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Hepatitis C prevention and treatment for substance users in the United States: acknowledging the elephant in the living room

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Like many countries, the United States faces a major epidemic of hepatitis C virus (HCV) infection. Nearly 3 million Americans are estimated to be infected with HCV (Alter et al., 1999), and some 35,000 new infections are believed to occur annually (Williams, 1999). The virus causes chronic infection in about 85% of those infected, and among those chronically infected, cirrhosis may eventually develop in from 5 to 20% (Freeman et al., 2001;Liang, Rehermann, Seeff, & Hoofnagle, 2000). HCV infection is thought to result in 8000–10,000 deaths annually. It is already the most common cause of chronic liver disease and the most common reason for liver transplantation in the United States, and morbidity and mortality from HCV infection are rising and are expected to continue rising in the coming decades (Armstrong, Alter, McQuillan, & Margolis, 2000).

In the United States, as in many other developed countries, injection drug users (IDUs) constitute the largest group of persons infected with HCV, and most new infections occur in IDUs. Injection drug use predominates as a mode of transmission in most countries where the endemicity of HCV is low. There are probably a million or more current IDUs with HCV infection in the U.S.; of the estimated 1.2–1.3 million current IDUs in the U.S. (Normand, Vlahov, & Moses, 1995), some 80–90% have been infected with HCV (Lorvick, Kral, Seal, Gee, & Edlin, 2001;Thomas et al., 1995), although recent studies have shown that prevalence rates in young IDUs and recent initiates are now much lower (Garfein et al., 1998;Hahn, Page-Shafer, Lum, Ochoa, & Moss, 2001;Thorpe, Ouellet, Levy, Williams, & Monterroso, 2000). The incidence of new infections among IDUs is also quite high, however, generally ranging from 10 to 20% per year in the U.S. (Garfein et al., 1998;Hagan et al., 1999,2001;Hahn et al., 2001;Thorpe et al., 2000). The situation is similar in other developed countries (Crofts, Jolley, Kaldor, van Beek, & Wodak, 1997;Patrick et al., 2001;Van Ameijden, Van den Hoek, Mientjes, & Coutinho, 1993;van Beek, Dwyer, Dore, Luo, & Kaldor, 1998). Moreover, initiation of heroin use and injection drug use is increasing among young people (CDC, 2001a). Controlling the HCV epidemic, therefore, will require developing, testing, and implementing prevention and treatment strategies that will be effective for persons who inject drugs. Fortunately, substantial research and clinical experience exists in the prevention and management of chronic viral infections among IDUs, particularly because of the HIV epidemic. Learning from this experience will be critical for efforts to control HCV.

The public health response to the HCV epidemic in the U.S. to date has, unfortunately, fallen short of what is needed to stop the epidemic. Until recently, official documents produced by the U.S. Public Health Service about its response to the HCV epidemic were silent on most of the interventions described in this article (CDC, 1998;CDC, 2001b;NIH, 1997a). In 2002, NIH issued an updated Consensus Statement on the Management of Hepatitis C that took a substantially more comprehensive approach to the problem (NIH, 2002). This statement

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challenges the medical, scientific, and public health communities to address numerous problems that remain unsolved and continue to contribute to the HCV epidemic.

Preventing morbidity and mortality from HCV can be divided into primary, secondary, and tertiary prevention (Table 1). This paper summarises recommendations for effective prevention in each of these categories, and discusses some of the barriers that have hampered their implementation.

Primary prevention: reducing injection drug use

Because injection drug use is responsible for the majority of new infections, reducing the number of people who inject drugs is an important way to prevent the spread of HCV (Alter & Moyer, 1998).

