Prohibition and Hepatitis C Discrimination

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Hepatitis C is an infectious, virulent and resilient blood borne virus first identified in 1989. Globally, it is estimated to have infected around 170 million people and the epidemic is rapidly spreading [1]. New infections in Australia increased by 45 percent between 1997 and 2001 to 16,000 annually, and current estimates suggest that over 250,000 Australians have antibodies to the virus; that's about one percent of the population [2]. In industrialised nations, the epidemic is mostly found among people who are ex or current injecting drug users.

In Australia, more than 90 percent of new hepatitis C infections occur among people who inject drugs [3]. The sharing of any injecting equipment, including spoons, filters and tourniquets is a risk for hepatitis C transmission [4].

Other risks for infection include tattooing, body-piercing and the sharing of utensils like razors and toothbrushes [5]. Also at risk are those people who received medical blood products prior to the introduction of hepatitis C antibody screening in 1990. Sexual transmission is thought to be very rare, particularly within monogamous heterosexual relationships [6], and mother-to-child transmission is also considered to be rare [7].

For a majority of people, hepatitis C is not life threatening however it is associated with significant long-term morbidity. Treatments for hepatitis C are long - between six and twelve months duration - and the therapeutic drugs are associated with significant physical and psychiatric side-effects. Not all people will be able to successfully eradicate the infection following treatment. Most people with hepatitis C will need ongoing medical monitoring over the course of their lives.

A brief history of prohibition

Sociologist Harry Levine calls global drug prohibition the "invisible system" because until recently few people outside of some drug policy, harm reduction and academic circles have known that a sovereign state's national drug policy, like Australia's, is directed by a world-wide system created by the U.S.A. and supervised by the U.N. [8]. Yet, over the last century every government from capitalist democracies to Nazi Germany have embraced drug prohibition. Prohibition has been a politically and socially adaptive policy for administrations of all creeds: governments use prohibition as a means of gaining additional police and military powers to fight all manner of crime under the guise of protecting its citizens from the often exaggerated spectre of illicit drugs [8]. Importantly, anti-drug messages and drug demonisation, which are defining characteristics of prohibition, articulate a moral ideology of specific political and social values; any social problem, from property theft and violence to sexual promiscuity, can be linked to and blamed on drugs and drug "addiction" [8]. While many politicians and government bureaucrats may sincerely believe in prohibition's "War On Drugs", no other "health-oriented" cause has yielded governments so many resources for political propaganda, law enforcement and military power as prohibition.

But prohibition has had disastrous consequences for public health in the U.S., Europe, Australia and increasingly in many Asian countries, where H.I.V./AIDS and hepatitis C epidemics have escalated exponentially due to an increase in injecting drug use. Today it is estimated that the global turnover of the illicit drug trafficking industry is around 500 billion U.S. dollars annually [8]. Taxpayers in the U.S., Britain and Australia see billions of dollars funnelled annually into interdiction efforts yet illegal drugs in these nations are as plentiful as ever and street prices are often cheaper than they have ever been [9-14]. An economically rational evaluation of this attempt at stamping out illicit drugs would have seen prohibition scrapped decades ago. Indeed, as John Erlichman, one of the original architects of America's war on drugs during the Nixon administration has said:

> **"... the people in the (U.S.) federal government ... know darn well that the massive war they have mounted on narcotics is only going to be effective at the margins. If they don't know it, they ought to know it". [15]**

Perhaps prohibition's greatest achievements have been to stigmatise drug users and to thwart the emergence of a sophisticated debate among societies regarding drug use and alternative drug policy. Instead, by escalating a moral panic and scapegoating drug users as criminals and focusing on "addiction" and the misuse of drugs, prohibition constructs, ascribes and reinforces a direct association between all illicit drug use and criminality [8]. Today, anyone associated with illicit drug use inhabits one of the most maligned social

identity positions in our society. In the following extract, U.S. psychiatrist Szasz discusses the scapegoating of drug users within modern American society by alluding to the social processes behind stigmatisation.

