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Injecting Drug Users' Understanding of Hepatitis C

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INJECTING DRUG USERS' UNDERSTANDING OF HEPATITIS C

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ABBREVIATIONS

A&TSI	Aboriginal and/or Torres Strait Islander
ALT	Alanine aminotransferase test
BBVI	Blood-borne viral infection
GP	General Practitioner
HBV	Hepatitis B virus
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
IDU	Injecting drug user
IDUQOL	Injection Drug User Quality of Life scale
LFT	Liver Function Test
NDARC	National Drug and Alcohol Research Centre
NSP	Needle and syringe program
NUAA	NSW Users and Aids Association
PCR	Polymerase chain reaction
QOL	Quality of life
SD	Standard deviation

EXECUTIVE SUMMARY

Most Australians who have hepatitis C contracted the virus through the shared use of drug injecting equipment. Further, the prevalence and incidence of hepatitis C virus (HCV) are high among Australian injecting drug users (IDUs), around 50 to 60 percent and 15 percent respectively. The task, therefore, of controlling the spread of hepatitis C depends largely on controlling transmission among IDUs. Although there is a considerable body of research describing hepatitis C epidemiology and infection risk factors, very little research has examined IDUs' understanding of hepatitis C. The aim of the current study, therefore, was to examine IDUs' knowledge of hepatitis C, their understanding of virus transmission, the clinical markers and symptoms of the virus, and treatment in particular. How IDUs prioritise hepatitis C relative to other life areas was also examined.

A cross-sectional survey, using an interviewer administered, structured questionnaire, was conducted across inner-city, suburban and regional sites of New South Wales. Participants were recruited through advertisements at needle and syringe programs (NSPs), methadone clinics, and snowballing (word-of-mouth) techniques. Participation was not determined by hepatitis C status.

One hundred and forty nine IDUs were interviewed. The median age of the sample was 34 years and approximately two-thirds were male. The median age of first drug injection was 17 years, with the most commonly reported illicit drugs injected in the last month being amphetamine (62%) and heroin (61%). Over half of the sample (62%) was in treatment for drug use at the time of interview, with the majority in a methadone or buprenorphine program. Over half the sample rated their knowledge and understanding of hepatitis C as either 'good' (30%) or 'very good' (23%).

Testing for hepatitis C was common among the sample, with all but one participant tested for hepatitis C in their lifetime, and the majority (74%) tested one or more times in the past 12 months. 'Routine screening' was the main reason selected for their last test (39%), followed by 'mandatory testing' (13%) and then 'risky behaviour' (12%). Seventy-six percent of the sample believed they had hepatitis C at the time of interview. Despite most participants reporting recent and often multiple testing, a number of IDUs were clearly confused about the results of the various tests. Only about 40 percent of those tested during or after 2000 reported receiving pre- and post-test counselling.

Significant gaps in IDUs' knowledge of hepatitis C were uncovered in the study, with respect to transmission risks, symptoms, clinical markers and treatment. For instance, substantial proportions of participants believed it was possible to contract hepatitis C by re-using their own needle (48%), or from dirt (17%). Forty-two percent of participants believed antibodies to hepatitis C gave protection against acquiring the virus (42%), and over one-third (35%) believed that some people are immune to hepatitis C. IDUs' understanding of their own hepatitis C infection was similarly confused, with one in five participants who reported having hepatitis C believing they could not infect others (19%), and that they were immune to hepatitis C (19%). One in three participants stated they did *not* have antibodies for hepatitis C, and an even greater number were unsure, despite reporting themselves to have hepatitis C.

Very few IDUs were found to prioritise hepatitis C highly relative to other life areas. For many IDUs, hepatitis C appears to be a relatively low priority compared with the numerous health, welfare and social concerns that exist among this often economically and socially marginalised group. However, health was frequently selected as one of the most important life areas determining quality of life, which may incorporate symptoms and sequelae resulting from hepatitis C impacting on day-to-day life.

Given the high prevalence and incidence of hepatitis C among Australian IDUs, and that many continue to share injecting equipment, the findings of this study are of great concern. The fundamental misconceptions held about hepatitis C, particularly regarding 'antibodies' and their perceived role in providing immunity, place IDUs at serious risk of transmitting and contracting hepatitis C. These findings warrant further development of, and research into, strategies to improve IDUs' understanding of hepatitis C.

1 INTRODUCTION

1.1 Background

The hepatitis C virus (HCV) was first identified in 1989 (Choo et al., 1989) and scheduled as a notifiable disease in Australia in 1990 (National Health and Medical Research Council, 1997). It has since emerged as one of the most frequently notified diseases in Australia (National Health and Medical Research Council, 1997) and poses a major public health challenge, both in Australia and globally (Kaldor et al., 2000).

The high prevalence and incidence of hepatitis C continue to result in large numbers of chronically ill people. At least half of those infected will go on to experience liver disease and, after approximately 20 years of infection seven percent will develop cirrhosis, and after 40 years of infection 20 percent will develop cirrhosis. Corresponding rates of mortality are one percent after 20 years and four percent after 40 years of infection (Dore et al., 2002). Hepatitis C has been implicated in the increasing rate of liver cancer in Australia (Law et al., 2000) and is the leading cause of end-stage liver disease (Kim, 2002).

Worldwide, approximately 170 million people are estimated to have chronic hepatitis C infection and there are three to four million new infections each year (World Health Organization, 2000). In Australia, an estimated 210,000 people were living with hepatitis C at the end of 2001 (Law et al., 2003), a figure which is expected to increase to between 321,000 and 836,000 by 2020 (Hepatitis C Virus Projections Working Group, 2002). The potential cumulative health care costs of hepatitis C infection over the next 60 years have been estimated at approximately $4 billion (Brown & Crofts, 1998).

Hepatitis C is a blood-borne infection and the majority of infections occur via parenteral transmission (for a full discussion of transmission and risk factors see MacDonald et al., 1996). In Australia, blood and blood products have been screened since 1990 and, therefore, the risk of medically acquired infection is very low (Dore et al., 2003). Other potential modes of infection include tattooing and body piercing, although when performed by professionals practicing infection control, the risk is significantly reduced. Household transmission via the shared use of toothbrushes and razors or other items where blood-to-blood exposure is possible is also a risk factor, but the actual risk of transmission via this mode is considered very low (Dore et al., 2003). Although sexual transmission is possible, the available evidence indicates only a very small number of cases are likely to have occurred via this mode in Australia (Sladden et al., 1997), and it is, therefore, considered low risk (Dore et al., 2003).

It is the shared use of injecting equipment by injecting drug users (IDUs) that is by far the most common mode of hepatitis C transmission in Australia, and this practice poses an extremely high risk of infection. According to national surveillance data, the proportion attributable to drug injection is approximately 90 percent (National Centre in HIV Epidemiology and Clinical Research, 2002). The task, therefore, of controlling the spread of hepatitis C depends largely on controlling transmission among IDUs (Crofts & Aitken, 1997). While prevention initiatives such as needle and syringe programs (NSPs) and methadone maintenance treatment have helped to maintain low prevalence and incidence of HIV among Australian IDUs, they have been less effective in stopping the spread of hepatitis C, which was already prevalent prior to the introduction and expansion of these programs (Dore et al., 2003).

1.2 Prevalence of hepatitis C among injecting drug users

Hepatitis C is the most prevalent blood-borne viral infection (BBVI) among Australian IDUs. The prevalence of hepatitis C among Australian IDUs has been continually high since the mid 1970s, estimated to be between 63% and 50% among needle and syringe programs attendees from 1995 to 1997 (MacDonald et al., 2000) and 54% in 2000 to 60% in 2004 (National Centre in HIV Epidemiology and Clinical Research, 2005).

1.3 Incidence of hepatitis C among injecting drug users

The incidence of hepatitis C is also high. Crofts and Aitken (1997) reported an incidence of 11 per 100 person years among a cohort of Victorian IDUs. Van Beek and colleagues (1998) reported an even higher incidence of 21 per 100 person years among young IDU clients attending a primary health care centre. Dolan et al. (2003) has reported a very high hepatitis C incidence of between 24 and 48 per 100 person years for prisoners, depending on whether they were in methadone treatment or not. More recently, Maher et al. (in press) reported an incidence of 30.8 per 100 person years among IDUs in South West Sydney. According to the Hepatitis C Estimates and Projections Working Group, the estimated annual incidence of hepatitis C is approximately 15% (Law et al., 2003).

1.4 Injecting drug users' knowledge of hepatitis C

The risk factors associated with hepatitis C infection among IDUs are relatively well established and include needle and syringe sharing, the sharing of injecting paraphernalia such as spoons, water and filters (known as 'indirect' sharing), incarceration, age, sex, ethnicity, length of injecting career and frequency of injecting, the injection of opiates and injecting practices and environments. Although there has been a plethora of research describing hepatitis C epidemiology and infection risk factors (for a review see Hocking et al., 2001), very few studies have examined IDUs' understanding of hepatitis C. This includes the way IDUs interpret the medical terms, clinical markers and symptoms associated with hepatitis C, the perceived risks of transmission, and their knowledge and experience of treatment.

