# Alcohol and other drug treatment experiences of hepatitis C-positive and negative clients: implications for hepatitis C treatment

Loren Brener and Carla J Treloar

**Abstract**

To assess whether HCV-positive clients perceive that alcohol and other drug (AOD) staff discriminate against them, this study compared the treatment experiences of 120 HCV-positive clients with those of 120 HCV-negative clients attending the same AOD treatment facility. Despite the overall findings of favourable attitudes of HCV-positive clients toward their health care workers, these attitudes were less positive than those of their HCV-negative counterparts. Clients with HCV also rated their interpersonal treatment by their health care workers less favourably. These findings suggest that HCV-positive clients' attitudes towards their health care workers and their experiences of differential treatment by these health care workers might be a barrier to HCV treatment uptake in AOD treatment facilities.

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**What is known about the topic?**

Hepatitis C virus (HCV) is a substantial public health issue in Australia and treatment uptake for HCV is low. One way to increase HCV treatment access and uptake may be to provide this treatment through existing alcohol and other drug (AOD) services which are accessed by large numbers of people with HCV. However, research has shown HCV discrimination to be prevalent in the health care sector, and this may be an obstacle to the successful delivery of HCV treatment in AOD facilities.

**What does this paper add?**

Through survey and focus groups, this study found that despite generally favourable attitudes of HCV-positive clients toward their health care workers, these attitudes were less positive than those of the HCV-negative counterparts.

**What are the implications?**

The findings suggest a need for incorporating consumers' views in service planning and training of health care workers to prepare them for the concerns and possible previous experiences of their clients.

BY THE END OF 2005 it was estimated that there were 225 000 Australians infected with hepatitis C virus (HCV), with 9700 new infections in 2005, most acquired through injecting drug use. HCV is an important public health concern, as is the provision of hepatitis C treatment to this group of people. HCV is treatable, with cure rates of 50%–80% depending on genotype and other factors.[1] However, treatment is long (24 or 48 weeks depending on genotype), with significant physical and psychiatric side effects, most notably depression.[2] Uptake of treatment in Australia is low, at around 3500 people per year.[3] Treatment numbers are required to be doubled to avert projections of significant health burdens and costs related to advanced liver disease in the coming decades.[4]

One area of the health service already in contact with high numbers of people with hepatitis C is the alcohol and other drug (AOD) sector. This sector is the focus of interest in Australia and elsewhere as the new site of delivery of HCV treatment.[5-7] However, we need to establish whether this would be an appropriate site to deliver HCV treatment and what the impedi-

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ments may be to this being a successful site of treatment delivery.

There is existing literature on the relationship between staff attitude and client experience in AOD services.[8-10] How clients view their treatment and their health care provider as well as their past experiences in the health care sector affect the quality of care and treatment outcomes. In addition, research has shown that people with HCV may experience prejudice and discrimination in the health care sector.[11-18]

Prejudicial attitudes of AOD health care workers towards HCV-positive clients are likely to influence their treatment of their clients with HCV. One way to determine if prejudice affects treatment is to compare the experiences within the same treatment facility of a group of clients who have HCV with those who do not. The goal of this study was to assess whether people with HCV report being treated differently by their health care workers in the same treatment facility than people without HCV. The research also examined whether these two groups of clients hold different attitudes towards their health care providers. This is an important first step to understanding the service delivery cultures in which HCV treatment may soon be delivered.

## Methods

### *Sample*

The sample consisted of 120 clients with HCV and 120 clients without HCV. These clients were recruited from the same treatment facilities Recruitment sites were concentrated around the Sydney metropolitan area.

