatment services. Collaborative efforts to extend and assure coverage for these essential services should be undertaken by public and private insurers in Maine. Models to explore may include current efforts underway in New Mexico as well as Maine's own successful Medicaid HIV Waiver.

6. Improve HCV surveillance capacity and initiate special studies to increase understanding of the extent and dynamics of HCV infection in Maine. Human resources are needed to refine and extend current HCV data gathering and analysis, and to communicate the information to health providers and policymakers.

We stand at a critical point in time in Maine in the HCV epidemic--a crossroads of crisis and opportunity.

Continued inaction in the face of the HCV epidemic in Maine will lead us down the road of crisis in the near future. The crisis will manifest itself in new HCV infections that could have been prevented, lost years of life for those unaware they are infected, and increased financial costs to both individuals and society.

Alternatively, we can embrace the many challenges presented by the HCV epidemic and choose the opportunity to respond to many needs in new and creative ways. The opportunity we can choose is to construct a unique Maine-specific blend of public-private collaboration to mobilize needed human and financial resources to meet HCV head-on. The choice is ours.