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**Piloting peer-delivered hepatitis C testing and
counselling based at a needle and syringe program.**

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[OH-1]

INTRODUCTION [OH-2]

Thirty-five per cent of injecting drug users (IDUs) who participated in the 1998 Australian Needle and Syringe Program survey reported that they had not been tested for hepatitis C in the previous 12 months, and 16% had never been previously tested. Given that injecting drug use is the major risk factor for hepatitis C infection in Australia, and an estimated 50% of Australian IDUs have already been exposed to hepatitis C these proportions of IDUs who have never or only infrequently been tested are cause for concern. It is possible that incomplete coverage of testing is causing the true prevalence of hepatitis C in IDUs to be underestimated, as has been shown to occur for HIV

Extending hepatitis C testing coverage among IDUs will require careful consideration of the peculiar characteristics, experiences and needs of this extremely marginalised group. IDUs commonly experience a range of barriers to testing, and many who are successful in obtaining testing report dissatisfaction with the procedure. Recent research has confirmed a wealth of anecdotal evidence of antipathy to formal health services and clinical settings (where hepatitis C testing is readily available) on the part of many IDUs. There is clearly room for improvement in the ways in which hepatitis C testing and counselling are made available to IDUs. In this paper we report on a pilot project which provided hepatitis C testing and counselling at a needle and syringe program, and discuss the implications of the data and experiences generated for the potential provision of this service in future.

METHODS

Our pilot hepatitis C testing and counselling service was based at Western Region AIDS & Hepatitis Prevention (WRAP), a busy needle and syringe program located in Footscray, in Melbourne's west. (Footscray is a socioeconomically disadvantaged area and currently hosts an active street drug market.) As an accredited HIV and hepatitis C test counsellor and a trained venepuncturist, I offered free hepatitis C testing and counselling to IDUs visiting WRAP from August 1999 to end January 2000. IDUs who had never had a hepatitis C antibody test, or had tested negative but more than 12 months prior to contact, and those who had never received or properly understood a test result were eligible for free testing. Eligible people were invited to complete a questionnaire which covered reasons for not getting tested, barriers to testing, knowledge of hepatitis C, drug injecting history and other risk behaviour for blood-borne virus transmission. Pre- and post-test counselling accompanied every test, and additional information and support was provided whenever requested. Tested participants were asked to return to receive their results ten days after their interview. IDUs who did not meet the eligibility criteria were nevertheless able to take advantage of free counselling about hepatitis C.

The testing and counselling service was advertised primarily by visual materials at WRAP and by staff alerting IDUs to its existence.

Flyers were added to the bags in which WRAP users received their needles and syringes, and the service was advertised in the Hepatitis C Council publication 'Good Liver'.

Counselling protocols

Pre- and post-test hepatitis C counselling was delivered along standard lines. In addition, all 47 tested IDUs were given structured educational counselling about hepatitis C; this was also offered to IDUs encountered in the project who were not eligible for testing but who wanted information.

Serological testing and data analysis

Venous blood specimens were screened for hepatitis C antibodies by the Victorian Infectious Diseases Reference Laboratory using an Abbott 3rd-generation Enzyme Immuno-Assay.

Wilcoxon matched-pairs signed-rank tests were used to assess the significance of mean differences in responses from IDUs interviewed twice.

[OH-3]

RESULTS

Our results are divided into three sections: information about the 47 IDUs who received hepatitis C testing and counselling; an evaluation of risk behaviour change reported by the 20 IDUs interviewed twice; and an exploration of the concerns expressed by individuals encountered in 310 counselling episodes.

The 47 tested IDUs

The IDUs interviewed and tested at WRAP differed little from IDUs surveyed in a recent research project conducted in Footscray . Ages at interview ranged between 16 and 48 years with a median of 22; 33 (70.2%) were male; 29 (61.7%) were unemployed; most (68.1%) were single or not living with their regular sexual partner. Nine (19.1%) had been in prison or a YTC.

Test results

Overall, 28 of 47 venous samples (59.6%) had evidence of HCV exposure. Of the 38 IDUs who had not previously been tested or given a test result, 21

(55.3%) were antibody-positive. Of the 29 individuals *never* previously tested, 14 (48.3%) had been exposed to HCV.