Substance abuse prevention

HCV can be rapidly acquired after the onset of injection drug use (Garfein, Vlahov, Galai, Doherty, & Nelson, 1996;Lorvick et al., 2001). Efforts to control hepatitis C, therefore, must include a commitment to help people who do not inject drugs avoid starting to do so. Unfortunately, few drug use prevention programs have been rigorously evaluated and shown to be effective (Gerstein & Green, 1993). Nevertheless, evidence-based principles of effective strategies have been identified (Sloboda & David, 1997;Tobler, 1997). Effective strategies for preventing drug use among youth include educating and training parents, strengthening families, providing alternative venues for building skills and confidence, mobilizing and empowering communities, and other structural approaches (CSAT, 1994). Unfortunately, public spending has often not been directed toward programs that use those strategies (Ennett, Tobler, Ringwalt, & Flewelling, 1994;Gerstein & Green, 1993;Gorman, 1998). Moreover, to be effective, programs must be supported by structural social and economic change to reduce social inequality and economic disparity, create supportive social environments, and increase economic opportunities for young people, particularly in economically disadvantaged communities (Aguirre-Molina & Gorman, 1996;World Health Organization, 1986).

Substance abuse treatment

Opiate agonist therapy is effective treatment for opiate addiction (Lowinson et al., 1997;Strain & Stitzer, 1999). It has been shown to diminish and often eliminate opiate use and reduce transmission of many infections, including human immunodeficiency virus (HIV) (Ball & Ross, 1991;Gerstein & Lewin, 1990;Hartel & Schoenbaum, 1998;Metzger, Navaline, & Woody, 1998;NIH, 1997b;Sorensen & Copeland, 2000). Yet while substance abuse is generally recognised as a major problem facing the nation, and enormous public resources are expended for interdiction and the arrest, prosecution and incarceration of those engaging in illegal drug use, sufficient resources have not been allocated to provide access to substance abuse treatment to those who need it (Amaro, 1999;NIH, 1997b). The availability of substance abuse treatment is severely limited and large numbers of substance users do not have access to treatment. Methadone maintenance treatment in the U.S. is hobbled by both underfunding and onerous federal regulations; the current capacity is enough for only 15–20% of heroin users in the U.S. (Institute of Medicine, 1995). Unfortunately, funding for the support of substance abuse treatment programs has eroded during the course of the AIDS epidemic. There are now actually fewer treatment programs available and, within programs, fewer services (Etheridge, Craddock, Dunteman, & Hubbard, 1995;Metzger et al., 1998). Substantial expansion of substance abuse treatment capacity, to allow drug users who wish to stop or reduce their drug use access to treatment, will be critical to reduce the spread of HCV infection (Alter & Moyer, 1998). Resources must be provided for long-term methadone maintenance; time-limited “detoxification” is not a treatment for substance abuse (Gerstein & Harwood, 1990). Particular

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efforts are needed to design programs for young IDUs and recent initiates to injection, many of whom have not yet become infected with HCV. Substance abuse treatment for HCV-infected IDUs, on the other hand, can reduce the further spread of the infection (secondary prevention).

Secondary prevention: reducing HCV transmission

At least 60% of new HCV infections in the United States are thought to occur in persons who use illicit drugs by injection. To stop the transmission of HCV among IDUs, several types of interventions are needed.

Access to sterile syringes

Persons who inject drugs need access to sterile injection equipment in order to avoid acquiring and transmitting HCV and other bloodborne infections (U.S. Public Health Service, 1997). To accomplish this goal, several steps are needed. First, paraphernalia and prescription laws, which prohibit public health workers and pharmacists from making syringes available to drug users through syringe exchange programs and pharmacy sales, must be repealed (Gostin, Lazzarini, Jones, & Flaherty, 1997). Second, syringe exchange and distribution programs must be widely expanded and publicly supported and funded (Heimer, 1998;NIH, 1997c;Normand et al., 1995;Strathdee & Vlahov, 2001;Vlahov & Junge, 1998). Police, for example, must not interfere with drug users attending needle exchange programs (Grund, Heckathorn, Broadhead, & Anthony, 1995). And finally, physicians and pharmacists must be educated to understand that providing access to sterile syringes is a lifesaving intervention for persons who inject drugs (Burris, Lurie, Abrahamson, & Rich, 2000;Case, Beckett, & Jones, 1998;Gleghorn, Gee, & Vlahov, 1998;Rich, Macalino, McKenzie, Taylor, &, Burris, 2001;Singer, Baer, Scott, Horowitz, & Weinstein, 1998;Wright-De Aguero, Weinstein, Jones, & Miles, 1998). Health care professionals do their patients a disservice if they withhold access to sterile injection equipment in order to enforce the “War on Drugs” at the expense of their patients’ health and safety.

