

Abstract

A recently discovered hepatitis C virus is a common cause of chronic liver disease in industrialized countries. Because it is basically blood-borne and because blood donors are systematically screened, the only major group now at risk of infection are injecting drug users. There are increasing reports of stigmatization, affronts to dignity and discrimination as a result of the hepatitis C status of individuals, but little action is being taken to prevent or redress these. In an attempt to stimulate such action, we collected 37 reports of such incidents in Australia in 1994, in the domestic, work, recreational, day care and funeral settings, but the most common involved health care settings and health professionals. In general, action did not follow from such incidents, despite the fact that Australia has a very strong framework of anti-discrimination legislation and process. It is urgently necessary that these issues be addressed, both in themselves and as a necessary prerequisite for controlling the continued massive spread of hepatitis C among injecting drug users.

Un virus de l'hépatite C récemment découvert est la cause de maladies chroniques du foie dans de nombreux pays occidentaux. Etant donné que ce type d'hépatite est d'origine sanguine et considérant que les donneurs de sang sont systématiquement soumis à un test de dépistage, le seul groupe à risques est constitué par les toxicomanes recourant à des intraveineuses. Il existe un nombre croissant de comptes rendus de stigma, d'affronts à la dignité et de discriminations dus au fait que ces individus sont atteints l'hépatite C, mais force est de constater que peu d'actions sont entreprises en vue de la prévention ou du redressement de telles situations. En tentant de stimuler une action dans ce domaine, nous avons recueilli 37 comptes rendus d'incidents ayant eu lieu en Australie en 1994, dans le cadre domestique, le cadre du travail, celui des loisirs, des garderies d'enfants ou même des entreprises de pompes funèbres, la majorité des cas ayant cependant eu lieu dans le contexte médicale. En règle générale, aucune action n'a été prise suite à ces incidents, bien que l'Australie bénéficie d'une structure importante en matière de garanties procédurales et de législation anti-discriminatoire. Il est absolument nécessaire que ces problèmes soient traités, aussi bien en tant que tels qu'en tant que conditions préalables à un contrôle de l'épidémie d'hépatite qui se répand rapidement parmi les toxicomanes.

Un virus de hepatitis tipo C, descubierto recientemente, es una causa importante de la enfermedad crónica del hígado en países de occidente. Dado el hecho que este virus se lleva en la sangre, y que los donantes de sangre son examinados universalmente, el único grupo principal bajo riesgo de infección son aquellos que usan drogas inyectadas. La cantidad de reportes de casos de estigmatización, ataques a la dignidad y discriminación como resultado del estado de hepatitis C del individuo aumentan, pero se está tomando poca acción para prevenir o rectificar esta situación. Como un esfuerzo para promover este tipo de acción, hemos recaudado 37 reportes de incidentes en Australia en 1994 como los que hemos descrito, casos dentro del hogar, en el trabajo, en la recreación, en guarderías y en funerales, pero lo más común han sido los incidentes en centros de salud y con profesionales en el campo de la salud. En general, no se tomó ninguna acción después de estos incidentes, a pesar de que Australia tiene un fuerte marco legislativo y un fuerte proceso legal contra la discriminación. Es absolutamente necesario que estos puntos sean abordados en sí mismos, y como condición previa y necesaria para controlar el contagio masivo y continuo de la hepatitis tipo C entre usuarios de drogas inyectadas.

THE NEXT PLAGUE: Stigmatization and Discrimination Related to Hepatitis C Virus Infection in Australia

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Discrimination on the grounds of impairment or disability is illegal in a broad range of circumstances in Australia. Many issues covered by anti-discrimination legislation in Australia have arisen in the context of HIV infection and AIDS. Increasingly, there are reports of stigmatization and discrimination against people infected with (or merely seropositive for) another virus, hepatitis C virus (HCV). Much of this clearly falls into the category of discrimination under current legislation, and is therefore illegal, but as yet with one exception actions to remedy discrimination against HCV-infected people have not occurred in Australia.

Background

HCV, discovered in 1988, is a blood-borne virus which causes: an acute hepatitis in a small proportion of those infected; long-lasting infection in up to 80 percent; and long term (10-40 years) end-stage liver disease, especially cirrhosis and primary liver cancer, in up to 20 percent of those chronically HCV-infected. The virus is efficiently transmitted by blood, and is very inefficiently transmitted sexually or from mother to child. HCV has spread widely in Australia, related especially to injecting drug use and, before the introduction of universal donor screening in 1990, through trans-

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fusion of contaminated blood and receipt of blood products.^{1,2} A test for antibodies to HCV became available in 1990. This test has been widely applied since, both for screening of blood and tissue donors and for diagnostic purposes. However, as distinct from the situation pertaining to HIV testing, there are no guidelines relating to counselling for HCV testing nor a requirement to provide such counselling. Nor has there been any systematic effort to inform medical practitioners or the public about the meaning of HCV test results. As in the case of HIV, control of an epidemic of an infectious agent associated with behaviors seen to be antisocial or illegal can be extremely difficult.