Subsequent to acquiring hepatitis C, a person will produce hepatitis C antibodies. However, approximately a quarter of those initially infected with hepatitis C clear the virus, so not all those with hepatitis C antibodies are actually infected (or infectious), but anyone who has been infected (i.e. exposed), irrespective of whether or not they have cleared the virus, will have hepatitis C antibodies. Yet most diagnoses occur using only hepatitis C antibody testing, a polymerase chain reaction (PCR) test (testing for viral RNA) is required to determine viremia; it is only with this test that a person will know their actual status.

There is currently no vaccination against hepatitis C and no one is immune, including those who have had prior exposure and have since cleared the virus. This is in contrast to hepatitis B, where prior infection affords lifelong immunity (accept in cases of chronic infection, which occurs in about 5% of cases). All people actually infected with hepatitis C (but not simply those with antibodies), therefore, have the potential to pass on the virus. It is these issues which potentially cause confusion and, albeit limited, there is evidence that this may be the case.

One qualitative study involving 59 IDUs in London found there was much confusion and uncertainty surrounding hepatitis C, including its medical and transmission risks (Rhodes et al., 2004). Participants expressed confusion over the differences between various forms of hepatitis virus, the symptoms of hepatitis C, and said that they lacked knowledge about potential transmission risks associated with sharing injecting paraphernalia. Further, communication of hepatitis C testing and diagnosis was reported as poor, leaving many injectors confused or anxious as to the meaning and implications of their antibody status. Australian research has also found that IDUs presenting for hepatitis C testing often report receiving inadequate, or no, pre- and post-test counselling (Loxley et al., 2000), although there is some evidence of increasing dissemination of hepatitis C information by doctors at diagnosis (Hopwood & Treloar, 2003).

A North American study (Heimer et al., 2002) comparing HIV and hepatitis (B and C) knowledge found that, although IDUs were well aware of the nature, effects and consequences of HIV infection, they were ill-informed about hepatitis and hepatitis risk. The 493 inner-city IDUs surveyed for this study were almost three times more likely to respond 'don't know' to items assessing knowledge of hepatitis compared to HIV pertaining to routes of infection, detection of disease, viability of the organism within ambient environments, potential treatment and prevention measures.

Similarly, recent qualitative research conducted in Australia on the risks of injecting revealed that IDUs had a poor understanding of what it means to have hepatitis C infection (Southgate & Weatherall, 2003; Southgate et al., 2005). The IDUs were unclear about what it meant to have 'antibodies', with many participants believing this meant they had cleared the virus and, therefore, were no longer infectious. There was also noted confusion around the symptoms related to hepatitis C, and confusion with other BBVI and hepatitis viruses. For example: a number of IDUs believed that if they do not suffer jaundice they have not become infected with hepatitis C.

Southgate et al. (2003; 2005) found that many IDUs demonstrated a good technical knowledge of the transmission of hepatitis C, such as being aware of the risk of sharing needles and syringes. Indeed this is supported by an overall reduction in the prevalence of needle sharing in Australia (Crofts et al., 1996; Crofts & Aitken, 1997; MacDonald et al., 2000). However, a number of IDUs appeared to be confused and misinformed believing hepatitis C could be contracted from unhygienic practices such as using toilet water to inject or wash with or that it could be contracted from 'dirt'. Although highly informative, the limitations of this study include a small sample of IDUs (N=24) drawn from one, rather unique, inner-city Sydney setting (Kings Cross) and the collection of limited demographic and behavioural information. Therefore, further research is required to determine if these findings are consistent and the issues in particular that cause confusion.

1.5 Quality of life

Quality of life (QOL) is an important part of assessing and understanding the burden of disease and planning policy and evaluation (Brogly et al., 2003b; Muldoon et al., 1998). Although the definition of QOL is debated, there is consensus that QOL pertains to physical, psychological, and social functioning, and more recently that it includes abilities, relationships, perceptions, life satisfaction, and wellbeing (Berzon et al., 1993; Dauphinee, 1999).

Hepatitis C has been found to reduce health-related QOL (Foster, 2004; Thein et al., 2005) and is, therefore, likely to have an impact on overall QOL. IDUs face a number of complex health, welfare and social problems and despite the very high prevalence and incidence of hepatitis C among IDUs, it is just one of these many problems. Yet, there is currently little understanding of how IDUs prioritise hepatitis C relative to other life areas.

The Injection Drug User Quality of Life Scale (IDUQOL) was designed to measure QOL in IDU populations (Brogly et al., 2003b). The IDUQOL uses a subjective approach and, unlike most standardised QOL measures, allows for the individual to select the aspects that construct their QOL and to weight the importance of each aspect (Brogly et al., 2003b). It is therefore an ideal instrument to assess both quality of life among IDUs and also how hepatitis C is prioritised.

1.6 Study aims

In summary, there is a paucity of research describing IDUs' knowledge of hepatitis C and perception of transmission risks, although existing studies suggest that there may be significant gaps in their knowledge. A lack of knowledge of hepatitis C will prevent IDUs from implementing measures that could reduce their risk of contracting the virus and increase the likelihood of transmission to others. As noted by Southgate et al. (2005), IDUs "take up the clinical language of medicine and health promotion and actively use it to make sense of living with HCV and to assess the likelihood of infecting others".

The current study was undertaken to assess IDUs' understanding of hepatitis C using a quantitative approach and a sample drawn from inner-city, as well as suburban and regional settings. Specifically, the study aimed to examine IDUs' knowledge and understanding of:

1) hepatitis C transmission;
2) the symptoms and clinical markers of hepatitis C; and
3) hepatitis C testing and treatment.

The study also aimed to examine quality of life and how IDUs prioritise hepatitis C relative to other life areas using the IDUQOL.

2 METHODS

2.1 Participants and recruitment

Injecting drug users (IDUs) drawn from four sites, inner-city (Surry Hills, Sydney, NSW), outer metropolitan/suburban (Blacktown and Parramatta, Sydney, NSW) and regional NSW (Newcastle, NSW) were invited to participate in the research.

Participants were recruited through advertisements at needle and syringe programs (NSPs), methadone clinics, and snowballing (word-of-mouth). IDUs who reported injecting drug use at least once per month during the past six months, were aged 18 years or more and fluent English speakers were eligible. Participation was not determined by hepatitis C status (actual or perceived).

2.2 Instrument

A questionnaire was purposefully designed and pilot tested to obtain demographic information, drug use and treatment history, injecting behaviour and details of BBVI test history.

A series of questions examined IDUs' knowledge of hepatitis C and their understanding of having the virus including that of clinical terms and symptoms. Topic areas covered included blood-borne viral infection risks (based on the Opiate Treatment Index, Darke et al., 1991), sources of information used and experience of hepatitis C testing and treatment (where applicable). A series of true/false statements were also devised to elicit participants' beliefs about relative risks of transmission and their understanding of clinical markers and treatment.

An adapted form of the IDUQOL (Brogly et al., 2003b) was used to assess QOL, with the life area card 'Cure for AIDS' replaced with a card representing 'Hepatitis C'. This was done because a) the prevalence of HIV is low among Australian IDU (MacDonald et al., 1997; National Centre in HIV Epidemiology and Clinical Research, 2005) and, therefore, unlikely to be selected. Conversely, given the high prevalence of hepatitis C, it was of interest to examine how this would be rated. The IDUQOL is interviewer administered and consists of titled picture cards depicting 17 life areas and a response form. The life areas are: health, housing, partnership, family, money, resources, education, sex, friends, drugs, drug treatment, feeling good, being useful, independence and free choice, leisure activities, Hepatitis C, and spirituality. The IDUQOL has good psychometric properties (Brogly et al., 2003b; Brogly et al., 2003a) and has been found to be acceptable among Australian IDU (Kimber & Day, 2003). The IDUQOL took approximately 15 minutes to complete.

2.3 Procedure

The questionnaire was piloted with participants recruited through street press (n=15) and found to be acceptable with only minor amendments required. Pilot questionnaires were excluded from the analysis.

Interviews were carried out by trained interviewers (including some peers) employed by the National Drug and Alcohol Research Centre between July and September 2004. Excluding the IDUQOL (outlined below) the interview took approximately 30 minutes to complete. Referral to the NSW Hepatitis C telephone helpline was offered to all participants and debriefing, including appropriate and correct hepatitis C information, was provided at interview completion.