> **"If history teaches us anything at all, it teaches us that human beings have a powerful need to form groups and that the sacrificial victimization of scapegoats is often an indispensable ingredient for maintaining social cohesion among the members of such groups." [16]**

After almost a century of global prohibitionist drug policies, people have been socialized to hold certain beliefs about drug users and question, for example, their value as members of society, their ability to find and maintain employment, and their capacity to form relationships with family and others [17].

Illicit drug users are assumed to be addicted and to have close ties with crime in order to finance their addiction. People who use illicit drugs are stereotyped as criminal, lacking social worth and a danger to the community because they are likely to spread their negative characteristics to others. This seems especially true if the drug user comes from a poor socio-economic background and injects heroin [18, 19].

Apart from the stigmatizing of specific behaviours, people experiencing illness may also be stigmatised [20]. Some diseases, like H.I.V./AIDS have a history of eliciting stigma and sick people are often labelled and excluded from a range of social contexts [21]. As Turner says:

> **"The panic and uncertainty that accompany epidemic disease may lead to a desperate search for explanations ... Stigmatization seems to provide a partial (although spurious) answer ... the convenience of having an already despised or suspect group in the vicinity allows for quick attribution of causality and blame." [16]**

Turner highlights the utility of social identity theory in understanding how people with hepatitis C come to be marginalised and discriminated against. Social identity theory involves three basic assumptions: people categorize others into in-groups and out-groups; people are motivated to strive for a positive self-concept and gain a sense of self-esteem by identifying with a particular in-group; and people's self-concept partly depends on how they evaluate their in-group compared with other groups [22].

In short, this theory describes people's desire to belong to a "superior" group, and to claim the psychological, social and material benefits obtained from such membership. It predicts that a high status group with a strong professional identity, such as health care workers will act both symbolically and physically, to distance themselves from people involved in an illegal activity that is synonymous with the transmission of hepatitis C [23-25], in order to preserve in-group safety and uphold in-group values.

Boundaries are created to satisfy health care workers' needs for security and to bolster a collective self-concept and sense of esteem. Health care workers identify strongly with their profession or "group", and our theory predicts that the higher the status of an in-group and the stronger members identify with their in-group, the more in-group bias or favouritism is observed among members and the stronger their differentiation from outsiders will be.

Those who participate in stigmatised illicit activities are categorised as being "all the same". Healthcare workers achieve a positive differentiation from people with hepatitis C through categorising and stereotyping; reinforcing a perception that "we are not like them". Within the medical professional's world-view, healthy people and behaviours are constructed in very specific terms with no tolerance for accommodating alternative understandings, and a belief in one's moral superiority often legitimates poor treatment of out-groups.

We now apply this theoretical framework to data from an Anti-Discrimination Board of N.S.W. enquiry [26] and to a study of people with hepatitis C conducted by the N.C.H.S.R. [27]. These data highlight the efficacy of prohibition to polarise identity and power among social groupings, in this case people with hepatitis C and health care workers.

Health care

In 2001, the N.S.W. Anti-Discrimination Board Enquiry into Hepatitis C related Discrimination reported that health care is a key environment in which discrimination is likely to occur. The Enquiry found that in the minds of many medical professionals hepatitis C and injecting drug use are synonymous, and that following a patient's disclosure of hepatitis C infection, doctors, nurses and specialists are commonly reported to behave in an abusive manner. According to two health care workers who specialise in the treatment of hepatitis C:

> **"People are automatically assumed to be current users when they disclose their [hepatitis C] positive status to health care workers."**
>
> **"Some nurses practise punitive measures when they identify patients as being ex or current users."**

Data from our own studies support these assertions. A quote from a patient with hepatitis C describes her experience at a large inner-Sydney hospital:

> **"The only time I've really noticed [hepatitis C related discrimination] has been when I've been in hospital, being treated by some nurses. Then I found it quite bad. And whether that is because of Hep. C or whether that's an indication that I was a junkie, I don't know. But even as recently as two or three years ago, I have been treated very badly by some nurses."**