The continuing association of HCV infection with injecting drug users (IDUs) raises issues of discrimination and stigmatization against those infected with HCV, for two reasons. First, arousing concern of HCV as an important public health problem is more difficult when the (reasonably accurate) perception among politicians, community and public health bureaucrats is that the current epidemic is predominantly among IDUs. Second, public health efforts to address the problem including such measures as needle and syringe exchange programs, or encouraging IDUs to use their drugs by non-injecting means—although rational—may be controversial among some segments of the community.

Support groups for people infected with HCV have been started in several states, and are working with limited resources to provide advice and assistance. To gain attention and increase understanding of the problems of stigmatization and discrimination experienced by people infected with HCV, we carried out a systematic collection of case histories of people with HCV infection.

Methods

During the last half of 1994, using a standard form, members of hepatitis C support groups, foundations and councils collected detailed information from members and callers to the support lines. This form included questions concerning demographics, the setting of the incident(s), the nature of the incident(s), the implications of the incident(s) for the person, and whether the incident(s) were reported and to whom.

This study was not intended to be quantitative, documenting the frequency of such experiences nor the resulting problems. Rather, it sought to highlight the existence of these problems and to gain some idea of the situations in which they occur.

Results

Thirty-seven case histories were collected, detailing 41 problematic incidents. 58 percent of the incidents were reported by women. The average age of the respondents was 34 years (range 17-74 years); many were single (43 percent); 23 percent were married, 15 percent in *de facto* relationships, 8 percent separated, 8 percent divorced and 3 percent widowed.

Reported incidents occurred in a wide range of settings. While most involved a health care setting (46 percent), 22 percent occurred in a domestic context, 20 percent at work, and the remaining ten percent in recreational, social security, day care, funeral or prison settings. The following examples illustrate the range and types of incidents reported.

Health Care Setting

Problematic incidents occurred at both individual and institutional levels. While some health care professionals and institutions have reacted to patients with HCV by seeking to impose overly rigorous infection control procedures, others have reacted with almost total neglect. Incidents in the health care setting are reported as doubly distressing, because health care professionals are often turned to for assistance in dealing with problems experienced in other settings.

- A female patient was told that positive HCV results were confirmed about her partner three weeks earlier. She asked the general practitioner why the partner had not been notified or told the test was done. The doctor replied that nothing could be done about HCV and that no literature was available.
- “[My] doctor’s attitude made me feel like a low, second class citizen. [He] told me not to work with children, [that I] should have a hysterectomy, avoid all sport...I felt like I had the plague...[I had] no more contact with them, [for their] general attitude was to

palm me off, reject me, [and provide] no follow-up care or consideration.

- Infection control signs were placed outside the patient's room. As a result, cleaning staff told the patient they would not enter the room to clean.
- "I was ignored. [The] woman in the next bed for the same operation was asked to shower and was seen to. At the last minute they rushed me through. In the surgery, a man was shouting about refusing to do the operation...After surgery I bled badly but was left to myself and discharged from the hospital pretty quickly. None of my medication was prepared. I was pushed out door quickly. The other lady in the room wasn't treated like this."
- "I went for a check-up at the dentist. I admitted that I was HCV positive...The dentist and assistant immediately put on gloves and masks...They then covered every article in the surgery with green hospital cloth and I was told not to spit in the bowl. The dentist did the work and then proceeded to scrub the chair before I left the surgery."
- "[My] dentist told me I would have to be the last patient of the day to allow time overnight for infection control [chemicals] to work on surfaces."

Domestic Setting

Disclosure of hepatitis C status to a spouse, a relative, a flatmate or a neighbor often resulted in hysterical responses, for which the HCV-infected person reported being quite unprepared.

- "[I] told [my] partner of [my] hep C diagnosis...some time later I found out I was pregnant. [My] partner told [me] to leave—[that I am] a murderer [who has] given [HCV] virus to him and [the] unborn baby."
- A woman's family will no longer hug or kiss her since disclosure of her HCV status because of fear of transmission. The family justified their actions by saying they had spoken to a doctor who said she was infectious.