2.3.1 Injecting Drug Users Quality of Life (IDUQOL) scale

The IDUQOL begins by asking participants to rate their overall quality of life on a scale of 0 to 10, where 0 is the worst they can imagine and 10 is the best they can imagine. They are then asked to describe the five areas in their life that currently most determine their quality of life. The participant is then shown the life area cards and asked to select the cards depicting their five most important areas (which may not necessarily be the same five areas they identified independently) and asked to describe what each of these means to them (life area selection). Participants are then asked to apply a weighting to each of these areas by distributing 25 chips across the five cards, according to their relative importance, where more chips indicate a life area is more important (life area weighting). Participants are then asked to rate these life areas according to how well each life area is progressing on a scale of 0 to 100, where 0 is the worst they can imagine and 100 is the best they can imagine (life area rating). In the final part of the IDUQOL, participants are asked once again to rate their overall QOL on a scale of 0–10.

2.4 Ethics

All participants were volunteers, provided informed consent and were reimbursed A$30 for travel and time expenses. The reimbursement of participants is considered both necessary and ethical in illicit drug use research (Marsh & Loxley, 1992; McKeganey, 2001) and has not been found to coerce participants (Fry & Dwyer, 2001) or adversely affect drug use or data quality (Festinger et al., 2005). The research was approved by the Human Research Ethics Committees of the University of NSW and the three Area Health Services involved in the study (i.e. South Eastern Sydney, Western Sydney and the Hunter).

2.5 Data analysis

Continuous variables were assessed using *t*-tests. Medians are reported where data were highly skewed. The chi square (χ^2) statistic was used for univariate analysis of categorical data.

3 RESULTS

3.1 Sample characteristics

One hundred and forty-nine IDUs were surveyed: 55 from inner-city, 56 from suburban and 38 from regional sites. Demographic characteristics of the sample are shown in Table 3.1. The median age of participants was 34 years and almost two thirds were male. The majority of the sample (89%) reported Australia as their country of birth, with the remainder reporting a range of countries across Europe (5%), Oceania (5%), the Middle East (1%) and North America (1%). Seven percent reported being homeless or living on the street and a further 12% reported unstable living circumstances (i.e. in a refuge, hostel, shelter or squat).

The majority of the sample (85%) reported being unemployed (65%) or on a pension (20%). Six percent were in part time or casual employment, four percent reported that they were engaged in home duties, three percent in full time employment and one percent were students. Nine percent reported being paid for sex work in the month preceding interview.

Educational status was varied, with a mean of 11 years completed education (including kindergarten, where attended). Approximately one-third of the sample had completed a trade or technical qualification as their highest level of education (28%), and just over one-tenth had completed a university or college qualification (13%).

Over half of the sample (62%) was in treatment for drug use at the time of interview, with the majority in a methadone or buprenorphine program. A large proportion of the sample reported a prison history, and of this group, one-fifth (17% of the entire sample) reported last being incarcerated in 2004 (the year of interview).

Table 3.1: Demographic characteristics of the sample

	Total (N=149)
Median age (range; SD)[a]	34.0 years (20–52; 7.2)
Gender[a]	%
male	62
female	36
transgender	1
Australian-born	89
Aboriginal and/or Torres Strait Islander	19
Homeless/unstable circumstances*	19
Current drug treatment	
methadone or buprenorphine	55
counselling	3
other	3
rehab	1
not in treatment	38
Unemployed/pensioner	85
Sex work (last month)	9
Mean years of school completed (range; SD)	11 years (2–21; 2.0)
Education	%
University/college qualification	13
Trade/technical qualification	28
Ever incarcerated	81
last in prison in 2004	17

[a] 1 case missing data

*Includes homeless/street, refuge/hostel/shelter and squat living arrangements

3.2 Injecting history

Median age of first drug injection was 17 years (Table 3.2). The majority of the sample (77%) reported having injected another person, with the median number of people ever injected being 10 (range 1–300). Among the 53% of the sample who reported injecting another person in the last 12 months, this figure reduced to a median of three people (range 1–100). Thirty-nine percent of the sample had taught another person to inject, the median being two people (range 1–100). Twenty percent of the sample reported teaching a person to inject in the last 12 month, the median number of people being two (range 1–21).

Table 3.2: Injecting history, injection of others and initiation of others

	Total (N=149)
Median age first injected (range; SD)	17 (10–38; 5.3)
Ever injected another person[a]	77%
Among those who had ever injected another person	
median number of people *ever* injected (range; SD)	10 (1–300; 53.8)
Among those who had injected another person in the last 12 months	
median number of people injected last 12 months (range; SD)	3 (1–100; 21.8)
Ever taught another person to inject[b]	39%
Among those who had ever taught another person to inject	
median number of people *ever* taught to inject (range; SD)	2 (1–100; 14.3)
Among those who had ever taught another person to inject in the last 12 months	
median number of people taught to inject last 12 months (range; SD)	2 (1–21; 5.1)

[a] 3 cases missing data

[b] 1 case missing data

3.3 Lifetime and current drug use

Data regarding drug use and injection for the most commonly injected illicit drugs in NSW at the time of interview are presented in Table 3.3. The overwhelming majority of the sample had both used and injected heroin and amphetamine at least once in their lifetime, with high proportions also reporting use of methadone, cocaine and benzodiazepines. A substantial proportion of the sample also reported lifetime injection of methadone and cocaine (68% and 62% respectively).

Table 3.3: Lifetime and current drug use

	Total (N=149)				
	Ever used (%)	**Ever injected (%)**	**Injected last 6 months (%)**	**Injected last month (%)**	**Median no. injections last mth***
Heroin	97	97	69	61	9
Methadone	91	68	34[a]	28	6
Other opioids	48	36	24	17	5
Amphetamines	95	95	72	62	5
Cocaine	68[a]	62	22	16	2
Benzodiazepines	75	30	8	6	2

[a] 1 case missing data

*Among those who had injected in the last month

The most commonly reported illicit drug injected in the last month was amphetamine (including methamphetamine; reported by 62% of the sample) on a median of five occasions. Injection of heroin was also common, with 61% of the sample reporting injecting heroin a median of nine times in the preceding month. Just over one-quarter of the sample (28%) reported injecting methadone on a median of six occasions in the month prior to interview.

3.4 Injecting and blood-borne virus risk

In the last month, the majority of participants had injected at home (79%) or a friend's place (42%). Other injecting locations included streets, parks or benches (35%), public toilets (32%), cars (22%) and the Sydney Medically Supervised Injecting Centre (16%).

Over half the sample (52%) reported that they had re-used their own needle in the last month, with 26% doing so three or more times. Most of these participants (85%) reported that they had not cleaned the re-used syringe with bleach on any of these occasions. Sixteen participants (11%) reported using a syringe after another person in the last month, virtually all of whom also reported never cleaning the syringe with bleach during that time. Twenty-one percent of the sample had been injected by another person in the last month, with half of these participants stating this had occurred more than five times.

A substantial proportion of the sample reported using injecting equipment after another person in the past month: 40% a spoon, 35% a drug solution/mix, 33% water, 29% a filter and 12% a tourniquet.

As described previously (Table 3.1), 81% (n=120) of the sample reported that they had been incarcerated in the past. Of these, approximately one quarter (22%) had received a tattoo, nearly half (44%) had injected and one-third had shared a syringe while in prison (Table 3.4). Among those who reported injecting in prison, the proportion who had shared a syringe was high (75%).

Table 3.4: Blood-borne virus risk behaviours in prison

	n=120
Ever received a tattoo in prison	22% (n=26)
Ever injected in prison	44% (n=53)
Ever shared a syringe in prison	33% (n=40)
of those who had injected in prison, % who shared a syringe	75%

3.5 Hepatitis C, hepatitis B and HIV testing

According to self-report, almost all participants had been tested for a BBVI (HBV 87%, HIV 97% and HCV 99%). Among those who reported being tested, the median number of weeks since their last test was 26 weeks for hepatitis B (range < 1–1040), HIV (range < 1–728) and hepatitis C (range < 1–520). Eighteen percent of those tested reported having HBV, although there was some confusion around HBV status. Fifty-three percent of the sample reported being vaccinated against HBV (42% fully and 11% partially). Based on the results of their last test, seven participants (5%) believed that they were HIV positive.

Only one participant reported never being tested for hepatitis C. Of those who were tested, based on the results of their last test, 74% responded they had hepatitis C, four percent that they had hepatitis C in the past but no longer, and five percent ‘other’ (e.g.

"have hep C but it is inactive", "I have the virus but I'm not infectious", "didn't get result"). General practice clinics were the most commonly reported setting of the most recent test (Figure 3.1). Based on participants' recollection of the testing, 38% of those tested during, or after, 2000 reported receiving pre-test counselling (62% reported that they had not received pre-test counselling and one percent reported being unable to remember). Similarly, 39% reported post-test counselling (58% reported that they had not received post-test counselling and one percent each could not remember, did not pick up the results and were due to pick up the results). It should be noted that in order to minimise confusion about the term 'counselling' in the context of hepatitis C testing (rather than drug and alcohol, mental health or other forms of psychological counselling), participants were asked "The last time you were tested, did a doctor or other professional discuss hepatitis C, the test and the meaning of the test before you had it (pre-test counselling)?" and "The last time you were tested, did a doctor or other professional discuss hep C, the test and the results with you after you had it (post-test counselling)?".

