Hepatitis C-related discrimination in New South Wales

CAROLYN DAY, ROHAN JAYASURIYA AND GRAHAM STONE

Carolyn Day is with the National Drug and Alcohol Research Centre, University of New South Wales. Rohan Jayasuriya is at the Graduate School of Public Health, University of Wollongong. Graham Stone is with HIV, Program AIDS, Northern Sydney Health, Manly Hospital.

Acknowledgements: The HepCare trial was funded by the Commonwealth Department of Health and Family Welfare and the NSW Health Department.

Abstract

Hepatitis C-related discrimination was examined. Intake interviews with 606 HepCare trial participants from New South Wales were analysed to determine the prevalence and correlates of hepatitis C related discrimination. The sample was a mean age of 37 years, 54% were males, 79% reported a history of drug injecting and 35% were current injectors. Forty percent of the sample reported experiencing hepatitis C-related discrimination. Multivariate analysis revealed that current injectors, 35-44 year olds, females, those who had recently consulted a general practitioner and those who had been referred to a specialist for their hepatitis C were more likely to report discrimination than other groups. More research is required to attain a better understanding of hepatitis C-related discrimination.

Hepatitis C is blood-borne viral infection commonly affecting people with a history of injecting drug use (MacDonald *et al.*, 1996). An estimated 210 000 Australians were living with hepatitis C in 2001 (Law *et al.*, 2003). Reports of discrimination related to a person's hepatitis C status have emerged in Australia. An Enquiry into hepatitis C-related discrimination in NSW found that the discrimination impacted on the health, financial, social and emotional well-being of those affected (Anti-Discrimination Board of New South Wales, 2001). The Enquiry also found healthcare services were one of the most common settings in which discrimination occurred (Anti-Discrimination Board of New South Wales, 2001). These findings supported earlier work by Crofts and colleagues, who found that while discrimination occurred in a variety of settings, almost half occurred in health care settings (Crofts *et al.*, 1997)

Recent research found that approximately a quarter of injecting drug users (IDU) interviewed experienced hepatitis C-related discrimination, much of which was also reported to occur in health care settings, and that the discrimination was largely related to their drug user status (Day et al., 2003). It is, however, unclear whether current IDU or those with a history of injecting drug use (past IDU) are more likely to be discriminated against than those who have never injected drugs. Canadian research into HIV-related discrimination revealed that negative attitudes are more often directed toward IDU than other HIV risk groups (MacCarthy et al., 1999). There is currently a paucity of academic research into hepatitis C-related discrimination in Australia and the extent of the problem is not well understood (Treloar et al., 2002).

Data collected from a hepatitis C case management trial are presented to provide additional empirical evidence on this emerging issue. The current study aimed to examine 1) the prevalence of hepatitis C-related discrimination (within the preceding two years) among a community sample of people living with hepatitis C; 2) to determine whether hepatitis C-related discrimination is more likely to be reported by current or past drug

Australian Health Review [Vol 27 • No 2] 2004

injectors compared to those who report never injecting drugs and; 3) examine whether those who reported hepatitis C-related discrimination were more likely to also have reported recent contact with healthcare professionals.

Methods

A cross-sectional survey was carried out at intake to the HepCare trial (Commonwealth Department of Health and Aged Care, 2001). Participants in the trial were recruited from three NSW Area Health Services, one Sydney and two regional, through newspaper advertisements, general practice and clinical settings. The trial target population was individuals with a diagnosis of hepatitis C infection. The trial excluded children under 14 years, persons with development disability and unable to give informed consent. Participants were interviewed face-to-face during the recruitment phase of the trial and in the comprehensive intake interview.

As part of the intake interview participants were asked a range of questions related to their hepatitis C status and experience. These questions included whether they had experienced hepatitis C-related discrimination in the preceding two years, whether they had consulted a general practitioner (GP) about their hepatitis C in the preceding 12 months and whether they had been referred to a specialist.

Correlates of hepatitis C-related discrimination were assessed using the chi square statistic (x2). Multivariate logistic regression was used for factors significantly associated with discrimination. Injecting drug use was included in the model as an a *priori* factor. All data were analysed using SPSS 11.0.

Results

The mean age of the sample was 37 years (SD 9.2) and 54% were males. A history of injecting drug use was reported by 475 (79%) participants, of whom 211 (35%) had injected in the previous 12 months (current injecting drug users).

Forty percent (224) of participants reported experiencing hepatitis C-related discrimination in the two years preceding interview (Table 1). Multivariate analysis revealed that current injecting drug users (IDU) were more likely to report discrimination compared to those who had never injected (29% v. 40%; P<.05). Participants aged 35-44 years were more likely than those aged 45 years or more to report discrimination (40% v. 26%; P<.05), but there was no difference between those aged less than 35 years and those aged 45 years or more (36% v. 26%). Females were more likely to report discrimination than males (43% v. 33%; P<.05). Participants who reported consulting a GP in the preceding 12 months (39% v. 22%; P<.01) were more likely to report discrimination, as were those who had been referred to a specialist for their hepatitis C (41% v. 33%; P<.01).