It should be noted that syringe exchange programs (Kaplan, 1995;Laufer, 2001) and increased access to sterile syringes (Holtgrave, Pinkerton, Jones, Lurie, & Vlahov, 1998) have already been shown to be cost-effective and cost-saving to society because they enable drug users to prevent HIV transmission. The prevention of HCV transmission results in even greater savings. Legalizing over-the-counter sales of syringes in pharmacies, moreover, would not cost the public anything.

Outreach to injection drug users

Community-based outreach programs are effective at helping drug users reduce their risk behaviours for acquiring bloodborne viral infections (Booth & Wiebel, 1992;Broadhead et al., 1998;Coyle, Needle, & Normand, 1998). To prevent HCV transmission, it will be particularly important to implement programs specifically designed for young IDUs and those who have recently begun injecting. IDUs know considerably less about hepatitis C than about HIV (Seal, Ray, Lorvick, Kral, & Edlin, 1999). Outreach programs must (1) educate IDUs about how to avoid acquiring and transmitting HCV infection, (2) support behaviour change to reduce high-risk behaviour, (3) provide client-centered counselling and (4) provide linkages to services, including HCV testing and care for infected persons.

HCV counselling and testing

Client-centered counselling and testing have been shown to reduce HIV risk behaviours and HIV incidence (Holtgrave, Qualls, & Graham, 1996;Kahn, 1998;Kamb et al., 1998). Identifying persons with HCV infection is also important to allow them to make decisions

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about seeking treatment. Persons who are HCV antibody positive require a test for HCV RNA to determine whether they are currently infected or not. IDUs who are HCV antibody negative should be re-tested every six months, because the treatment of persons with new HCV infection is more than 90% effective at eradicating virus (Jaeckel et al., 2001). To meet these goals, HCV counselling and testing programs and services will need to be greatly expanded.

Reducing injection equipment sharing

Efforts to reduce HIV spread among IDUs in some locations appear to have reduced HCV transmission as well (Edlin et al., 2000). It should be noted, however, that HCV may be more readily transmitted than HIV through the sharing of injection equipment other than syringes, such as cookers, cottons, etc. (Hagan et al., 2001;Thorpe et al., 2000), raising the standard for safer injection practices. Syringe exchange programs have been effective in allowing IDUs to avoid sharing syringes but less effective at helping them avoid sharing other injection equipment (Bluthenthal, Kral, Erringer, & Edlin, 1998). HCV may be transmitted if blood contact occurs during the giving and receiving of injections (Flynn, Anderson, Clancy, & Britton, 1996;Kral, Bluthenthal, Erringer, Lorvick, & Edlin, 1999), which may be especially common the first time drugs are injected. To prevent HCV transmission, programs must emphasise reducing the sharing of all injection equipment and avoiding any blood contact between persons (U.S. Preventive Services Task Force, 1996;U.S. Public Health Service, 1997).

Tertiary prevention: reducing liver disease in infected persons

Medical treatment for HCV infection

Current antiviral therapy for HCV infection can eliminate the virus from as many as 40–80% of infected persons, depending on the viral genotype (Manns et al., 2001). Because injection drug users constitute the largest number of chronic HCV infections and are the source of most new infections in the United States, controlling hepatitis C will require treatment strategies that are effective in persons who inject drugs (Edlin et al., 2001). Recent advances in HCV treatment regimens now allow effective treatment of HCV in some persons with as few as 48 doses of pegylated interferon (Zeuzem et al., 2000). This is fewer than the number of preventive therapy doses required for the treatment of latent tuberculosis infection (CDC, 2000). Many studies have shown that active drug users can complete preventive tuberculosis therapy in programs that take into account the circumstances of their lives (Chaisson et al., 2001;Lorvick et al., 1999;Salomon et al., 1997;Smirnoff, Goldberg, Indyk, & Adler, 1998;Tulsky, Pilote, & Hahn, 2000).