Relevant facilities for recruitment were identified through networking and through the input of key informants. Fifteen sites were chosen to generate the sample of 240 clients (120 of each group) and included two hospital drug health departments, four drug and alcohol treatment facilities, three hospital liver clinics, five primary health care facilities for people who inject drugs and one general practice known to cater to clients who inject drugs. The services chosen were selected on the following basis — that they catered to a large number of HCV-positive clients, they were services which were receptive to research and they had the resources to facilitate data collection so that it occurred in an "arms length" manner (ie, health care workers talking to clients about the research, as the researcher could not ethically approach clients directly) as specified by the relevant Human Research Ethics Committees. Directors of these facilities were contacted and informed of the study and they then discussed the study with their staff. Two different strategies were utilised in recruiting clients via fliers placed in the waiting room of services with a contact number of the researcher should they be interested in participating, and via invitation from health workers who informed participants that the researcher would be at the service on a particular day and invited them to be present and participate in an interview. The second strategy was more successful, as very few participants contacted the researcher on receipt of the flier.

### *Procedure*

Data were collected during 2005. Participants who contacted the interviewer, or who arrived at the venue when the interviewer was conducting interviews, completed an interviewer-assisted questionnaire on laptop computer. The questionnaire had open and closed-ended questions assessing their treatment experiences at the facility they were attending and asked the participants to rate their treatment by their health care worker on a scale from 1 to 10 (lower numbers indicative of less positive treatment and higher numbers with more positive treatment). They were then asked a series of structured questions such as whether they found staff to be friendly, whether the waiting time was long and whether they were made to feel like they were pressuring the health care worker for medication (see the Box). The issues raised in the questionnaire were designed based on responses from three focus groups held with people who had hepatitis C and were also injecting drug users. The focus groups addressed the participants' experiences in the health care

**Questionnaire: experiences of treatment by health care workers**

| | HCV-positive | | HCV-negative | | | |
|---|---|---|---|---|---|---|
| **Questions/statements** | **M** | **SD** | **M** | **SD** | **F** | ***P<*** |
| 1. On a scale from 1–10, 1 being very poor and 10 being very good how would you rate your treatment by your health care worker?* | 8.00 | 2.08 | 8.58 | 1.75 | 4.90 | 0.05 |
| 2. Does your health care provider prescribe pain relief for you if you complain of pain?† | 2.25 | 1.26 | 1.87 | 1.12 | 4.37 | 0.05 |
| 3. How long do your consultations with your health care workers usually last?‡ | 3.30 | 1.25 | 3.22 | 1.21 | 0.25 | 0.65 |
| 4. Do you feel welcome when you go and visit your health care worker?† | 1.25 | 0.60 | 1.02 | 0.16 | 16.10 | 0.01 |
| Which one of the following concerns do you have when you go and see your health care worker?§ | | | | | | |
| 5. The staff should be more friendly | 1.29 | 0.56 | 1.12 | 0.35 | 7.69 | 0.01 |
| 6. The waiting time should be less | 1.53 | 0.70 | 1.47 | 0.66 | 0.58 | 0.45 |
| 7. I should not be made to feel like I will rob them | 1.29 | 0.60 | 1.08 | 0.30 | 11.78 | 0.01 |
| 8. I should not be made to feel like I am pressuring them for medications | 1.39 | 0.71 | 1.13 | 0.45 | 11.49 | 0.01 |
| 9. I should not be made to feel like I am a risk to their safety | 1.30 | 0.62 | 1.08 | 0.31 | 11.28 | 0.01 |
| 10. I should not be made to feel like I will not follow a treatment plan | 1.40 | 0.64 | 1.16 | 0.43 | 11.51 | 0.01 |

*Item 1 is scored on a scale of 1 to 10. †Items 2 and 4 are scored on a four-point scale ranging from always to never, lower numbers indicative of a more favourable response. ‡Item 3 is scored on a five-point scale with higher numbers indicative of more time spent with the health care worker. §Items 5 to10 are scored on a three-point scale ranging from not a concern to a major concern, lower numbers indicating less of a concern.

sector, and issues raised in the focus group discussions were used to inform the design of the structured items put to participants in the current study.

Participants were asked to respond to an open-ended question to examine whether clients had a complaint about their health care worker and if they thought that such a complaint would then be taken seriously, and if not, why not. Data were recorded on laptop computers using Media Lab[19] and responses were typed either by the participant or by the researcher.