[OH-4]

Injecting behaviour

Median duration of injecting was three-and-a-half years (mean 4.7, range 0.5-20.1); 68.1% had been injecting for fewer than five years. The median number of injections reported in the week before interview was eight (mean 11.4). Forty-five (95.7%) described themselves as primarily heroin injectors, one reported using heroin and amphetamines equally often, and one was an amphetamine user. Twelve had injected amphetamines in the month prior to interview. Twenty-three people (48.9%) said they usually injected "on the street" (which included in a park or public toilet, on a beach, in a car or a derelict building), the rest usually injected at home or at a friend's home. Nine (9.1%) had injected with someone else's needle in the past month, and 27 (57.4%) had ever done so. Of 20 people who claimed never to have used a needle and syringe which had already been used by someone else, six (30.0%) had been exposed to hepatitis C antibodies.

[OH-5]

Reasons given for never being tested for hepatitis C

Twenty-nine people had never been tested for hepatitis C antibodies. Four of those 29 had been injecting for eight or more years.

Twelve people said they had not been tested because they did not think they were at risk, yet three of these had used someone else's needle to inject in the month prior to interview, and six had ever done so. Six of the 12 (including two who claimed never to have shared a needle) tested positive for HCV antibodies. Four justified their answer by saying they had not been injecting drugs for long (six months to a year), but two of them tested positive.

[OH-6]

Other reasons given for not previously being tested were lack of an appropriate testing situation (six responses), never having given hepatitis C testing any thought (four), that hepatitis C was not worth worrying about (three), lack of knowledge about hepatitis C (two), and fear of getting a positive result (one).

Eighteen interviewees said they had a regular doctor; five said they had felt unable to ask him or her for hepatitis C testing because of fear of disclosure of drug use and the (perceived) likelihood of discrimination.

Reasons for being tested

Reasons given for wanting to be tested in the pilot program (respondents could supply more than one) were condensed to four broad factors. Convenience and

ease of testing in the pilot program were cited by 32 people (68.1%); thirteen (27.7%) said they felt comfortable at the prospect of being tested by a peer in a familiar environment; ten (21.3%) were uncomfortable about disclosing their IDU status to their regular doctor or expected to be poorly treated in clinical settings; nine (19.1%) were motivated by a recent risky incident.

[OH-7]

Effects of testing and counselling on behaviour

Twenty IDUs were re-interviewed to establish whether counselling had improved their knowledge of hepatitis C and whether their risk behaviour and injecting practices had altered. The median time between interviews was 73 days (mean 85, range 23-204).

At each interview respondents were asked to describe ways in which hepatitis C virus could be transmitted from person to person. The numbers of correct responses (including "blood", "blood of an infected person", and "sharing needles") were totalled and compared serially. Correct response totals were significantly greater in the second interview (means 2.4 vs. 5.4, $p < 0.005$). Qualitative improvement was also discernible in the answers supplied when respondents were asked what they knew about hepatitis C across their two interviews. Six respondents who could give no information about hepatitis C transmission at interview one were able to say, at interview two, that the virus was spread by blood contact and that using other people's injecting equipment was a risk. Another ten who initially demonstrated some basic knowledge gave significantly more detailed and accurate answers at interview two. Understanding of the potential health effects of hepatitis C infection also markedly improved between interviews for most individuals, with nine who initially had no or extremely limited knowledge being able at interview two to identify the liver as the organ affected and supply other details about the natural history of infection. Although there was no evidence of regression, the degree of retention of knowledge imparted during pre- and post-test counselling was quite variable and unrelated to length of time between interviews.

Reported injecting practices and risk behaviour improved across pairs of interviews. Five individuals had used someone else's needle and syringe in the month prior to their first interview but only two had done so in the time to their second (mean 90 days, range 34-126). (Unlike the three people who did not report sharing at interview two, the repeat sharers habitually scored and injected in street settings, and described desperate circumstances surrounding the occasion at which they had last shared, so they had vastly less ability to effect behaviour change.) Mean reported frequency of use of a new needle and syringe improved significantly between interviews (60.0% of occasions at interview one vs 84.2% at interview two, $p < 0.01$). (Re-using syringes carries risks of septicaemia, and means injecting partners can mistakenly use each other's syringe or contaminate shared drugs and injecting paraphernalia.)