HCV treatment is more complex and less effective than preventive TB therapy. Adherence, psychological side effects, and the possibility of re-infection present challenges to effective treatment for some drug users. Fortunately, an array of effective strategies exists to overcome each of these challenges (Edlin et al., 2001). Before discussing these in more detail, however, it should be emphasised that for most patients, HCV treatment should be considered elective at this time. Treatment can be more definitely recommended for patients with relatively advanced hepatic fibrosis, in whom the clinical sequelae of advanced liver disease may be imminent (Yano et al., 1996;Heathcote et al., 2000). The treatment of patients who already have cirrhosis has been shown to reduce the incidence of liver cancer and probably death. Patients with acute HCV infection should also be informed that treatment may be more effective at eradicating virus when started shortly after acquiring the infection (Jaeckel et al., 2001;Quin, 1997). For most patients, however, who are not in one of these categories, the benefits of antiviral treatment for HCV infection do not unequivocally outweigh the disadvantages. Most patients will never develop cirrhosis or liver cancer. Clinical trials have demonstrated sustained

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viral clearance in 40–80% of treated patients (Manns et al., 2001), and histological damage appears to improve in treated patients (McHutchison, Gordon, & Schiff, 1998;Sobesky et al., 1999), but trials have not examined the effects of treatment on clinical endpoints—symptomatic disease or death—which would require many years of follow-up. Because treatment appears to provide histological and virological benefits, patients should have access to it. Histological benefit would be expected to translate into clinical benefit; and, most infected people would undoubtedly want to clear the infection, which appears to mean that they are rid of the virus, even if clinical benefit has not been proven. But the absence of data on clinical outcomes makes it impossible to know how likely treatment is to reduce the risk of developing clinical disease. It is still entirely possible that the patients who achieve sustained viral clearance after treatment are not those who would have developed cirrhosis or liver cancer had they not been treated. When the benefit of treatment is uncertain, the side effects can be severe, disease progression will not occur in most untreated patients, and better therapies are likely to be developed in coming years, the decision to undergo treatment in patients must depend highly on patients' personal preferences, such as their desire to be rid of the virus.

From the public health standpoint, however, providing therapy for HCV-infected drug users who opt for it is beneficial, because viral clearance would appear to mean that a person can no longer transmit the infection. Unfortunately, significant barriers to treating HCV infection in active drug users exist. Many do not have a trusting relationship with a physician who can help them endure the difficulties of HCV therapy. Patients must work at adhering to the regimen, physicians must be responsive to patients' experiences of side effects, and both parties must be able to communicate openly about their expectations and frustrations. Many drug users do not have relationships with providers that will support this kind of collaboration. Many physicians become frustrated with drug users who fail to follow through with medical advice, appointments, and prescribed medication. And users, for their part, often feel that they encounter treatment in health care systems that is judgmental and unresponsive to their needs (Batki & Sorensen, 1999;Lewis, 1997;Shine, 1996;Wartenberg, 1991).

Fortunately, however, extensive experience treating IDUs for medical conditions, especially HIV infection, has led to the development of effective principles for engaging drug users in health care relationships (Table 2). Successful programs invariably adopt a respectful approach to substance users, understand the medical and behavioural sequelae of addiction, and refrain from moralistic judgments (Bamberger et al., 2000;Batki & Sorensen, 1999;Marlatt, 1998;O'Connor, Selwyn, & Schottenfeld, 1994;Robertson, 1998;Selwyn & O'Connor, 1992;Wartenberg, 1991). These strategies embody a harm reduction approach (Des Jarlais, Friedman, & Ward, 1993;Marlatt, 1998). Harm reduction stresses implementing interventions and making changes that are attainable and beneficial when the elimination of all harm is not possible in the short run. For drug users who cannot or will not make the global behaviour change of stopping drug use entirely, many measures can nevertheless reduce the harmful consequences of drug use. Harm reduction strategies, not "zero tolerance", are accepted medical and public health practice for health behaviours other than illicit substance abuse, such as diet, exercise, smoking and medication adherence.