Participants also completed a few other questions and tasks unrelated to the current paper. The questionnaires (and other tasks) were individually administered and whenever necessary the interviewer assisted the participant in completing the questions. The measures took between 10–15 minutes to complete. The majority of participants were interviewed at the treatment facility they were attending in a confidential space. For those participants who initially contacted the researcher by telephone, a suitable location was organised to conduct the interview. Participants were reimbursed $20 for time and effort in participating in this research. The study had ethics approval from the University of New South Wales Human Research Ethics Committee as well as from Sydney South West Area Health Service, South Eastern Sydney and Illawara Area Health Service (Central network and Northern network) and South Eastern Sydney and Illawara St Vincent's Hospital Human Research Ethics Committee.

## Results

### *Sample characteristics*

The HCV-positive sample consisted of 68 males and 52 females and the HCV-negative sample had 69 males and 51 females. For the HCV-positive group, the mean age was 38 years (SD, 9.02), while the mean age of the HCV-negative group

was 39 (SD, 13.24). HCV-negative participants had a slightly higher level of education (on average having completed the final year of high school) than the HCV-positive participants (on average having discontinued schooling between years 10 and 12) ($F_{1,234}=3.88$; $P=0.05$). The HCV-negative participants were also more likely to be employed (38%) than the HCV-positive participants (23%) ($\chi^2=6.76$; $P<0.01$. These demographic variables did not influence any of the analyses reported below, and are not reported further.

### *Attitudes towards health care workers and experiences in treatment facilities*

HCV-positive and HCV-negative client responses to the questions assessing experiences in the treatment facility were significantly different on 8 of the 10 items (see the Box). There were no differences in opinion between the groups regarding the consultation length and acceptability of waiting times. However, when asked to rate their interpersonal treatment by their health care worker, the HCV-negative clients gave a more favourable rating than the HCV-positive clients. HCV-positive clients also felt that staff were less likely to prescribe pain medication to them, that staff were less friendly towards them, and they also felt less welcome at the health care centre than did HCV-negative participants. Compared with HCV-negative clients, HCV-positive clients were more likely to report being made to feel that they would rob their health care worker, that they would pressure their health care worker for medications, that they would not follow a treatment plan, and that they would present as a safety threat (see Box).

### *Making complaints*

In relation to the question about whether the clients felt their complaint about the health care service would be taken seriously, 105 HCV-negative clients responded that they never had cause to make a complaint. The 15 participants who did respond to this item felt that their complaint would be taken seriously. On the contrary, many of the HCV-positive clients felt that their complaints were not attended to by staff. Of the 41 HCV-positive participants who responded to this question, 24 participants felt that staff would not take the complaint seriously or not believe the complaint. This they felt was primarily related to the association of their hepatitis C with their current or past history of injecting drug use:

> ... because they think we [injecting drug users] are all a joke, nothing we say to staff matters, [they] only listen when they want something out of you. (Participant 8b)

> ... because I'm an addict and feel that sometimes, health care workers may be thinking that I am trying to get opiates/benzos etc. (Participant 31b)

> ... because we are seen as drug addicts and intoxicated ... and we make up stories — they think we make up stories sometimes. (Participant 37b)

Four HCV-positive participants also felt that health care staff were too busy to take the complaints seriously and eleven others felt that staff did not care, were not interested or did not listen. While these participants did not specifically relate the reason for staff not attending to concerns to the drug use of the client group, it is relevant to note that none of the HCV-negative group mentioned any of these concerns and, as noted, the majority felt that staff would always listen to their complaints. Of the total HCV-positive sample, only two clients felt that staff would listen and take their complaint seriously. In the explanation provided by one of these participants it is evident that she relates this to her belief that she has been a "good" client and that is the reason why staff would listen to her complaint.