During the Enquiry, health care workers were reported to view illicit drug use as a criminal rather than a public health issue. Many reportedly saw illicit drug use as an "evil" pursuit that stemmed from a moral inadequacy whereby users could not resist taking drugs [25]. This socially pervasive interpretation positions drug users as self-indulgent, weak willed and criminal, and is an outcome of decades of anti-drug messages and demonisation of drug users; elements integral to the prohibition message. This next quote from a woman with hepatitis C on a methadone maintenance program highlights such power imbalances in her therapeutic relationship with some health care workers:

> **"I present as a nice North Shore mum, but when I go to the methadone clinic staff are rude, unhelpful, badly informed, and their treatment of people who can't fight back is contemptible. They make fun of their clients, comment on their clothes and mental condition and generally act like they are infinitely superior. This is a private clinic. What the hell happens at public ones?"**

To avoid abuse from medical professionals, some people with hepatitis C adopted a policy of non-disclosure of their infection. When asked to whom she discloses her infection when seeking medical services, a research participant from a N.C.H.S.R. study replied: "... Nobody, tell nobody. Often I would change doctors as often as I could to avoid telling them that I had hepatitis C ..." (Woman, 45)

Non-disclosure has significant implications for the medical treatment of people with hepatitis C and for their access to health services. According to service providers, discriminatory attitudes and practices from the health care sector were having an effect on people accessing hepatitis C related and other health services. Some groups of affected people, like injecting drug users and people from culturally and linguistically diverse backgrounds were so fearful of discrimination that they refused to seek medical treatment. Our two data sets revealed that discrimination against injecting drug users was so common in health settings that some service providers believed injecting drug users and people with hepatitis C only go to see a doctor "when they absolutely must", and many expected to experience discrimination in medical settings. Service providers indicated that this self-limiting behaviour reduces the incidence of discrimination, and contributes to an under-estimation of its severity.

"Innocent" and "guilty" victims

It is apparent that medical professionals often make a distinction between "innocent" and "guilty" victims of some epidemics [21]. Blame for hepatitis C infection may be attributed to one's inherent deviance and criminal lifestyle, and in the eyes of some medical professionals this justified their exclusion from treatment. During the enquiry, a hepatitis C service provider claimed that health care workers generally feel that:

> **" ...[people with Hep. C only have themselves to blame and that they are less worthy of health care services because they are, or were, injecting drug users, even if fleetingly."**

Consistent with a prediction of social identity theory, there appeared to be less concern for the rights to confidentiality of stigmatised or "guilty" patients than for others. Confidentiality was compromised through for example the use of colour-coded wrist bands signifying hepatitis C and large signs displayed above beds declaring "Hepatitis C positive". Our data found that breaches of medical confidentiality led to relationship breakdown and personal information leaking into friendship networks, workplaces and among families.

Hepatitis C related discrimination was not only levelled at individuals but reportedly affected health service provision for affected people. A C.E.O. of a N.S.W. Area Health Service highlighted the material effects of systemic discrimination:

> **"... the ongoing discriminatory attitudes often held by health workers, including general practitioners, and those in the wider community hamper the further development of co-ordinated health and welfare services for people living with hepatitis C."**

In summary, these data provide evidence of hepatitis C related discrimination from health care workers due to a widespread confounding of hepatitis C and injecting drug use. This conflation resulted in some medical professionals abusing and excluding patients from treatment on the basis of their association, or presumed association with illicit practices.

Drug law reform

Indeed, injecting drug use is a most efficient vector of hepatitis C transmission. Yet, Federal and State governments in Australia refuse to engage with the issue of drug law reform as a means of preventing further transmission, even though key stakeholders during the enquiry commented that current drug policy is exacerbating the risks for hepatitis C transmission. Service providers, clinicians,

academics and affected individuals recommended drug law reform as an option to reduce viral transmission as well as hepatitis C related discrimination.