Success treating HCV infection in IDUs requires collaboration between experts in hepatitis and substance use to create programs specifically designed for drug users (Backmund, Meyer, Von Zielonka, & Eichenlaub, 2001;Sylvestre, 2002). Particular efforts are required to address the challenges posed by adherence, psychological side effects, and the potential for re-infection (Edlin et al., 2001). Effective strategies for improving adherence range from basic clinical practices—such as establishing a consistent, trusting physician-patient relationship, providing clear information about intended effects and side effects of medication, and paying careful attention to perceived side effects—to specialised tools such as electronic reminder systems,

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directly observed therapy, and cash incentives (Friedland & Williams, 1999;Lorvick & Edlin, 2000;Lorvick et al., 1999;Panel on Clinical Practices for Treatment of HIV Infection, 2001; Reiter et al., 2000). Simplifying complex treatment regimens, treating depression, or helping a homeless patient find housing can help improve adherence. Patients may benefit from individual counselling addressing barriers to and facilitators of adherence. To minimise psychological side effects, patients should be screened for depression and other mental health problems before HCV treatment, treated if necessary, and monitored for these problems during HCV treatment. Patients wishing substance abuse treatment must have access to it, and medical services should be integrated with substance abuse treatment (Weisner, Mertens, Parthasarathy, Moore, & Lu, 2001). Alcohol treatment is particularly important because of the strong deleterious effect of heavy alcohol intake on the progression of hepatitis C. Finally, because those successfully completing HCV therapy may be at risk for re-infection (Proust et al., 2000), drug users need detailed counselling and support to avoid risky injection practices, including referral to syringe exchange or prescriptions for syringes if necessary (Burris et al., 2000;CDC, 2002;Rich et al., 2001), in case they continue or return to injecting drugs. IDUs can master safe injection practices and many do inject safely.

Integration of medical and social services

HCV prevention must be provided, either on site or by referral, in all public programs and institutions serving illicit drug users, including public health clinics and hospitals, substance abuse treatment programs, correctional institutions, programs for high-risk youth, HIV counselling and testing sites, STD clinics, mental health clinics, and the like. Likewise, HCV treatment must be provided in the context of comprehensive medical and social services. Attention must be paid to important unmet needs, including hunger, housing, and untreated mental health conditions.

Provision of services to incarcerated populations

Substance abuse, including injection drug use, is prevalent in prison populations, in no small part because so many people are incarcerated for drug-related crimes. Prison offers an ideal opportunity to provide HCV treatment in a setting where barriers to adherence can be eliminated or minimised (Allen et al., 2003).

Social and political barriers to prioritising and implementing effective HCV prevention for drug users in the United States

The U.S. National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) have published guidelines for the prevention and treatment of hepatitis C (CDC, 1998;NIH, 1997a). CDC has also released a National Hepatitis C Prevention Strategy (CDC, 2001b). Until 2002, the documents produced by both agencies virtually ignored the need for prevention and treatment strategies for IDUs. None of these documents discussed developing hepatitis C prevention or treatment programs for IDUs. None set forth recommendations or plans for expanding substance abuse prevention or treatment, implementing syringe exchange programs, removing the legal barriers to syringe access, conducting community-based outreach, or organising HCV counselling and testing programs or treatment programs for IDUs or incarcerated persons. In fact, both NIH (1997a) and CDC (1998) guidelines recommended that persons who inject drugs not be treated for hepatitis C (and in the NIH guidelines, this provision was applied, inexplicably, not just to IDUs but to all illicit drug users). It was as though the needs of drug users, the burden of disease that they bear, and the importance of providing services to them in order to control the HCV epidemic had somehow been rendered invisible in the formulation of these policy documents. Like the proverbial elephant in the living room (Hastings & Typpo, 1984), it is impossible not to notice the enormous need for

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HCV prevention and treatment for IDUs, and yet there seems to have been a tacit and perhaps unconscious agreement in the conference room that their needs would not be spoken of. As a consequence, recommended measures skirted the margins of the HCV problem, rather than addressing its core, and those most severely affected by the HCV epidemic received no help. How did we get into this state of affairs?