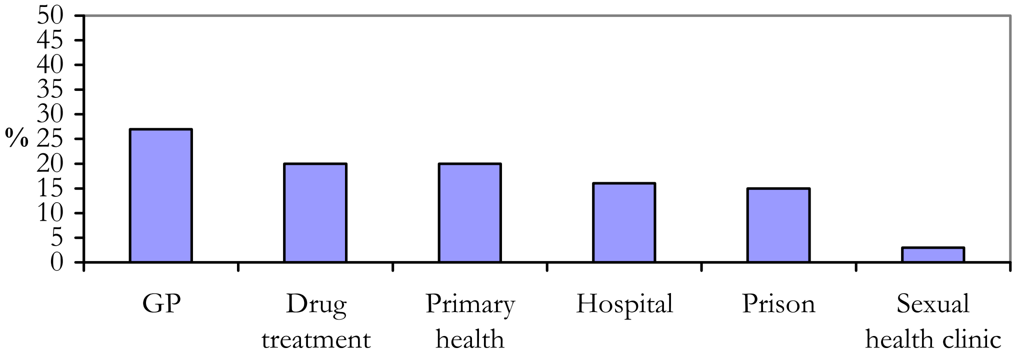

Figure 3.1: Setting of last hepatitis C test

3.6 Reasons for hepatitis C testing

Among the 148 participants tested for hepatitis C, 'routine screening' was the main reason selected for their last test (39%), followed by 'mandatory testing' (13%) and 'risky behaviour' (12%) (Figure 3.2). Fourteen percent of participants reported other varied reasons, including being tested when pregnant, following needle stick injuries, general concern and curiosity. It should be noted that 'mandatory testing' in this study refers to participants perception of the testing, rather than testing as required by law or policy.

The reason given by the one participant who had never been tested was that they "haven't got around to it". Participants who believed they had never tested positive for hepatitis C reported the main reasons they would get tested again as 'risky behaviour' (62%), 'routine screening' (38%) and 'partner/friend diagnosed with hepatitis C' (19%). Less commonly selected reasons were 'Hep C symptoms' (10%), 'feeling unwell' (10%) and 'doctor/other health professional recommendation' (10%).

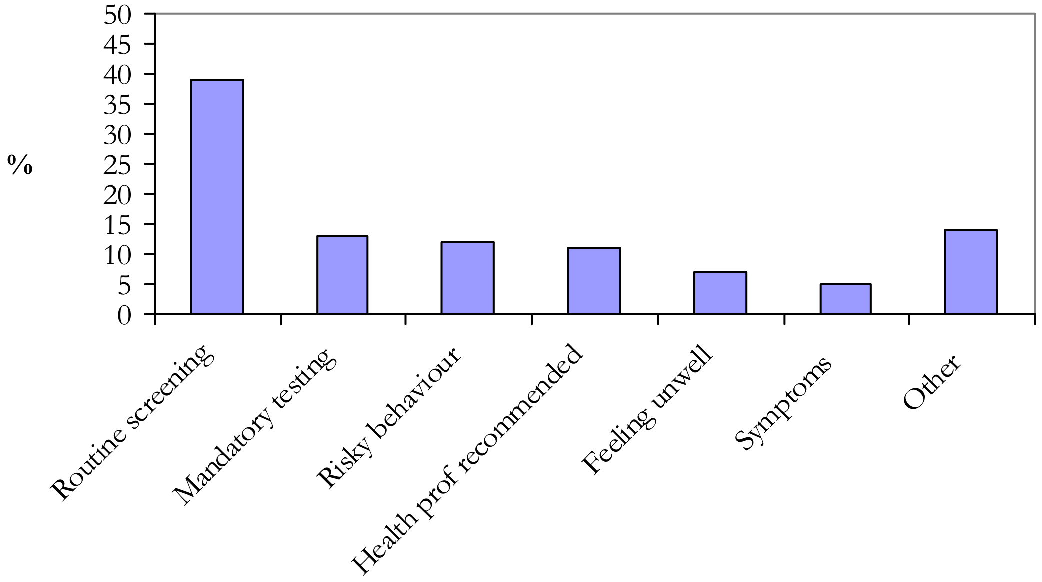

Figure 3.2: Primary reason for hepatitis C testing

3.7 Hepatitis C symptoms prior to testing

When asked whether they had experienced any signs of hepatitis C infection prior to testing, 31% of participants reported they had (n=46). The most commonly reported symptoms among this sub-sample were lethargy (70%), followed by feeling unwell (43%) and nausea (37%) (Figure 3.3). Seventeen percent reported jaundice like symptoms (yellowing of the eyes or skin) prior to testing. A range of other signs of infection were reported by over one third of participants, many of which could be generally categorised as liver pain (e.g. 'tender liver, liver pains') and depression related (e.g. 'feeling down and unmotivated').

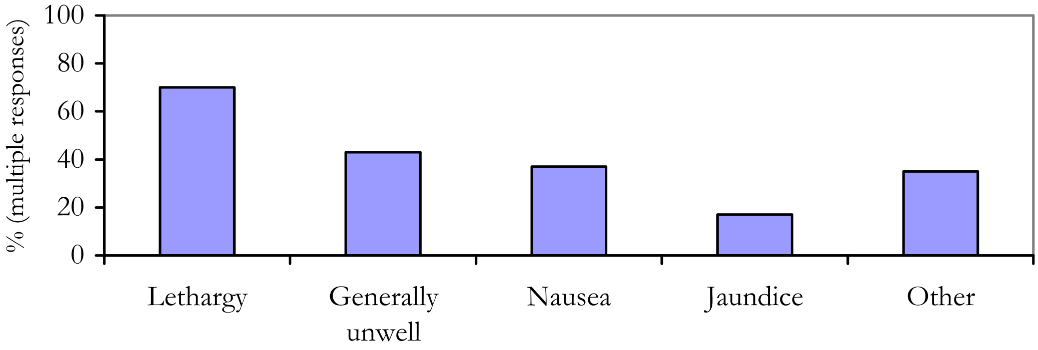

Figure 3.3: Symptoms experienced prior to hepatitis C testing

3.8 Hepatitis C knowledge (self-rating)

Participants were asked to rate their knowledge/understanding of hepatitis C on a scale of 1–5 (excellent = 1; poor = 5). Half the sample rated their knowledge as either 'good' (30%) or 'very good' (23%), and 15% rated their knowledge as 'poor' (Figure 3.4).

Figure 3.4: Participants' rating of their knowledge of hepatitis C

3.9 Hepatitis C understanding

A series of detailed questions concerning participants' hepatitis C status was asked in order to elicit their understanding of their infection. Seventy-six percent of the sample believed they had hepatitis C at the time of the survey ('do you have hepatitis C?'), with a further four percent unsure of their status. Of the twenty-nine participants (20%) who believed they did not have hepatitis C, five (17%) believed themselves to have previously been infected.

When participants who believed they were infected with hepatitis C were asked if they had antibodies for hepatitis C, only 31% responded that they did, and a further 40% were unsure. Twenty-eight percent believed that they did not have hepatitis C antibodies. Only one participant, who believed they had *never* been infected with hepatitis C, also believed that he had hepatitis C antibodies. One participant reported they did not have hepatitis C presently, but had in the past, and now had hepatitis C antibodies.

Of the 113 participants who believed they had hepatitis C, 19% thought that they could not pass it on to others. One participant reported "I can't pass it on, 'cause I have a good liver". A further 13% were unsure whether or not they could.

Nineteen percent of those who reported having hepatitis C believed that they were immune to hepatitis C and 23% were uncertain. Of the 29 participants who reported that they were not infected with hepatitis C, only one believed herself to be immune, because "I'm a carrier, but I don't have the disease". A further six were unsure whether or not they were 'immune' (21%).

When participants were asked how they came to their understanding of their hepatitis C status, 78% of those tested stated that they were informed by the diagnosing doctor. Other primary sources of information used by participants included the diagnosing health professional (other than a doctor) (7%), reading and self education (5%), organisations (5%, mainly prison), medical specialists (3%), friends (1%) and others with hepatitis C (0.7%).

Some of the key findings pertaining to participants' understanding of their hepatitis C status, infectiousness and immunity have been summarised in Table 3.5.

Table 3.5: Participants' perception of hepatitis C status, infectiousness and immunity

	%
Those who believed they were infected with hepatitis C, but not infectious	19
Those who believed they were infected with hepatitis C, but uncertain whether they were infectious	13
Those who believed they were infected with hepatitis C, but immune to hepatitis C	19
Those who believed they were infected with hepatitis C, but did not have antibodies	28
Those who believed they were infected with hepatitis C, but uncertain whether they had antibodies	40

3.10 Hepatitis C knowledge

A series of true/false/don't know statements were devised to elicit participants' knowledge about hepatitis C, including the relative risks of transmission, clinical markers and treatment.