> I think I would be listened to. I know that I would be taken seriously because I have never caused any trouble here. (Participant 53b)

## Discussion

In this study, both groups of clients reported positive attitudes towards their health care workers, however HCV-positive clients still reported

less positive attitudes to their health care workers than clients without HCV being treated in the same facility. The clients' responses to the questions about their experiences at the health service also show some important differences between HCV-positive and HCV-negative client groups. While there were no differences in clients' perceptions of waiting times and consultation length, HCV-positive and HCV-negative clients reported differences in other aspects of perceived staff attitude and behaviour. These differences are grounded in stereotypical characterisations of people who inject drugs, for example stealing, safety threats, shopping around for prescription medication, not following treatment requirements and pressuring staff for medications.

This finding suggests that these HCV-positive clients may have internalised the negative views held by society about injecting drug users as they perceived health care workers to discriminate against them on the basis of stereotypical behaviours associated with injecting drug users but not on other general concerns such as the waiting times and length of consultations.[20-22] The relevance of internalised stigma is that the stigmatised group may come to believe that the stigma is deserved and that their group is less socially valuable than other groups. Group devaluation may impact negatively on personal self-esteem and self-worth and at an institutional level can serve to justify experiences of discriminatory behaviour by health care workers.[23-24] This, in turn, may prevent people with HCV from accessing health care services and specialist AOD and HCV treatment facilities.[21]

The positive attitudes of HCV clients towards their health care workers found in this study may be a product of various factors. Since the release of the report into hepatitis C-related discrimination conducted by the Anti-Discrimination Board of NSW in 2001, there had been a focus on decreasing HCV-related discrimination among health care workers.[25-27] Health care workers may have recently become more aware of the way they relate to their clients with HCV and may be attempting to behave in a less discriminatory manner. A further consideration is that the data were collected in the Sydney metropolitan region. Sydney has the greatest concentration of injecting drug users and people with HCV in Australia.[28,4] Staff working at AOD facilities in metropolitan Sydney are more likely to have experience with these populations and with HCV, and to have had training to deal with HCV-positive people sensitively and sympathetically. Results may have been quite different if the sample had included regional or rural sites in New South Wales. However, in stating this, it must also be noted that analysis of other measures from these samples reported elsewhere revealed that there was no difference in client perceptions of treatment as a function of amount of contact that the health care workers had with HCV-positive clients.[29] That is, health care workers who had a bigger HCV-positive client caseload did not appear to be treating their HCV-positive clients better than those who saw very few HCV-positive clients.

A final point to note in this regard is that the attitudes of HCV-positive clients towards their health care providers could have been influenced by the context in which data were collected. Clients were mostly interviewed at the treatment facility, albeit in private spaces. This association between the research and the treatment facility may have led clients to feel compelled to give a favourable account of their health care workers and their treatment experiences. Despite these concerns, the data still show a pattern of differences in the reported treatment of HCV-negative and HCV-positive clients by their health care workers.

This study has shown that clients with HCV are treated differently and not quite as well as clients without HCV by staff at AOD health care facilities. The strength of this study lies in the design of matching HCV-positive clients and HCV-negative clients to a treatment facility and comparing their experiences. These reported differences have been enhanced by the commentary provided in open-ended response which highlights the association between hepatitis C and injecting drug use and shows that HCV-positive clients feel that they are not listened to (their complaints are not taken seriously) primarily because of their past or

present injecting drug use. Moral judgements about people who inject drugs contribute to the negative images associated with this population.[30] People who inject drugs are seen as spreading bloodborne viruses with their injecting practices or engaging in criminal activities to sustain their drug use. They often are portrayed in the media as "junkies" who inject in dark alleys and pollute mainstream society with their "chaotic" behaviour and drug-related illnesses which they have brought upon themselves.[31-32]

It would be interesting to address these issues in a more detailed manner, and future research would do well to include in-depth interviews with HCV-positive and HCV-negative clients as well as with their health care workers at the services they are attending. Such interviews would provide more insight into the differences in how these two groups are treated by staff from both a client and from a health care worker perspective. Future research with detailed investigation of factors associated with attitudinal data would be useful.