Discussion

Our data suggest that hepatitis C-related discrimination affects a substantial minority of people with hepatitis C. Current drug injectors were more likely to report discrimination than those who reported never injecting drugs, a result consistent with earlier research (Day *et al.*, 2003). Past injectors were no more likely than those who never injected; the discrimination therefore appears to be related to current injecting rather than a stigmatisation of injecting per se. Detailed information about the discriminatory event(s) was not reported, so it was not possible to draw conclusions on the nature of the discrimination.

The study also found females were more likely to report discrimination than males. This may be due to a variety of reasons, in particular greater contact with healthcare services (Australian Bureau of Statistics, 1996). Alternatively, it may be because women with hepatitis C are considered 'deviant', a result of their (perceived) injecting drug use and, departure from socially prescribed roles, such as has been reported for HIV positive women (Lawless *et al.*, 1996). Further work on this issue is necessary.

Discrimination was more common among participants with recent contact with GPs and specialists. There are a number of potential reasons for this. For example, people who experience discrimination may be more symptomatic, requiring more frequent contact with these services and under more pressure to disclose their hepatitis C status to others. It should not be assumed that the discrimination occurred in these settings. Nevertheless the relationship is important given hepatitis C-related discrimination has been reported to occur in health care settings (Anti-Discrimination Board of New South Wales, 2001; Treloar *et al.*, 2002; Crofts *et al.*, 1997).

The impact of hepatitis C-related discrimination on health care utilisation, especially among those who inject drugs, may have deleterious effects by way of reduced contacts with health services among this already marginalised group who typically have complex health needs (Aitken *et al.*, 2002). Healthcare professionals dealing with hepatitis C positive patients may require training in dealing with IDU given that current IDU were more likely to experience discrimination than those who had never injected drugs.

Finally, more than a third of people in this study living with hepatitis C experienced related discrimination and this was more likely to occur to current injecting drug users and women. More work is needed to extricate the many issues associated with hepatitis C-related discrimination, in particular its impact on healthcare service utilisation and the implication for transmission.

References

Aitken, C.K., Kerger, M. & Crofts, N. (2002). Peer-delivered hepatitis C testing and counselling: a means of improving the health of injecting drug users. *Drug and Alcohol Review*, 21, 33-37.

Anti-Discrimination Board of New South Wales (2001) C-Change: report of the enquiry into hepatitis C related discrimination, Anti-Discrimination Board of New South Wales, Sydney

Australian Bureau of Statistics (1996) National Health Survey 1995. First results, ABS, Canberra

Commonwealth Department of Health and Aged Care (2001) Hepcare Hepatitis C Case Management Trial: Evaluation Report, Commonwealth Department of Health and Aged Care, Canberra

Crofts, N., Louie, R. & Loff, B. (1997). The next plague: stigmatization and discrimination related to hepatitis C virus infection in Australia. *Health and Human Rights*, 2, 87-97.

Day, C., Ross, J. & Dolan, K. (2003). Hepatitis C related discrimination among heroin users in Sydney: Drug user or hepatitis C discrimination? *Drug and Alcohol Review*, 22, 316-320.

Law, M., Dore, G., Bath, N., Thompson, S., Crofts, N., Dolan, K., Giles, W., Gow, P., Kaldor, J., Loveday, S., Powell, E., Spencer, J. & Wodak, A. (2003). Modelling hepatitis C virus incidence, prevalence and long-term sequelae in Australia, 2001. *International Journal of Epidemiology*, 32, 717-724.

Lawless, S., Kippax, S. & Crawford, J. (1996). Dirty, diseased and underserving: the position of HIV positive women. *Social Science and Medicine*, 43, 1371-1377.

MacCarthy, G.M., Koval, J.J. & MacDonald, J.K. (1999). Factors associated with refusal to treat HIV-infected patients: the results of a national survey of dentists in Canada. *American Journal of Public Health*, 89, 541-545.

MacDonald, M., Crofts, N. & Kaldor, J. (1996). Transmission of hepatitis C virus. *Epidemiologic Reviews*, 18, 137-148.

Treloar, C.J., Hopwood, M.N. & Loveday, S.K. (2002). Hepatitis C-related discrimination in healthcare. *Medical Journal of Australia*, 177, 233-234.

Australian Health Review [Vol 27 • No 2] 2004

Table 1: Factors associated with experiencing discrimination in the preceding 12 months using multivariate logistic regression

Characteristic	No. participants	% discrimination	Adjusted odds ratio	95% CI	P
Age					
45+	97	26			
30-44	415	40	1.89	1.11 - 3.21	.019
<30	89	36	1.37	0.69 - 2.74	.373
Gender					
Males	326	33			
Females	261	43	1.56	1.09 - 2.23	.015
IDU status					
Never	129	29			
Past	260	39	1.47	0.91 - 2.39	.113
Current	211	40	2.03	1.18 - 3.48	.011
Consulted a GP	in last 12 months				
No	78	22			
Yes	520	39	2.60	1.44 - 4.71	.002
Referred to a sp	pecialist				
No	264	33			
Yes	330	41	1.74	1.18 - 2.55	.005

Cl= Confidence interval; ns= not significant at 0.05.