3.10.1 Risks of transmission

As shown in Table 3.6, substantial proportions of the sample held incorrect beliefs or were unclear about various aspects of hepatitis C transmission. Although the vast majority of the sample (96%) knew that injecting drugs carried a high risk of hepatitis C transmission, close to half of the sample (48%) believed it was possible to acquire hepatitis C from reusing their own needle that no-one else had used. Many participants were also confused about the risk of hepatitis C transmission involved in sharing household items such as toothbrushes or razors, with approximately 80% failing to endorse the statement that the risk is low. Similarly, more than half of the sample (59%) believed incorrectly that unprotected sex with hepatitis C positive persons was a high risk activity in terms of hepatitis C transmission. Just under half of the sample (44%) believed that hepatitis C positive mothers are at high risk of transmitting hepatitis C to their child through pregnancy, childbirth and breastfeeding, and approximately one third

(28%) did not know that this, in fact, was low risk. A substantial minority of participants (17%) thought it was possible to contract hepatitis C from dirt and a further 28% were unsure whether it could be acquired from dirt or not.

3.10.2 Clinical markers

There was also some uncertainty relating to the clinical markers of hepatitis C, primarily with regard to participants' understanding of antibodies and immunity (Table 3.6). Although most of the sample answered correctly that people with hepatitis C antibodies can infect other people with hepatitis C (73%), many thought that antibodies to hepatitis C also gave protection against acquiring the virus (42%). Over one-third of the sample (35%) wrongly believed that some people are immune to hepatitis C and a further 20% were unsure. Approximately one-quarter of the sample (26%) mistakenly believed that hepatitis C was always associated with jaundice, and a further 13% were unsure. However, most of the sample answered correctly that there was more than one hepatitis C strain (85%) and that in some cases the virus naturally clears (71%). Similarly, the majority answered correctly that a normal liver function test result was not an indication of hepatitis C negativity (76%) or infectiousness (77%) and that once cleared, hepatitis C can be acquired again (75%).

3.10.3 Treatment

Although the majority of the sample knew that there is medical treatment available for hepatitis C (77%), many were confused about herbal treatments, reporting uncertainty as to whether they could cure hepatitis C (34%), or wrongly believing that they could (15%). There was also confusion surrounding infectiousness after successful medical treatment with Interferon, with approximately one third (32%) believing it was still possible to pass on the virus and over one third (41%) unsure.

Table 3.6: Participants' knowledge of hepatitis C

Statements*	Total (N=148) **Incorrect answer (%)**	 **Don't know (%)**
Risks of transmission:		
People who have unprotected sex with hepatitis C positive people are at **high** risk for hepatitis C (false–low risk)	59	4
People who have close contact with someone who has hepatitis C are at **very low** risk for hepatitis C (e.g. hugging, kissing and sharing household items such as cups or forks) (false–no risk)	41	1
People who share household items such as toothbrushes or razors are at **low** risk for hepatitis C (true)	79	1
People who inject drugs are at **high** risk for hepatitis C (true)	3	1
People who get tattoos or body piercing are at **high** risk for hepatitis C (false–medium to low risk^)	17	6
Hepatitis C positive mothers are at **high** risk of transmitting hepatitis C to their child through pregnancy, childbirth and breastfeeding[a] (false–low risk)	44	28
It is possible to contract hepatitis C from reusing your own fit that no-one else has used (false)	48	15
It is possible to contract hepatitis C from dirt (false)	17	28

*Correct answer in parentheses. Based on information derived from Australian Government Department of Health and Ageing and the Australian Institute of Primary Care (2001) and the Hepatitis C Council of New South Wales (2001).

^It was explicitly stated to participants that the survey item referred to tattooing and body piercing *in general*. By contrast, *unsterile* tattooing and piercing *by someone who is hepatitis C positive* is considered high risk for transmission

[a] 2 cases missing data

Statements*	Total (N=148) **Incorrect answer (%)**	 **Don't know (%)**
Clinical markers:		
All people with hepatitis C get jaundice (go yellow) (false)	26	13
Some people naturally clear the hepatitis C virus (true)	14	15
Antibodies to hepatitis C give you protection against contracting the virus (false)	42	24
People with hepatitis C antibodies can infect other people with hepatitis C (true)	9	18
If a person's Liver Function Tests are fine they do not have hepatitis C (false)	16	8
If a person's Liver Function Tests are fine they can no longer pass hepatitis C on to other people (false)	9	14
There is more than one kind of hepatitis C (true)	7	8
People who have cleared the hepatitis C virus cannot contract it again (false)	10	15
Some people are immune to hepatitis C (false)	35	20
Treatment:		
There is a medical treatment for hepatitis C (true)	14	9
Herbal remedies can cure hepatitis C (false)	15	34
A person who has been treated with Interferon and has cleared the virus can infect other people with hepatitis C (false)	32	41

*Correct answer in parentheses, based on information derived from Australian Government Department of Health and Ageing and the Australian Institute of Primary Care (2001) and the Hepatitis C Council of New South Wales (2001).

3.11 Hepatitis C testing experience and understanding of results

Diagnostic testing was common among the sample, with the majority (74%) reporting one or more of five different tests in the past 12 months. Hepatitis C antibody testing was the most common (64%), followed by the alanine aminotransferase test (ALT)/liver function test (LFT) (50%), PCR (12%), liver ultrasound (10%) and the liver biopsy test (3%).

Participants who had reported undergoing diagnostic testing in the last 12 months were asked open ended questions about the result and meaning of their tests. Two-thirds of participants who had a hepatitis C antibody test in the past 12 months responded that the results of that test were 'positive', 'positive for antibodies' or 'antibodies present' (66%). However, some were unsure or confused about what these results meant in terms of their prognosis or their ability to infect others. For example, statements regarding their test results included: "I've had an exposure, but can't pass it on because I have antibodies" (self-reported test result: "positive"); "It means I'm going to get sick" (self-reported test result: 'positive'); "I'm diseased and should stay away from clean people" (self-reported test result: 'positive'); "I'm not sure….I have the virus?" (self-reported test result: 'positive'); and "It's dominant in myself, but I can't pass it on to anyone else" (self-reported test result: 'Hep C negative, but positive for antibodies'). Some appeared to use the term 'antibodies' to describe having a resistance to hepatitis C, for example: "I've built up antibodies, so my liver won't be affected" (self-reported test result: 'negative'). One participant believed the virus was "dormant" despite having antibodies (self-reported test result: 'antibodies present').

Over one quarter (26%) of those undergoing an ALT/LFT reported that they did not know the results of that test. One participant stated about their ALT/LFT result, "the doctor told me, but it didn't make sense". An even greater proportion (66%) of those undergoing a PCR test did not know, or remember, the result. Three of the 15 participants (20%) who reported having a liver ultrasound in the past 12 months also reported not knowing the result of that test.

Of the 113 participants who believed they had hepatitis C, 20% reported that they had seen a gastroenterologist or other liver specialist for hepatitis C in the past. Sixteen percent had tried herbal remedies (e.g. St Johns Wort), 14% had tried complementary therapies (e.g. acupuncture, massage) and three percent had received Interferon/Ribavirin treatment.

When participants who believed they had hepatitis C were asked how severe they thought their infection, the majority rated it as mild (50%) or moderate (22%). A further 11% of participants responded that they "didn't know", nine percent "quite bad" and six percent "very bad". Participants were then asked whether they based this opinion on their symptoms (or lack thereof), their test results (as advised by clinician), or otherwise. More participants based their opinion on their symptoms (or lack of) (67%) rather than their test results (20%). Other responses included, "[very bad, based on] my age, it just has to be bad" (1%), "[moderate, based on] the fact I can't give it to other people" (1%), "[moderate, based on] colour of urine and faeces" (1%), "[mild], compared to other people I know who have it" (1%), "[mild, based on] both clinical markers and symptoms" (1%).

3.12 Hepatitis C information and advice

All participants were asked where they got their information about hepatitis C. Leaflets and other written material (e.g. from NSPs, GPs) provided the main sources of information about hepatitis C, with 60% of the sample naming this option. Also selected by approximately one-quarter or more of the sample as main sources of information were GPs (verbal information; 45%), user organisation publications (e.g. Users News, Junk Mail; 32%), friends /family /partners /other users (32%), drug treatment services (24%) and NSPs (verbal information; 23%) (Figure 3.5 and Table 3.7). Eighteen percent of the sample identified other various main sources of information (e.g. TAFE, medical textbooks, the newspaper). The most commonly reported 'other' main source of information about hepatitis C was prison, reported by nine percent of the sample.