The withdrawal of rights and withholding of needed services from drug users is normative in public policy in the United States outside the health care setting. In public discourse, users of illicit drugs are often portrayed as perpetrators of social ills (Massing, 2000;Musto & Korsmeyer, 2002). This portrayal supports punitive public policies, which, in turn, reinforce the stigmatisation (Currie, 1993;Reinarman & Levine, 1997). The United States, for example, spends tens of billions of dollars annually on incarcerating drug users (Office of National Drug Control Policy, 2000) but only a fraction of this amount on treating substance abuse (Coffey, Mark, & King, 1997; Murphy, Davis, Liston, Thaler, & Webb, 2000). As a consequence, the doors to prison are wide open for illicit drug users, while the door to substance abuse treatment is all too often firmly shut (Gerstein & Harwood, 1990). The persecution of drug users with the force of law in the U.S. probably warrants terms like “narcophobia” or “addictphobia” (Jones & Anderson, 1999) that have been applied to these policies to describe their irrational and pernicious nature. For example, a provision passed by the U.S. Congress as part of so-called “welfare reform” prohibits anyone convicted of a drug offense from ever receiving food stamps for the rest of their lives, regardless of whether they ever use drugs again (United States Code, 1999). Other provisions deny housing and education benefits to current and former drug users. Such “zero tolerance” policies place a higher value on penalising unwanted behaviour than on actually reducing it. They are aimed not at curbing drug use but at punishing the drug user (Gostin, 1990). The goal is ostensibly to decrease drug use by increasing the personal cost to drug users of their use, but while this approach is demonstrably ineffective (Drucker, 1999;Nadelmann, 1989) it has received priority over interventions that have been demonstrated to be effective (Ball & Ross, 1991;NIH, 1997b). Unfortunately, the drive to punish wrongdoers may be a deeply rooted human urge (Fehr & Gachter, 2002).

In this environment, it is particularly important that “zero tolerance” attitudes and policies be avoided in the health care system, whose mission is not to control behaviour but to provide relief from suffering. Intolerance, unfortunately, can find its way into the health care setting, where it can interfere with effective and compassionate care. Drug users are difficult to care for, and physicians rarely receive training in caring for them. Drug users may fail to follow their physicians’ advice, fully and truthfully disclose their lifestyles and behaviours, or keep their appointments. Physicians often find caring for drug users frustrating and, not understanding or approving of their behaviour, may respond with aversion, malice, or neglect (Chappel & Schnoll, 1977;Gorlin & Zucker, 1983;Groves, 1978;Jecker, 1996). Most physicians do not feel comfortable caring for injection drug users (Gerbert, Maguire, Bleecker, Coates, & McPhee, 1991). Indeed, half the physicians in a survey of one large urban hospital believed that patients who engage in self-destructive behaviour are not entitled to health care (Gross, 1999). Better education of physicians and health care providers in substance use and addiction, and exposure to models of compassionate care, are needed to overcome these barriers (Lewis, 1997;O’Connor et al., 1994;Shine, 1996).

Other factors may influence policies toward drug users with HCV infection as well. Scientists and health professionals who have been working on HIV/AIDS have had two decades of experience learning about the complexities of addressing difficult problems affecting disenfranchised communities. They have learned many lessons, often the hard way, about the necessity of overcoming prejudices, bridging cultural gaps, and avoiding discrimination in order to effectively serve marginalised populations. They have learned to recognise the role of social, cultural, and behavioural factors in disease transmission and control. Hepatitis C

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treatment experts may benefit from the lessons learned and the experience gained by several groups of professionals during two decades of responding to HIV. Substance abuse treatment professionals have expertise working with drug users in treatment. Harm reduction workers and substance abuse researchers have expertise working with out-of-treatment drug users. And many AIDS medical providers have expertise providing medical care to drug users both in and out of substance abuse treatment. Involvement of these professionals in HCV prevention and treatment efforts will greatly improve their effectiveness.