Frequency of hand washing after injecting (27.5% of occasions vs 43.4%, $p < 0.05$) also significantly improved. Most of the 20 repeat interviewees received their antibody test results well before their second interview (the mean time between receipt of results and second interview was 76 days, while the mean time between interviews was 85 days), so receipt of test results may well have influenced subsequent behaviour.

Almost everyone receiving their first-ever hepatitis C antibody result exhibited an extremely strong emotional response. IDUs who had assumed they had not been exposed to hepatitis C expressed horror and/or disbelief at an antibody-positive result, while those who expected a positive result were elated at testing negative. The strength of the typical response meant that counselling had to be carefully delivered to get the appropriate prevention messages across. Our data show no difference between the degree of behaviour change and positive or negative hepatitis C test results, suggesting that IDUs who had their positive status confirmed or revealed generally reacted to subsequent counselling in the desired manner - by reducing frequency of behaviour which could lead to transmission. Conversely, overall improvement in reported behaviour by antibody-negative IDUs can be interpreted as resulting from new incentive to avoid hepatitis C exposure.

[OH-8]

Counselling of non-tested IDUs

Three hundred and ten counselling episodes took place during the six months of the project's operation, and this activity consumed the majority of my time.

Many IDUs requesting counselling were seeking practical, jargon-free information about testing (including PCR and liver function tests). Others had known their hepatitis C status for years but wanted more detailed and personalised information about their prognosis or managing an infection. Many reported symptoms of hepatitis C infection ranging from minor early symptoms to more serious advanced ones, but none had ever had a liver function test and few had consulted a doctor about their infection since their initial diagnosis. Many displayed a frightening lack of knowledge and confusion about hepatitis C. Questions regularly asked during counselling included:

- Is the virus in the dope?
- Can I have children?
- Can I have sex?
- Do I need to seek out old sex partners and tell them about my infection?

Surprisingly poor knowledge on the part of many people who had been recently tested for hepatitis C was partly explained by the lack of associated counselling. A disturbingly high proportion of people claimed to have received no pre- or post-test counselling when tested by their methadone prescriber or GP, and

some claimed medical practitioners had given them what they later discovered was wildly inaccurate information about hepatitis C. Many described not being believed by health care workers when asking for help or being aware of harshly judgmental attitudes toward them following disclosure of their drug use or hepatitis C status.

All counselling episodes were initially directed at hepatitis C issues, but almost invariably other issues related to illicit drug use were covered. Discussions frequently ranged over problems with housing, finances, the law, relationships, employment, licit drugs, mental and physical health - all in some way tied to illicit drug use.

These counselling sessions brought home the extent to which hepatitis C issues are entwined with all the other difficulties faced by injecting drug users. Problems are compounded by others in ways which are only discussed when the user feels secure in a counselling environment and confident that their counsellor understands them. As an illustration of the strength of feeling which exists about this issue, several long-term IDUs told me that they would often ask a new counsellor if he or she had ever injected drugs and if not, make an excuse and leave. Their experience was that people without direct knowledge of injecting drugs could not fully comprehend their problems and would often make impractical or even stupid suggestions about possible solutions. Other comments to similar effect were commonly made by IDUs during counselling.

Overdose response

At the time of our project's operation, WRAP staff were not trained or resourced to deal with overdoses, and my first aid training and experience meant that I was called often when an IDU overdosed in or close to WRAP. I attended 15 heroin-related overdoses during the course of the project, on most occasions administering Cardio-Pulmonary Resuscitation while waiting for an ambulance. In two cases, the condition of the patient was such that the user was unlikely to have survived without intervention.

DISCUSSION

Hepatitis C is the most common serious viral infection in Australia, and is responsible for significant health care costs. While there are some indications that prevalence among injecting drug users is falling, IDUs remain the population most profoundly affected by hepatitis C - at least 85% of diagnoses are in current or former IDUs. As our data and previous research show, even people who have been injecting for only a short time are at risk of infection, and even people who report never injecting with a shared needle and syringe can be exposed to the hepatitis C virus. To reduce the social and economic costs of

hepatitis C infection, we must extend the reach of hepatitis C testing and counselling and further reduce the number of IDUs who do not use or have access to these services. Antibody-negative IDUs need to be made aware of their status and enabled to remain free of the virus in future, and antibody-positive IDUs must be educated and encouraged to prevent further transmission and to ameliorate the potential consequences of their own exposure.