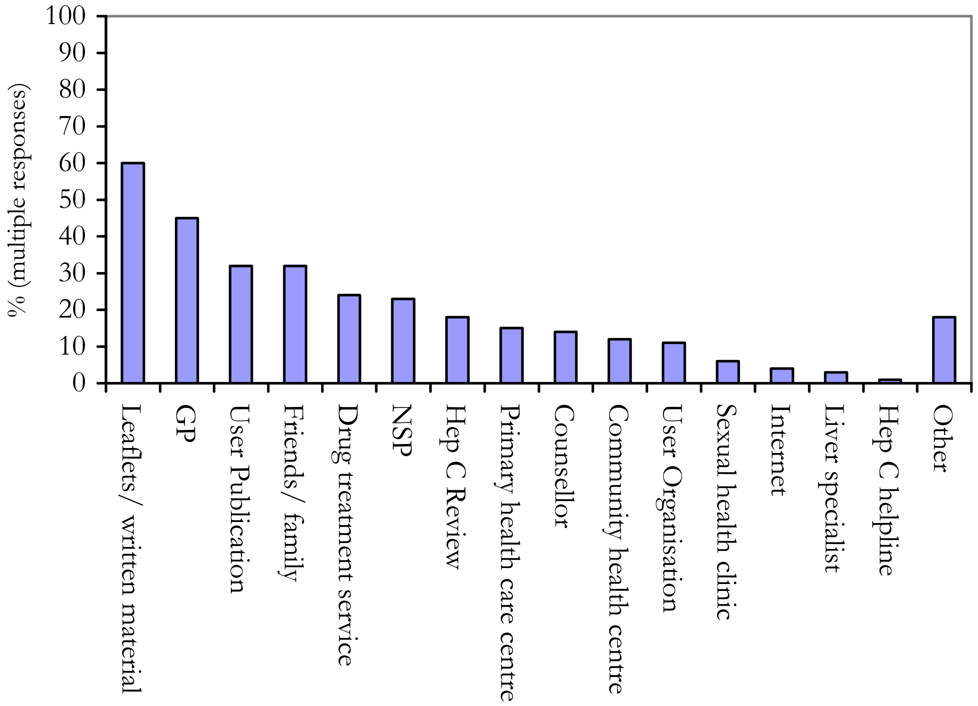

Figure 3.5: Sources of information about hepatitis C

When asked to select one main source of information, leaflets and other written material were used the most (24%), followed by GPs (18%) and friends /family /partners /other users (11%) (Table 3.7).

Overall, the majority of the sample reported that they were 'very confident' (48%) or 'confident' (35%) with the credibility of their main source of information in terms of providing accurate knowledge and explanation of hepatitis C. Fourteen percent and two percent of the sample respectively, reported that they were 'not very confident' or had 'no confidence' with respect to their main source of hepatitis C information. However, nearly one-third of the sample (28%) reported that the last time they sought and received information it did not provide enough detail and/or explanation. The majority (66%) thought that the information received did provide enough detail and/or explanation.

]

Table 3.7: Sources of hepatitis C information and perceived credibility

Main source of information*	Used by (%)	Main source (%)	Confidence in main source Total (N=148)
Leaflets/ other written material (excludes Hep C Review and user organisation magazines)	60	24	39% 'very confident' 44% 'confident' 11% 'not very confident' 3% 'no confidence'
GP (verbal information)	45	18	58% 'very confident' 27% 'confident' 15% 'not very confident'
User organisation publication	32	6	78% 'very confident' 22% 'confident'
Friends/family/partner/other users^	32	11	19% 'very confident' 38% 'confident' 31% 'not very confident' 13% 'no confidence'
Drug treatment service	24	7	64% 'very confident' 27% 'confident' 9% 'not very confident'
NSP (verbal information)	23	9	39% 'very confident' 39% 'confident' 23% 'not very confident'
Hep C Review	18	3	100% 'very confident'
Primary health care centre	15	4	50% 'very confident' 50% 'confident'
Counsellor	14	3	75% 'very confident' 25% 'confident'
Community health centre	12	3	50% 'very confident' 25% 'confident' 25% 'not very confident'
User Organisation (eg. NUAA)	11	2	67% 'very confident' 33% 'confident'

*Sources nominated by less than 10 participants not shown

^Excludes friends/family/partner/other users who were reported to be peer educators

3.13 Quality of life

Complete IDUQOL data were obtained for 104 participants. The mean initial QOL rating (how would you rate your quality of life on a scale of 0–10) was 5.4 (SD 2.2), and the final QOL rating was 5.9 (SD 2.2). The mean difference was 0.51, which was significant **(**t_{103} = 3.12, p=0.002), indicating a small, but statistically significant, increase in participants' perception of their quality of life at completion of interview.

The most commonly selected life area cards among this sample were family, health, housing, money and partnerships (Table 3.8). There were no differences between males and females in the life area cards selected. The two younger age groups (< 30 and 30– 39 years) were more likely to choose family compared to the 40 year old and over age group (72% and 62%, respectively vs. 41%, χ^2 = 6.08, *df* = 2, p=0.048).

Only eight participants (8%) selected the hepatitis C life area card. All of these eight participants believed they had hepatitis C, two-thirds of who were male and of various ages (mean 33.8 years, range 23– 46).

Table 3.8: Life areas determining participants' current quality of life

			Total (N=104)
Life area	**Number of participants selecting the life area (%)**	**Mean Weighting (SD)***	**Mean Rating of life area (SD)**
Family	61 (59)	6.9 (2.6)	56.8 (29.0)
Health	55 (53)	5.5 (2.0)	57.8 (26.4)
Housing	53 (51)	5.4 (2.2)	52.9 (33.5)
Money	49 (47)	4.6 (2.6)	38.7 (27.9)
Partnership	47 (45)	5.3 (2.1)	50.4 (32.3)
Feeling good	37 (36)	5.3 (3.4)	46.3 (27.8)
Friends	33 (32)	4.6 (1.3)	58.8 (26.1)
Drug treatment	32 (31)	4.6 (2.1)	53.1 (29.5)
Drugs	31 (30)	4.1 (2.5)	47.6 (32.8)
Spirituality	21 (20)	4.3 (1.9)	47.4 (37.6)
Independence	19 (18)	3.1 (1.9)	55.9 (34.3)
Education	16 (15)	4.4 (1.6)	45.9 (30.3)
Being useful	16 (15)	4.5 (3.2)	46.9 (25.7)
Leisure activities	15 (14)	4.1 (1.4)	50.4 (33.9)
Resources	13 (13)	4.2 (1.4)	73.4 (23.4)
Sex	9 (9)	4.7 (4.3)	77.8 (22.8)
Hepatitis C	8 (8)	4.6 (1.4)	51.9 (32.6)

*Weighting out of a possible 25

The mean global IDUQOL score was 54.2 (SD 21.2). Differences between global IDUQOL scores, demographics and hepatitis C status are presented in Table 3.9. There were no differences in global IDUQOL for any of the variables examined. Although not significantly different, those who believed themselves to have hepatitis C had a slightly higher global IDUQOL score than those who did not (54.9 vs. 51.6; Table 3.9).

Table 3.9: Global IDUQOL scores by demographics and hepatitis C status

Variable	n	Mean IDUQOL (SD)
Gender[a]		
Males	65	52.8 (20.8)
Females	37	55.5 (22.1)
Transgender	1	69.6 (n/a)
Age		
≤30 years	33	54.8 (23.2)
31-39 years	42	53.0 (20.2)
≥40 years	29	55.2 (21.0)
ATSI		
ATSI	20	46.0 (23.5)
Other	84	56.1 (20.3)
Education		
<11 years	48	51.7 (21.5)
≥11 years	56	56.4 (20.9)
Employment		
Employed or otherwise[b]	16	48.7 (21.6)
Unemployed/pension	88	55.2 (21.1)
Currently in drug treatment		
Yes	64	55.3 (20.5)
No	40	52.5 (22.5)
Hepatitis C positive[c]		
Yes	80	54.9 (21.5)
No	19	51.6 (21.8)

[a] 1 case missing

[b] Includes full-time, part-time, casual, students and home duties

[c] 5 cases missing

4 DISCUSSION

4.1 Main findings

The current study found that a substantial proportion of IDUs hold serious misconceptions about hepatitis C, one of the most disturbing being that some people are immune to the virus, a viewpoint held by over a third of the sample.

Not surprisingly, therefore, many of the participants' understanding of their own hepatitis C infection was similarly confused, with one in five participants who reported having hepatitis C under the impression that they could not infect others and/or were immune to hepatitis C. Among those who stated they had hepatitis C, nearly a third also stated they did not have antibodies for hepatitis C, and even more were unsure as to whether or not they had antibodies. Indeed, there appeared to be substantial misunderstanding of the clinical term 'antibodies', with a large proportion of the sample believing that antibodies to hepatitis C protected against hepatitis C infection. Unlike many other viruses, the development of antibodies against HCV does not produce immunity to the virus, so this is an understandable error, but of great concern nonetheless.