Moreover, while gay communities effectively mobilised to demand attention to the emerging AIDS epidemic, drug users have not organised to bring political pressure to bear to make the system responsive to their needs. Federal support through the Ryan White Comprehensive AIDS Resources Emergency Act provided funding for indigent persons to receive HIV treatment and for a national education and training network to educate healthcare providers about such care. Similar support for the needs of persons with HCV infection could foster the collaboration between experts in viral hepatitis and experts in substance abuse that is needed to address the HCV epidemic.

Finally, in the public health arena, the fear of political opposition to programs such as syringe exchange has paralysed public health departments and agencies in many jurisdictions. In a study of HIV prevention policies and practices for IDUs in six U.S. communities, public health departments in some cities where syringe exchange had not been implemented had never even had discussions about such programs, and many public health officials were uncomfortable or unwilling even to discuss their policies with study staff (Downing et al., 2002). The inertia created by this fear was often a greater barrier than any organised opposition to these programs. Once certain issues were considered off limits, public health workers grew so used to the restrictions that they did not notice them anymore, like the proverbial elephant in the living room. In communities that had overcome this inertia, it was often the presence of political or public health figures who exercised leadership on HIV prevention for IDUs who were able to effectively change the debate. Such leadership was often instrumental in implementing prevention interventions (Downing et al., 2002). Once programs were initiated, many fears were simply proven unfounded.

New, more comprehensive NIH statement

In 2002, NIH reconvened its consensus conference to update its guidelines because of new advances in medical regimens for hepatitis C (NIH, 2002). The 2002 Consensus Panel included several AIDS scientists, and a researcher with experience in AIDS and substance abuse was asked to address the conference (Edlin, 2002). The new Consensus Statement took a substantially more comprehensive approach than previous Public Health Service documents, raising important social and behavioural issues and challenging the medical, scientific, and public health communities to address the critical needs of injection drug users and other underserved and disenfranchised populations (Table 3). The new guidelines not only rescind the proscription against treating drug users, recommending instead a case-by-case approach, but now also comment specifically on a variety of critical issues that were not previously addressed in official statements or guidelines on hepatitis C. These issues include the importance of attention to mental health issues in the treatment of hepatitis C, the importance of attention to patients' adherence to medication, patient participation in decision making, addressing hepatitis C in correctional facilities, and, most notably, hepatitis C prevention in drug users. The onus is now on scientists, providers, policymakers, insurers, and government funders to implement the Panel's recommendations (Table 3).

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Conclusion

Substantial research and experience exist to inform efforts to address the enormous hepatitis C epidemics in developed countries such as the United States. Since transmission through contaminated injection equipment accounts for most HCV transmission, efforts must focus on preventing and treating substance abuse and providing services to drug users, including community-based outreach, access to sterile syringes and injection equipment, counselling and testing, and antiviral treatment. A major effort is needed to increase substance abuse treatment capacity in the U.S. Prevention programs for IDUs must emphasise the importance of avoiding all blood contact and the sharing of any injection equipment. Treatment will require programs designed specifically for drug users in which experts in both hepatitis and substance abuse collaborate. Physicians must recognise the value of gaining expertise and experience in caring for persons who use drugs. Providing services to drug users conflicts with social policies designed to increase the personal costs of drug use to users. But such policies are not consistent with the goals of medicine or public health. Public health professionals must provide policy makers and the public with the best possible advice about effective strategies to combat major public health problems such as the HCV epidemic. Public health officials must exercise leadership and prioritise needed interventions, regardless of the political climate. Advocates for harm reduction must organise to bring pressure to bear, in both the political and public health arenas, in support of sound hepatitis C prevention and control policies.