A submission from a prisoners' advocacy organisation blames society's prohibitive stance on drug use as "one of the leading risk factors to public health in N.S.W." because of the number of people in prison for drug-related crime, the level of hepatitis C infection within prisons and the ease at which the virus can be transmitted in that context and back into the wider community through recidivism:

> **"While so much has been achieved in the wider society to ... lower [hepatitis C] infection rates, the prison system and its discriminatory practices is actually an institutional incubator threatening to undermine wider social policy, practice and safety." This organisation suggested that by reducing the number of people receiving prison sentences for drug offences, the incidence of hepatitis C infection in society, as well as hepatitis C related discrimination, would be reduced [26].**

Conclusion

Prohibition's effects are far-reaching and have unwanted and unanticipated consequences for those unfortunate enough to be affected by hepatitis C. Continued discrimination and stigmatisation will obstruct efforts to prevent the further spread of the virus among the community. Addressing community ignorance of the virus may assist in ameliorating some people's experiences of discrimination however, increased knowledge alone will not be sufficient to reduce hepatitis C related discrimination within all domains.

As theory suggests, discrimination against people with hepatitis C serves a socially adaptive function for certain groups by reinforcing cultural and political norms and values that are at odds with people who belong to, or are perceived to belong to affected groups. While ending prohibition would not eliminate all discrimination against people with hepatitis C, legislative change is the first step in a process to counter stigmatisation and discrimination.

Law reform could pave the way for broader changes in the attitudes and social norms that currently polarise social identity and inform discriminatory practice. Removing the stigma of criminality is fundamental to reducing discrimination, to fostering trust among people with hepatitis C in a system that should care for them, and for engaging young people who inject with information about transmission prevention. Drug law reform would create an opportunity to address numerous drug-related health and social issues, not least by providing greater opportunities for education.

Unfortunately, on this issue our politicians are not leaders but followers treading the prohibitionist path of political expediency. Historically, because of the invisible system of global prohibition and an ill-informed electorate, politicians rarely have to deflect criticism regarding punitive drug policy.

Nonetheless, cracks in the armoury of prohibition are beginning to show from such diverse domains as the conservative U.S. think-tank, The Cato Institute [28] who in recent times has been highly critical of U.S. drug policy, to the growing global interest and support for policies of harm reduction.

A recent evaluation of the First National Hepatitis C Strategy conducted by leading epidemiologists, virologists and social researchers recommended that the Commonwealth Government increase resources for a range of harm reduction measures to curb a rapidly escalating hepatitis C epidemic [29].

But going beyond this, the evaluation recommended an "invigorated and innovative approach", including critical reflection of the policy of drug prohibition. However, Federal and State governments continue to demonstrate their commitment to prohibition, while vilifying as dangerous "drug-liberalisers" those who seek to engage with the issue of drug law reform.

The Federal Health Minister's [30] response to the evaluation report evoked the Christian construct of "original sin" and placed the responsibility for the hepatitis C epidemic on individuals, reinforced the association between criminality, drug use and disease and continued the simplistic rhetoric of the war on drugs:

> **"... [A] lot of [viral epidemics] are a function of personal behaviour ... Original sin is a serious problem in our make-up ... Certainly, here in Australia, the best way to avoid getting hepatitis C is not to use illegal drugs, not to inject yourself with things which are illegal. In the end, "just say no" is probably a pretty good message to illegal drug use." (Tony Abbott)**

As evidenced by such statements, there is a long way to go, but it is hoped that the growing critical analyses of prohibition will gather momentum as a generation of people born and raised during the "War On Drugs" reject the monumental waste of tax-payers" money that the policy incurs and the futility of the endeavour of pursuing the U.N.s fantasy of "a drug-free world". In the meantime, the social and health costs of continuing with this most callous approach to illicit drug users and those guilty by association (like people with hepatitis C) will continue to soar like birds of a feather.

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Carla's research interests are in the fields of hepatitis C and injecting drug use. She is primarily a qualitative researcher and is grounded in the discipline of health psychology. However, Carla constantly seeks to work across methods and disciplines. In particular, she sees it essential to work towards blending the insights that an individual-based discipline like health psychology can provide when issues such as hepatitis C and illicit drug use are considered in social, legal and political contexts. In particular, she is very interested in the influence of automatic process of behaviour (or mindlessness) as a tool for safe injecting messages. Carla is currently pursuing a program of research with the aim of developing a framework for peer education in hepatitis C prevention using principles of mindfulness to organise and frame safe injecting or blood awareness messages. Carla works in an applied way working directly with communities and organisations for people affected by hepatitis C, and in the policy sphere. This provides a tremendous immediacy and relevance to her research work.

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