The attitudes of health care workers are known to have an impact on treatment outcomes in drug and alcohol treatment settings.[9] The current research shows differences in the ways in which people with and without HCV report being treated by health care workers, and from clients' reports this difference in treatment relates to their history of injecting drug use. Indeed, the data show that these reported differences are related to behaviours that are stereotypically associated with injecting drug users. The findings of this study have relevance not only for current therapeutic programs offered for people with hepatitis C but also in rolling out hepatitis C treatment through drug and alcohol services, which will require more and different interactions between staff and clients. The success of this attempt to increase uptake of hepatitis C treatment will be, in part, dependent on facilitative relationships between drug and alcohol staff and clients.

The success of such endeavours has been related in part to staff knowledge of the issues, concerns, and difficulties that face people who inject drugs.[33-34] However, the data illustrate that despite this expertise, AOD staff may still have difficulties in dealing equitably with people who inject or have injected drugs and have HCV. Alternatively, people who inject drugs may anticipate that health care workers will discriminate against them, and they may relate to health care workers in ways that confirm this.[35] HCV-positive clients' perceptions of health care workers' attitudes and behaviour may be related to past discriminatory experiences or fear of future discrimination. This is not to denigrate HCV-positive clients' perceptions as baseless. Whatever the case, this research highlights the need to take into account the client or user perspective and to incorporate this into an understanding of how best to work with people with HCV. As others have noted, there is a vast difference between the perceptions and experiences of illicit drug users and those who design and provide drug treatment services.[36] Without an understanding of the users' perspective there is great risk of services being mistargeted for those who require them, and of the evaluation of those services missing, or misrepresenting, their value to clients. Our findings also point to a need for careful training of health care workers who will engage with this population to prepare them for the concerns and possible previous experiences of their clients.

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## Competing interests

The authors declare that they have no competing interests.

## References

1 Manns M, McHutchison J, Gordon S, et al. Peginterferon alpha-2b plus ribavirin compared with interferon alpha-2b plus ribavirin for initial treatment of chronic hepatitis C: a randomised trial. *Lancet* 2001; 358: 958–65.

2 Price S, Goyette J. Role of the psychiatrist in the care of patients with hepatitis C and HIV/AIDS. *Psychiat Q* 2003; 74: 261-76.

3 National Centre in HIV Epidemiology and Clinical Research. HIV/AIDS, viral hepatitis, and sexually trans-

missible infections in Australia annual surveillance report 2008. Sydney: National Centre in HIV Epidemiology and Clinical Research, University of New South Wales, 2008.

4 National Centre in HIV Epidemiology and Clinical Research. Hepatitis C Virus Projections Working Group: estimates and projections of the hepatitis C virus epidemic in Australia 2006. Canberra: Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis C Sub-Committee, 2006.

5 Astone-Twerell J, Strauss S, Hagan H, Des Jarlais D. Drug treatment programs' HCV service delivery to their HCV positive clients. *Addict Res Theory* 2006; 14: 289-302.

6 Dore GJ. Enhancing hepatitis C treatment uptake and outcomes for injection drug users. *Hepatology* 2007; 45: 3-4.

7 Matthews G, Kronberg I, Dore G. Treatment for hepatitis C virus infection among current injection drug users in Australia. *Clin Infect Dis* 2005; 40 Suppl 5: S325-9.

8 Caplehorn J, Hartel D, Irwig L. Measuring and comparing the attitudes and beliefs of staff working in New York methadone maintenance clinics. *Subst Use Misuse* 1997; 32: 399-413.

9 Caplehorn J, Lumley T, Irwig L. Staff attitudes and retention of patients in methadone maintenance programs. *Drug Alcohol Depend* 1998; 52: 57-61.

10 Reid G, Crofts N, Hocking J. Needs analysis for primary health care among the street drug using community in Footscray. Melbourne: The Centre for Harm Reduction, Macfarlane Burnet Centre for Medical Research, 2000.

11 Hopwood M, Treloar C, Bryant J. Hepatitis C and injecting-related discrimination in New South Wales, Australia. *Drugs Educ Prev Policy* 2006; 13: 61-75.