Our repeated finding that IDUs are comfortable being tested and counselled by a peer in a familiar and convenient environment has obvious implications for service delivery, especially for IDUs not previously tested. In these circumstances factors such as the illegality of heroin use and fear of stigma are negated, and IDUs feel able to discuss their lives at levels of depth and detail which rarely occurs under more formal or clinical conditions, thus the potential for the counsellor to address people's problems is vastly enhanced. It follows that educational counselling received from a credible and empathetic peer has a high probability of being absorbed and acted upon; our findings of increased knowledge about hepatitis C, reduced needle-sharing and improved injecting hygiene following counselling bear this out.

NSP staff are in more frequent contact with IDUs than any other workers in this field. By carrying out their duties in a non-judgmental manner, NSP workers rapidly gain the trust of the people they serve, learn about them and can empathise with them. For these reasons, NSP staff have the potential to deliver a greater range of services than they currently do. But giving NSP staff extra skills is useless if they do not have the time to undertake any additional tasks. Our experience demonstrates that IDUs will make use of hepatitis C testing and counselling (and counselling about drug use issues in general) when this service is provided in an appropriate and accessible manner. Furthermore, NSP staff regard a trained and experienced peer counsellor as a valuable resource. We have presented evidence that high-quality counselling can effect behaviour change in IDUs. The logical conclusion to be drawn from our results is that primary NSPs should be resourced to employ an extra staff member to deliver testing and counselling for hepatitis C and other blood-borne viruses and deal with overdoses (or alternatively to train an existing staff member and employ an extra NSP worker). Such a development would be a useful initial step towards improved primary health care for drug users, and generate further information about modes of delivering services to this marginalised population.

Abstract**Piloting peer-delivered hepatitis C testing and counselling at a needle and syringe program****Michael Kerger, Campbell Aitken and Nick Crofts**

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Between August 1999 and January 2000 the authors piloted the provision of a free peer-based hepatitis C testing and counselling/education service at Western Region AIDS and Hepatitis Prevention (WRAP) Footscray's primary needle & syringe program (NSP). The project was funded by NH&MRC grant #983608. This service (which as far as we know has never been established or trialled elsewhere) proved popular among WRAP clients, who requested and received more than 300 counselling episodes in six months. In addition, it provided support for busy NSP workers, who often did not have the time or specialised knowledge to respond to such requests. Forty-seven IDUs who had not had a hepatitis C antibody test in the previous 12 months - including 29 never-tested - were given tests and pre and post-test counselling. They were interviewed about reasons for not getting tested, knowledge of hepatitis C, and risk behaviour as well as barriers to safe use. Most people were attracted by the convenience and suitability of testing in the pilot program. The most common reason for never previously being tested was "didn't think I was at risk", but reported risk behaviour and test results showed otherwise. The effect testing and counselling had on risk practices was evaluated and found to be beneficial in several important respects. Our results suggest that NSPs are practical locations for hepatitis C testing, counselling and education (and potentially other primary health care services), and are more acceptable and appropriate to IDUs than traditional health services.

[241 words]

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Piloting peer-delivered hepatitis C testing and counselling based at a needle and syringe program.

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Australian Needle and Syringe Program survey-1998*

•Surveyed IDU Not tested for HCV.

In last 12 months	35%
Ever	16%

•Est. 50% of Australian IDUs have already been exposed to hepatitis C

MacDonald et al. Medical Journal of Australia 2000;172:57-61

Eligibility criteria for HCV Antibody testing

IDUs

- Who had never had a hepatitis C antibody test
- or*
- Who had tested negative but more than 12 months prior to contact
- or*
- Who had never received or properly understood a test result

*MacDonald M & the Collaboration of Australian NSPs,
HIV and HCV antibody prevalence among IDU attending selected needle and syringe programs in Australia,
1995 - 1999.

National Centre in HIV Epidemiology and Clinical Research, September 2000.