Participants' knowledge of aspects of the hepatitis C virus was often found to be uncertain or incorrect with respect to transmission risks, symptoms, clinical markers and treatment. Many IDUs believed it was possible to catch hepatitis C by re-using their own needle, or from dirt, suggesting IDUs may be associating transmission with unhygienic practices and possibly confusing health education messages with other infections. There was confusion over the symptoms of hepatitis C infection and the differences between various forms of hepatitis virus. Jaundice was mistakenly thought to always be associated with hepatitis C by one quarter of the sample, and participants reported having a "mild" or "moderate" case of hepatitis C based on their subjective assessment of symptoms.

Despite recent, and often multiple testing, many participants did not know the results of these tests, and/or misunderstood their meaning, suggesting communication of hepatitis C testing and diagnosis among IDUs needs to be improved. Only about 40% of those tested during or after 2000 reported receiving pre- and post-test counselling.

The research also found that very few participants prioritise hepatitis C highly relative to other life areas. However, health was frequently selected as one of the most important life areas determining quality of life, which is likely to incorporate symptoms and sequelae resulting from hepatitis C impacting on day-to-day life.

4.2 Risk behaviours

Sixteen participants (11%) reported sharing a needle or syringe in the preceding month, which is less than the 2004 national NSP survey where 18% of participants had used a needle or syringe after another person in the last month (National Centre in HIV Epidemiology and Clinical Research, 2005). Nevertheless, it is consistent with an overall reduction in the prevalence of needle sharing in Australia (Crofts et al., 1996; Crofts & Aitken, 1997; MacDonald et al., 2000). IDUs may be less cognisant of the dangers of sharing injecting paraphernalia other than needles however, as the prevalence of this practice, most notably the sharing of spoons (40%), drug solution (35%) and water (33%), was high. Other Australian studies have shown that many IDUs continue to engage in a range of putative risk practices for hepatitis C transmission, such as the shared use of injecting equipment other than needles and syringes and activities that would promote blood spread to surfaces and other people via hands and fingers (Maher et al., 1998; Dwyer et al., 2002).

4.3 Hepatitis C testing experience and understanding

The vast majority of the sample reported that they had been tested for BBVI, and most had undergone one or more different test for hepatitis C in the past 12 months. This is consistent with other research showing a high level of hepatitis C testing among heroin users (Day & Dolan, 2006). This finding suggests many IDUs are aware of the risk of acquiring hepatitis C and are thus being tested. It also indicates health care providers are testing IDUs, presumably because they are aware of the benefits of such testing. However, that many IDUs did not know the results of these tests, and/or misunderstood their meaning and implications, suggests communication of hepatitis C testing and diagnosis could be improved. Moreover, such misunderstanding reduces associated benefits and possibly exacerbates harm. Treatments for hepatitis C remain limited and a range of barriers exist to prevent IDUs from accessing such treatment (Doab et al., 2005; Stoove et al., 2005). These results suggest that although testing and surveillance of hepatitis C is widespread, support following diagnosis (or indeed a negative result) is limited.

Although most of the IDUs were able to report the results of their recent hepatitis C antibody test, a number were confused about the meaning of the diagnosis (see section 3.11). The extract from open ended responses, "I'm not sure….I have the virus?" summarises the uncertainty that often accompanied a hepatitis C diagnosis. Substantial numbers of IDUs reported they did not know and/or understand the results of their recent ALT/LFT and PCR test. Findings such as these raise questions about patient involvement in health care and about how knowledge about hepatitis C and antibody status can be better imparted to IDUs. In the current study, only about 40% of those tested during or after 2000 reported receiving pre- and post-test counselling. The lack of adequate hepatitis C pre- and post-test counselling has been described in other research (Gifford et al., 2001; Loxley et al., 2000; Gifford et al., 2003). Pre- and post-test counselling is necessary for a range of reasons, including prevention of further hepatitis C transmission to other users, if testing positive, or to assist in preventing infection if testing negative. It appears the messages used by clinicians in providing a diagnosis and to describe the infectivity of the virus need to be simplified, as has been recommended by others (Southgate et al., 2003). One potential strategy may be to provide IDUs with standardised, written results presented in a simple, easy to understand format.

Testing for blood-borne viruses provides an opportunity for IDUs to access information and referral. As has been noted previously (Hopwood & Treloar, 2003), the data suggest that a continued effort by general practitioners is needed to provide IDUs with comprehensive information about hepatitis C at diagnosis, and to refer to key agencies that provide information and support, such as the Hepatitis C Council and the Hep C Helpline.

It is also of interest that close to half the sample reported not being vaccinated against HBV. This figure is consistent with serological studies (Anderson et al., 1994; MacDonald et al., 2004), despite self-report being a less than ideal measure of vaccination coverage. IDUs remain a key target group for HBV vaccination (Heron & Campbell-Lloyd, 2000) and more effort is required to increase vaccination knowledge and coverage.

4.4 Hepatitis C understanding

The high proportion of participants reporting to have hepatitis C (76%) in this study is consistent with findings from the national NSP survey and other studies of IDUs (National Centre in HIV Epidemiology and Clinical Research, 2005; Day, 2003). However, many participants' understanding of their hepatitis C infection and its implications appeared confused. In line with the findings of a smaller qualitative study by Southgate et al. (2005), there appeared to be substantial misunderstanding of the clinical term 'antibodies', with almost one-third of those who stated they had hepatitis C also stating they did *not* have antibodies for hepatitis C (28%). A further forty percent of participants reporting to have hepatitis C were uncertain about whether or not they had antibodies.

Misunderstanding of the term 'antibodies' may explain why a substantial proportion of participants in the current study believed they could not infect others and/or were immune to hepatitis C (see section 4.5.2 for further discussion). Specifically, a third of those who reported they had hepatitis C believed they could not pass on the virus (19%), or were unsure if they could (13%). Just as disconcerting, over a third believed they were immune to hepatitis C (19%) or were uncertain about their immunity (23%). It appears a substantial proportion of IDUs hold serious misconceptions about their hepatitis C infection, leaving them vulnerable to re-infection and superinfection, and at risk of infecting others. In line with the recommendations by Southgate et al. (2005), these findings suggest that prevention efforts need to be broadened beyond messages of transmission risks to include education about the fundamentals of the hepatitis C virus itself and the meaning of antibodies in particular. These data also suggest that greater standardisation of the way in which test results are delivered may be needed and that less clinical jargon should be used when relaying test results. These results also highlight the need for thorough testing, including PCR testing for all antibody positive tests.

4.5 Hepatitis C knowledge

4.5.1 Risks of transmission

Participants' knowledge about transmission risks for hepatitis C was characterised by confusion and uncertainty. Other than knowing that injecting drugs carried a high risk of hepatitis C transmission, participants were confused about nearly every other mode of transmission assessed (see Table 3.6). Nearly half of the sample (48%) believed it was possible to infect one's self with hepatitis C by re-using their own needle (i.e. not used by another), suggesting some participants may be associating transmission with unhygienic practices. As reported by Southgate et al. (2005), some IDUs may not view the hepatitis C virus as an agent, external to the self and acquired from other people, but rather as the result of the unhygienic practice of re-using one's own needle. In this understanding, one's own blood, once lodged in a used syringe, is capable of generating hepatitis C as it changes or, as reported by Southgate *et al.* (2005), it "goes off". The misconception of the risk involved in re-using one's own needle may be the result of confusion around equipment disinfection—although the exact level of risk remains unclear, hepatitis C infection is less amenable than HIV to conventional sterilisation techniques using bleach (Hagan & Thiede, 2003).

Similarly, over one-third of participants thought it was possible, or were unsure whether, hepatitis C could be acquired from dirt. This misconception may stem from IDUs re-interpreting public health hygiene messages that refer to the benefits of hand-washing and wiping surfaces after injecting to prevent the inadvertent spread of hepatitis C, rather than be a literal reference to the virus living in soil (Southgate et al., 2005).

In general, IDUs' perception of the risk of hepatitis C transmission associated with non-parenteral activities appeared inflated, with the majority believing sharing household items such as toothbrushes or razors and unprotected sex with hepatitis C positive persons were high risk activities, when in fact, they are not. Importantly, however, the IDUs in the current study were aware that injecting carried a high risk of hepatitis C transmission, and as stated previously, rates of needle-sharing were low. Still, it is not clear whether or not the majority of participants knew exactly why needle-sharing is high risk, or whether they possessed a clear awareness of the risk of transmission through contaminated blood. That substantial proportions of the IDUs interviewed had recently used injecting equipment after another person, most notably spoons and drug solution/mix, further suggests knowledge of the blood-to-blood transmission of hepatitis C could be improved.