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Table 1

Strategies for HCV prevention and control

Primary prevention (preventing exposure): reducing injection drug use
1. Evidence-based substance abuse prevention
2. Expansion of substance abuse treatment
Secondary prevention (preventing infection): reducing HCV transmission among IDUs
3. Access to sterile syringes and other injection equipment
a. Repeal of paraphernalia and syringe prescription laws
b. Establishment of syringe exchange and distribution programs
c. Education of physicians and pharmacists to help IDUs gain access to sterile injection equipment
4. Community-based outreach to IDUs
5. Client-centered HCV counselling and testing
Tertiary prevention (preventing disease): reducing liver disease in infected persons
6. Medical treatment for HCV infection
7. Integration of medical and social services
8. Provision of services to incarcerated populations

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Table 2

Principles for managing health care relationships with substance-using patients

1.	Establish a climate of mutual respect.
2.	Maintain a professional approach that reflects the aim of enhancing patients' well-being; avoid creating an atmosphere of blame or judgment.
3.	Educate patients about their medical status, proposed treatments, and their side effects.
4.	Include patients in decision making.
5.	If possible, establish a multidisciplinary team consisting of primary care physicians, HIV specialists, psychiatrists, social workers, and nurses.
6.	Have a single primary care provider coordinate the care delivered by such a team to maximise consistency and continuity.
7.	Define and agree on the roles and responsibilities of both the health care team and the patient.
8.	Set appropriate limits and respond consistently to behaviour that violates those limits.
9.	Minimise barriers to participation (penalties for missed visits, etc.).
10.	Recognising that patients must set their own goals for behaviour change, work with patients to achieve commitment to realistic goals for healthier behaviours.
11.	Acknowledge that abstinence is not always a realistic goal; emphasise risk reduction measures for patients who continue to use drugs.
12.	Acknowledge that sustaining abstinence is difficult and that success may require several attempts.
13.	Be familiar with local resources for the treatment of drug users.

Adapted from O'Connor et al. (1994),Wartenberg (1991),Selwyn and O'Connor (1992),Marlatt (1998) and Robertson (1998).

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Table 3

Recommendations for IDUs in NIH hepatitis C consensus statement, 2002 (NIH, 2002)

Treatment
1. Treatment decisions for active IDUs should be made on a case-by-case basis.
2. Active IDU in and of itself is not a reason to exclude patients from antiviral therapy.
3. Active IDUs can be successfully treated for hepatitis C.
4. Methadone is not a contraindication to HCV treatment.
5. Treatment for drug and alcohol abuse should be made available to all patients who want and need it.
6. Experts in HCV and substance abuse should collaborate to treat patients.
7. Patients' adherence should be assessed, monitored, and supported.
8. Patients' psychological conditions, especially depression, should be assessed and treated and should be monitored while on hepatitis C therapy.
9. Alcohol abuse and dependence should be diagnosed and treated.
Access
10. The availability of treatment for IDUs and patients with psychological conditions should be increased.
11. The availability of diagnosis and treatment should be increased for African American and Hispanic populations and persons who are uninsured or have publicly funded healthcare.
12. Programs should be established to prevent, diagnose, and treat hepatitis C in correctional facilities.
Prevention
13. Substance use treatment capacity should be expanded.
14. IDUs should have access to sterile syringes though needle exchange programs, physician prescription, and pharmacy sales.
15. Physicians and pharmacists should be educated to recognise that providing IDUs with access to sterile syringes and education in safe injection practices may be lifesaving.
16. IDUs should be educated not to use others' injection equipment, to wash hands before and after injecting, and to avoid any contact with blood from other persons.
17. Community-based education and support programs for IDUs are needed.
18. HCV prevention education in correctional settings is a high priority.
19. IDUs and incarcerated persons should be screened for HCV.
Research
20. Strategies are needed to make treatment available to drug users, drinkers, prisoners, and patients with HIV co-infection or major psychiatric illness.
21. Research is needed on managing side effects and methods of increasing patient adherence.
22. Studies of the prevalence and management of hepatitis C in populations with publicly funded healthcare or no health insurance are needed.
23. The natural history of fibrosis in various groups, including IDUs, should be studied.
Collaboration
24. A comprehensive approach to collaboration among health professionals concerned with management of addiction, primary care physicians, and specialists involved in various aspects of hepatitis C is needed to deal with the complex societal, medical, and psychiatric issues of IDUs afflicted by the disease.

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