12 Taylor L. Hepatitis C: social justice concerns and global health needs. *Rural Soc Work* 2001; 6: 54-62.

13 Anti-Discrimination Board of New South Wales. C change: report of the enquiry into hepatitis C related discrimination. Sydney: 2001.

14 Crofts N, Louie R, Loff B. The next plague: stigmatisation and discrimination related to hepatitis C infection in Australia. *Health Hum Rights* 1997; 2: 86-97.

15 Day C, Ross J, Dolan K. Hepatitis C-related discrimination among heroin users in Sydney: drug user or hepatitis C discrimination? *Drug Alcohol Rev* 2003; 22: 317-21.

16 Gifford S, O'Brien M, Bammer G, et al. Australian women's experiences of living with hepatitis C virus: results from a cross-sectional survey. *J Gastroenterol Hepatol* 2003; 18: 841-50.

17 Hopwood M, Treloar C. The 3D project. Diagnosis, disclosure, discrimination and living with hepatitis C. National Centre in HIV Social Research, Monograph 6. Sydney: University of New South Wales, 2003.

18 Treloar C, Hopwood M. Infection control in the context of hepatitis C disclosure: Implications for education of health professionals. *Educ Health (Abingdon)* 2004; 17: 183-91.

19 Jarvis W. MediaLab v2004 [computer software]. New York. Empirisoft Corporation, 2004.

20 Gilmore N, Somerville M. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming "them" and "us". *Soc Sci Med* 1994; 39: 1339-58.

21 Lawless S, Kippax S, Crawford J. Dirty, diseased and undeserving: the positioning of HIV positive women. *Soc Sci Med* 1996; 43: 1371-7.

22 Lee R, Kochman A, Sikkema K. Internalized stigma among people living with HIV-AIDS. *AIDS Behav* 2002; 6: 309-19.

23 Buchanan J, Young L. The war on drugs — a war on drug users? *Drugs Educ Prev Policy* 2000; 7: 409-22.

24 Crocker J, Major B, Steele C. Social stigma. In: D Gilbert, S Fiske, G Lindzey (eds.). The handbook of social psychology, 4th edition. Boston: McGraw-Hill Companies, 1998: 504-53.

25 Department of Health and Aged Care. National Hepatitis C Strategy 1999–2000 to 2003–2004. Canberra: Commonwealth of Australia, 2000.

26 Department of Health and Aged Care. National Hepatitis C Strategy 2005–2008. Canberra: Commonwealth of Australia, 2005.

27 Wilkins R. NSW hepatitis C anti-discrimination project. December 2002–June 2003. Sydney: Workforce Development Program in Hepatitis, HIV and Sexual Health, 2003.

28 Hall W, Ross J, Lynskey M, et al. How many dependent heroin users are there in Australia? *Med J Aust* 2000; 173: 528-31.

29 Brener L, von Hippel W, Kippax S. Prejudice among health care workers toward injecting drug users with hepatitis C: does greater contact lead to less prejudice? *Int J Drug Policy* 2007; 18: 381-7.

30 Room R. Stigma, social inequality and alcohol and drug use. *Drug Alcohol Rev* 2005; 24: 143-55.

31 Elliott A, Chapman S. "Heroin hell of their own making": construction of heroin users in the Australian press 1992-97. *Drug Alcohol Rev* 2000; 19: 191-201.

32 Krug G. HCV in the mass media: the unbearable absence of meaning. In: NK Denzin (Ed) Cultural Studies: a research volume. Vol 2. London: Jai Press Ltd, 1997: 91-108.

33 Sylvestre D. Injection drug use and hepatitis C: from transmission to treatment. *Psychiatr Ann* 2003; 33: 377-82.

34 Zweben J. Hepatitis C: education and counseling issues. *J Addict Dis* 2001; 20: 33-42.

35 Strenta A, Kleck R. Physical disability and the perception of social interaction: it's not what you look at but how you look at it. *Pers Soc Psychol Bull* 1984; 10: 279-88.

36 Montagne M. Appreciating the user's perspective: listening to the "Methadonians". *Subst Use Misuse* 2002; 37: 565-70.

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