- A woman told a friend that she was HCV-positive. She was to have a liver biopsy and needed support from friends while she was in hospital. The friend told her that she wouldn't be able to help out with home duties or baby-sitting as she didn't want to catch HCV.
- When friends were told of a woman's recent HCV diagnosis. They stopped visiting and would no longer allow their children to play with her children.
- "Last weekend my flatmate attended a doctor's clinic. Because I am HCV positive, my flatmate was advised to move out...My flatmate was very anxious and confused. She did not move out but has begun using her own crockery and cutlery."
- A woman disclosed her HCV diagnosis to a new flatmate and was told to find new accommodation as the flatmate did not wish to catch HCV.
- A woman sick with HCV discussed her HCV with a neighbor...Two days later, graffiti were painted on a fence, on-going offensive phone calls began, the patient's daughter was harassed by neighbor children and a window was broken.

Occupational Setting

Incidents in the workplace ranged from exclusion by colleagues to demotion, transfer, redundancy and outright termination.

- A woman told workmates that her husband was HCV-infected. The next day she lost her job.
- Workmates found out about a person's HCV...They then started to make remarks and refused to actively associate with the person, (e.g. separate lunches, morning teas etc.).

Other Settings

Fear of transmission has also led to breaches of confidentiality, rejection, expulsion or ostracism and segregation in other settings.

- A person went to DSS (Department of Social Security) looking for information and was told not to wait in the

queue with others but rather to sit “over there” away from everyone.

- “I contacted the family day care coordinator in our area as I am currently on medication for HCV and am finding difficulty looking after my daughter on sick days...The proposed day care provider rang me...My HCV status had been passed on and she questioned me about it. She was pregnant and was concerned about this and also that my daughter would pass it on to the other children in care...She said she would talk to her husband about taking on another child and would ring me the next day...The next day I was told that she wouldn’t be able to take my daughter.”
- “A friend of mine died of an HIV/HCV related illness. He’d wished to have a viewing at his funeral...The funeral company...stated that under the policies...they could not allow [this] to happen...At the funeral service, the workers refused to touch the coffin, forcing his mother to become one of the pallbearers.”
- “After [my] mother disclosed [my] hep C positive status to workers [in the youth training centre] [prison setting]...everyone was told, fingers were pointed at me, I was teased. Excluded from the kitchen, from handling food and cleaning up. Not allowed to play contact sports.”

Implications and Reporting of Incidents

Most respondents (83 percent) stated that these incidents had substantial personal implications. These included an impact on personal relationships for 63 percent of respondents, social implications for 61 percent, occupational implications for 44 percent, and financial implications for 37 percent.

Only 11 percent of these 37 incidents were reported to any authority. Most incidents were reported to the Occupational Health and Safety Board (41 percent), followed by legal centres (25 percent), hospital boards (17 percent), and the dental board (17 percent). None led to any action under the various Discrimination Acts.

Discussion

As a nation, Australia's response to HIV/AIDS was rapid, comprehensive and generally successful.³ The issue of discrimination on the grounds of HIV infection or AIDS was reviewed several times by select committees and legislative and other actions to prevent social and individual harms are put in place.⁴ In contrast, despite more than five years of knowledge concerning the hepatitis C virus (HCV) epidemic, there still are no specific educational campaigns or policy initiatives in place. What little information is made available to the general public is exemplified by current pamphlets from both the Australian Gastroenterology Institute and the Victorian Department of Health which do nothing more than advise HCV-seropositive people to: "Advise health care workers, including your dentist, that you are hepatitis C positive."^{5,6} However, HCV-infected people would seem to be well advised to be extremely cautious at present in discussing information about their health.

The case histories presented here may not be sufficiently representative. Each support group was aware of many more cases which were not reported. In addition, many people declined to be interviewed for fear of exacerbating their situation.

There is an urgent need to prevent the major social harms which can follow HCV diagnosis and disclosure, as exemplified by the case histories described above and to address the root sources of stigmatization and discrimination against people with HCV. Education of medical and other health care providers about the modes of transmission and risks in different settings and campaigns aimed at the general public are clearly necessary. Patient education should also include information about methods of redress against discriminatory and stigmatizing practices and policies, and counselling services should also be made aware of these procedures.

Anti-discrimination Legislation in Australia

Discrimination on the basis of HCV status, real or implied, is theoretically covered by legislation in Australia and Australian States. It remains only for these avenues to be used to challenge discrimination in the context of HCV. Recent relevant federal legislation includes the Disability Discrimi-

nation Act of 1992 and the Human Rights and Equal Opportunity Commission (HREOC) Act of 1986. As an example of State law, the Victorian Equal Opportunity Act of 1995 deals with discrimination in that State. The definition of disability includes the presence in the body of organisms causing or capable of causing disease or illness—thus including HCV.