Tested IDU's

Total number IDU tested	= 47 (+ 1 non IDU disregarded*)	
Ages	16 – 48 years (median 22)	
Male	33	(70.2%)
Female	14	(29.78%)
Unemployed	29	(61.7%)
Single	32	(68.1%)
Prison/YTC	9	(19.1%)

Testing results

**One non IDU was a gay man from NZ who chose this method of testing as he felt it would be free of judgment regarding risks he faced from his preferred sexual practices*

Injecting Behaviour

•Duration of injecting	Median	3.5	years
	Mean	4.5	years
	Range	0.5-20.1	years
	< 5 years	68.1%	
•No.of injections in last week	Median	8	
	Mean	11.4	
•Primarily heroin injectors		45	(95.7 %)
•Injected speed in last month		12	(25.53%)
•Usually injected “on the street”		23	(48.9 %)
•At home or friend’s home		24	(51.1 %)
•Injected with someone else’s needle	In last month	9	(19.14%)
	Ever	27	(57.4 %)
•Never used syringe used before by someone else		20	(42.55%)
Of these	Ab +ve	6	(30%)

Reasons for never being tested

- **4** of **29** never tested for HCV had been using for **8+ years**
- Didn't think they were at risk **12**
- Of these.....used someone else's needle
 - Last month* **3**
 - Ever* **6**
 - HCV Ab +ve* **6**
- **4** Said by way of explanation they hadn't been injecting for long (6-12 months)
of these
- **2** Tested HCV Ab +ve

Other reasons for not being tested

- Lack of appropriate testing situation (6)
- Never thought about it (4)
- HCV not worth worrying about (3)
- Lack of knowledge about HCV (2)
- Fear of a positive result (1)

*18 Said they had a regular doctor

5 Feared disclosure or discrimination by doctor

Reasons for being tested

- Convenience & ease of testing 32 (68.1%)
- Felt comfortable with peer in familiar environment 13 (27.7%)
- Felt uncomfortable disclosing to regular doctor 10 (21.3%)
- Motivated by recent risk 9 (19.1%)

Effects of testing and counselling on behaviour

- **20** IDUs reinterviewed

- Time between Interview 1 & Follow up

Median **73** days Mean **85** days (Range.23-204)

- Correct response totals significantly greater in the 2nd interview

(means 2.4 vs. 5.4, $p < 0.005$)

- Discernible qualitative improvement in HCV knowledge across two interviews.

- No evidence of regression

- Retention of knowledge imparted during pre- and post-test counselling was variable and unrelated to length of time between interviews.

- Reported injecting practices and risk behaviour improved across pairs of interviews

- Mean reported frequency of use of a new needle and syringe improved significantly between interviews

(60.0% of occasions at interview one vs 84.2% at interview two, $p < 0.01$)

- Most received test results well before 2nd interview, so receipt of test results may have influenced subsequent behaviour.

Effects of testing and counselling on behaviour

- Almost everyone receiving their first-ever hepatitis C antibody result exhibited an extremely strong emotional response
- IDUs who had assumed they had not been exposed to hepatitis C expressed horror and/or disbelief at an antibody-positive result
- Those who expected a positive result were elated at testing negative
- No difference between the degree of behaviour change and positive or negative hepatitis C test results
- IDUs who had positive status confirmed or revealed reacted to subsequent counselling by reducing frequency of risky behaviour
- Antibody-negative IDUs developed new incentive to avoid HCV exposure.

Counselling of non-tested IDUs

- 310 Counselling episodes over 6 months of project
- Many were seeking practical, jargon-free information about testing (including PCR and liver function tests)
- Others wanted more detailed and personalised information about their prognosis or managing an infection

Questions regularly asked during counselling incl.:

- Is the virus in the dope?
 - Can I have children?
 - Can I have sex?
 - Do I need to seek out old sex partners and tell them about my infection
-
- Many reported **no** pre- or post-test counselling when tested by methadone prescriber or GP
 - Many got inaccurate information about hepatitis C
 - not being believed by health care workers or judgmental attitudes
 - problems with housing, finances, the law, relationships, employment, licit drugs, mental and physical health - all in some way tied to illicit drug use
 - hepatitis C issues entwined with all the other difficulties faced by injecting drug users
 - Problems are compounded by others in ways which are only discussed when the user feels secure in a counselling environment and confident that their counsellor understands them