IDUs need to have the knowledge to reduce their risk of hepatitis transmission, most notably by reducing contact with blood and all manner of paraphernalia sharing.

Targeted and accessible education and health promotion messages may be required to address the confusion between hygiene and blood awareness messages.

4.5.2 Clinical markers

Participants fared somewhat better in terms of their knowledge of many of the clinical markers associated with hepatitis C, with over two-thirds of participants answering most items correctly. For instance, the majority of participants were aware that there is more than one strain of hepatitis C (85%), and that once cleared, hepatitis C can be acquired again (75%). Evidently, some messages are being understood better than others.

However, participants' confusion surrounding the concept of 'antibodies' was again apparent. In qualitative research by Southgate et al. (2005) it was noted some IDUs were using the clinical term 'antibodies' to describe having a resistance to hepatitis C, somewhat like acquiring antibodies after having hepatitis B or common childhood infections such as chicken pox. In this study, well over one-third of the IDUs agreed with the statement "antibodies to hepatitis C give you protection against contracting the virus". Evidently, some IDUs are under the false impression they are protected from acquiring hepatitis C through the presence of antibodies. The misinterpretation of antibodies could also be related to confusion over the different hepatitis viruses, in particular hepatitis B, which is also prevalent among IDUs and for which having antibodies often infers immunity. Indeed, over one-third of participants in the current study believed that some people are immune to hepatitis C (35%). Clearly, there is a need to clarify the meaning of the term 'antibodies' as it pertains to hepatitis C at diagnosis and to debunk misconceptions of their protective effect.

As reported previously (Rhodes et al., 2004; Southgate et al., 2003; Southgate et al., 2005), a number of IDUs were confused over the differences between various forms of hepatitis virus and the symptoms of hepatitis C. Over one quarter of the participants in the current study believed incorrectly that hepatitis C was *always* associated with jaundice (26%). The belief that hepatitis C status can be determined by the symptom of jaundice has prevention implications, as some IDUs may assume they do not have hepatitis C and that it is safe to share injecting equipment. IDUs should be informed that jaundice is not a reliable sign for gauging either infection or infectiousness. In addition, they should be advised not to wait for signs of jaundice, or any other sign, before being tested for hepatitis C. In this study, approximately one-third of participants reported they had experienced signs of hepatitis C infection prior to testing, most notably lethargy and feeling unwell. Unlike hepatitis A and B, most (~80%) people do not experience symptoms during the initial (acute) phase of hepatitis C infection, and need to be informed as such. Many participants also reported having a "mild" or "moderate" case of hepatitis C based on their symptoms. The often asymptomatic nature of hepatitis C should be emphasised so that IDUs do not attempt to determine their status based on their symptoms, or lack thereof.

4.5.3 Treatment

As has been found previously (Doab et al., 2005), there is a poor understanding of treatment among IDUs. Although most IDUs knew that there was treatment available for hepatitis C, substantial proportions were confused about herbal remedies. They also, often wrongly, believed that it was still possible to pass on the virus following successful Interferon/Ribavirin treatment, which indicates many are unaware of curative potential of treatment and may reflect a lack of knowledge about treatment in general. Previous research has found that many IDUs believe that being a current IDU is an exclusion criterion for treatment, and recommended targeted education initiatives be used to improve understanding of the treatments available and access to treatment (Doab et al., 2005).

4.6 Quality of life

The global IDUQOL score in this study was 54.2. This score is similar to that of a sample of Canadian IDUs recruited in major cities and drug markets (Brogly et al., 2003b), as well as small samples of Australian IDUs, who scored a mean of 47.5 (Kimber & Day, 2003) and 53.9 (Day et al., 2005).

Hepatitis C was selected by only eight percent of participants as an area that most determined their quality of life, making it the least frequently chosen life area in the study. However, many participants selected health as an area of importance, upon which hepatitis C may well impact. Two-thirds of participants reported that their family was among the five life areas they believed most determined their quality of life at the time of interview (62%). The other life areas chosen by more than half of participants were health (55%) and housing (52%). These findings provide an insight into the life areas perceived as the most meaningful in determining the participants' quality of life. It is possible that hepatitis C infection may simply be a low priority compared with issues concerning relationships, housing, and other non-hepatitis C related health issues.

Although not significant, those who believed themselves to be hepatitis C positive had a slightly higher global IDUQOL score than those who did not (54.9 vs. 51.6; Table 3.8). This unexpected relationship has been noted in previous research (Day et al., 2005); although in subsequent multivariate analysis the relationship did not persist. The IDUQOL, however, is a global measure of quality of life and the lack of relationship with hepatitis C may reflect the lack of centrality of hepatitis C in IDUs' lives, especially given the often asymptomatic nature and protracted natural history of hepatitis C and its prevalence among IDUs (MacDonald et al., 2000). Participant numbers in the current study were considered insufficient for further analysis. More recent investigation of IDUs' QOL has been complemented by the use of a general population health status measure to allow comparison and discussion with the broader literature (O'Brien et al., in press).

4.7 Limitations

There are a number of limitations of the study. The study relied on a convenience sample of IDUs recruited primarily through NSPs and methadone clinics, who may not be representative of the broader IDU population who do not attend such health services. IDUs are a hidden population and it is not possible to obtain a random sample. However, a range of recruitment strategies were utilised, and sample characteristics and drug use were similar to other samples of IDUs. The sample included participants recruited from multiple sites (inner-city, suburban and regional areas), who were both in and out of drug treatment at the time of interview.

Due to largely ethical and practical considerations, this study did not review clinical records to confirm serology, limiting the study's ability to accurately determine the prevalence of infection among the sample. However, the relatively high proportion of people reporting to be hepatitis C positive is consistent with other research examining the prevalence of hepatitis C among IDUs (Day, 2003). Furthermore, serology is less important in the case of determining IDUs' understanding and beliefs of hepatitis C, as was the aim of the current study.

Also, as with all interviewer administered surveys, socially desirable response bias may influence the data. However, studies have found that IDUs are no more likely than any other population to report erroneously about themselves or their behaviours, especially when recall periods are kept short (Goldstein et al., 1995). Social desirability is most likely to have impacted on reports of risk behaviour, which has recently been shown to be reported less frequently in interviewer administered questionnaires compared to self-completed instruments (White et al., in press).

Finally, it is possible that participants may have been confused about some of the true/false statements, concerning the relative risks of hepatitis C transmission in particular. Extensive piloting of the questionnaire was conducted and attempts made to address any confusing items. Further, the qualifiers of ‘no risk’, ‘low risk’ and ‘high risk’ were explained thoroughly to participants at the time of interview. Nonetheless, interviewers noted a degree of confusion over some of these items, and future research may consider simplifying the items further.

4.8 Conclusions

The study uncovered a number of fundamental misconceptions among IDUs about hepatitis C in terms of transmission, symptoms, clinical markers and treatment. Many IDUs were misinformed about hepatitis C transmission, particularly the risks associated with the re-use of one’s own injecting equipment and unprotected sex. Of major concern is the misunderstanding of the term ‘antibodies’ among IDUs and their perceived role in providing immunity.

One in five IDUs who stated they had hepatitis C in the current study believed they could not infect others, and just as many believed they were immune. About one in three participants stated they did *not* have antibodies for hepatitis C, and even more were uncertain, despite reporting themselves to have hepatitis C.

Despite recent, and often multiple testing, many IDUs did not know the results of these tests, and/or misunderstood their meaning, suggesting communication of hepatitis C testing and diagnosis among IDUs needs to be improved. Only about 40% of those tested during or after 2000 reported receiving pre- and post-test counselling.

The study also found that although rates of needle-sharing were low, many IDUs continue to share other injecting equipment. The use of injecting equipment after another person was quite common with 40% sharing spoons, 35% the drug solution or mix, and 33% water in the past month.

Given the high prevalence and incidence of hepatitis C among Australian IDUs, and that many continue to share injecting equipment, the findings of this study are of great concern. The misconceptions about hepatitis C leave IDUs vulnerable to infection, and at risk of infecting others. IDUs need to have the knowledge to reduce their risk of hepatitis transmission. As recommended by Southgate et al. (2003), there is an urgent need to simplify, standardise and clarify the language and education messages around hepatitis C for IDUs, clinicians and other health workers to reduce this confusion. The meaning of the term 'antibodies' as it pertains to hepatitis C needs to be clarified for IDUs and misconceptions of their protective effect corrected. The erroneous belief that some individuals are immune to hepatitis C also needs to be specifically addressed.

The messages used by clinicians in providing a diagnosis and to describe the infectivity of hepatitis C need to be examined and simplified as well, as evidenced by the confusion surrounding test results. Providing IDUs with written results presented in a standardised, uncomplicated format to take with them may be a strategy worth exploring. Further research could focus on innovative education strategies to improve IDUs' understanding of hepatitis C status, re-infection, super-infection and the ability to infect others, as well as ways in which pre- and post-test counselling might be improved.

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