The HREOC Act gives HREOC power to investigate breaches of the Declaration on the Rights of Disabled Persons. In that Declaration, the term 'disabled person' means "any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency either congenital or not, in his or her physical or mental capabilities."⁷

The rights in this Declaration include the inherent right to respect for human dignity, the same civil and political rights as other human beings, the right to measures allowing self-reliance, and to medical, physiological and functional treatment and services enabling them to develop capabilities to the maximum and hastening social integration. The Declaration also covers equal opportunity in employment and social security, the right to live with families and to participate fully in recreational and social activities, to be protected from exploitation and to have recourse to the law and to access to legal aid for protection of their person and property, and for representatives to be consulted in matters pertaining to the rights of the disabled.

Infringements of the Declaration are not of themselves necessarily unlawful. The Commission may hold inquiries into complaints of discrimination or violation of human rights, but has no power to conduct formal hearings of complaints. It may endeavour to reach a conciliatory settlement, but cannot make or enforce an order. Its funding and staffing are limited. A theoretical possibility under the Act, therefore, is not often reflected in practice. HREOC is also empowered under the Disability Discrimination Act to hear complaints. This makes discrimination on the grounds of disability unlawful in the areas of employment, accommodation, education, access to premises, clubs, sport and the provision of goods, services, facilities and land.

The Commissioner performs the functions of investigation, conciliation, determination of complaints by public

hearing, research, education and programs as prescribed under the Disability Act. However, it should be noted that in order to obtain enforcement of Commission determinations proceedings must be carried in the Federal Court. A complete rehearing of the matter is required, making this jurisdiction less desirable from the complainant's perspective. If the Court is satisfied that discrimination has taken place it may make orders to give effect to the Commission's determination.

It is unlawful in the State of Victoria to discriminate under the State Equal Opportunity Act of 1995 on the basis of disability in the areas of accommodation, clubs, disposal of land, education, employment, local government, provision of goods and services and sport. The definition of disability covers HCV infection, and the legislation specifically covers care-givers. An Anti-Discrimination Tribunal may hear complaints, and may conduct investigations of a more general nature arising out of complaints. It may also undertake information and education programs. It is worth noting that the Victorian Commission has, in association with some of the present authors, produced a pamphlet dealing specifically with discrimination on the basis of HCV. It outlines examples in which remedies may be sought and the broad-ranging nature of remedies.

Imputed impairment is also a basis for an action in both the State and Federal contexts. Discrimination on the basis of race, on the assumption that certain races are generally more likely to have a particular disease, is also illegal. However, discrimination on the basis of disease is lawful where the discrimination may be categorized as reasonably necessary to protect public health. Exceptions also exist with respect to insurance where discrimination is based on reasonable actuarial or statistical data.

In both the Federal and State contexts, incidents which involve an affront to dignity, not falling under a specific category of complaint, such as education or accommodation, is unlikely to be considered in a formal legal setting. This is particularly true of activities taking place within a private or domestic context. The instances cited in this article relating to discrimination in health care settings, however, include discrimination in the provision of services, and may be rem-

edied in a variety of ways. Remedies may include the establishment of particular protocols, the payment of compensation or a review of service provider practice. Within occupational settings, conciliation may include provisions of accurate information on transmission of HCV to all employees. However, discrimination taking place within prison is often sanctioned on the basis of a legal definition of what is "reasonable." Thus these complaints are less likely to succeed.

Conclusion

This study was exploratory, designed to call attention to an area of urgent need which has been largely ignored in the Australian response to HCV. Australia's National Action Plan on HCV does not mention the issue of discrimination or examine strategies for its prevention, reduction or redress. It is hoped that this study for reasons both of public health and of human rights, public health and legal authorities in all countries where HCV infection exists must urgently address the issues around discrimination and stigmatization in the context of HCV.

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References

1. N. Crofts, J. Hopper, R. Milner, D.S. Bowden, A. Breschkin, S.A. Locarnini, "Hepatitis C Virus Infection Among a Cohort of Victorian Injecting Drug Users," *Medical Journal Australia* 157 (1993):237-241.
2. N. Crofts, T. Stewart, P. Hearne, X.Y. Ping, A.M. Breschkin, S.A. Locarnini. "Spread of Bloodborne Viruses Among Australian Prison Entrants," *British Medical Journal*, 310 (1995):285-288.
3. N. Crofts et al., "Involving the Communities: AIDS in Australia and New Zealand," *AIDS* 8(suppl) (1994):S45-53.
4. Intergovernmental Committee on AIDS (IGCA).
5. "Hepatitis C: An Information Leaflet for Patients and Interested Members of the General Public," Australian Gastroenterology Institute, November 1991.

6. "Hepatitis C: The Facts," Infectious Disease Unit, Public Health Branch, Victorian Government Department of Health and Community Services, May 1995.
7. Declaration on the Rights of Disabled Persons, UNGAR3447 (XXX), 9 December 1975.