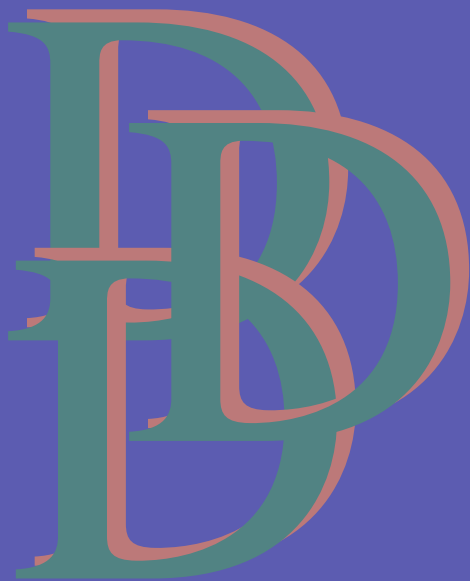


THE 3D PROJECT

Diagnosis
Disclosure
Discrimination &
Living with -hepatitis C



MAX HOPKINS
CARLA TEBBARD



The 3D Project

**Diagnosis, disclosure, discrimination
and living with hepatitis C**

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Monograph 6/2003

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NC

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Many thanks to the survey participants and interviewees for their time and energy.

This report explores the exigent conditions associated with living with a chronic illness, namely hepatitis C infection. Intersecting these demands are the effects of stigma and social marginalisation. Many people with hepatitis C infection have to navigate and negotiate daily a field strewn with misinformation, conflicting identities and unequal power relations, often while labouring under significant ill-health and surviving on low incomes.

EXECUTIVE SUMMARY

The 3D Project, a quantitative and qualitative study, surveyed people in NSW with hepatitis C infection and aimed to describe their experiences of hepatitis C diagnosis, disclosure and discrimination. The sample for the quantitative arm was drawn from people who read *The Hep C Review* (a quarterly magazine of the Hepatitis C Council of NSW) and callers to the Council's information and support telephone service (n=450). Current injecting drug users (n=54) were recruited from a central Sydney needle and syringe program (total N=504). All participants completed a self-administered questionnaire that focused on the three domains of hepatitis C diagnosis, disclosure and discrimination. The age of participants ranged between 18 and 77 years (mean 42 years). There were approximately equal numbers of men and women. Most participants (57.5%, n=290) cited injecting drug use as the source of their hepatitis C infection and over a quarter (27.4%, n=138) had injected drugs in the month prior to completing the questionnaire. Survey participants were mainly older, ex-injecting drug users. Most had no education beyond Year 12 and were on low incomes.

The qualitative arm of the study involved semi-structured, indepth interviews with 19 of the survey participants: 12 females and 7 males. Mean age was 45 years (range 22–72 years), the majority were born in Australia, currently employed and most had acquired their infection from injecting drug use. Data from this arm of the study is used to illustrate points throughout the text of this report.

DIAGNOSIS

Of participants who received a hepatitis C positive diagnosis (i.e. diagnosed after 1988, n=417), a majority (78.2%, n=326) were first told of their infection by a doctor. When asked if their doctor had explained what it means to have hepatitis C, nearly a third of participants (29.5%, n=123) said that they had received 'no explanation'. A further 174 (41.7%) reported that their doctor had 'partly explained' hepatitis C virus infection and 116 participants (27.8%) reported that their doctor 'had explained' what it means to have hepatitis C infection. Women were more likely to report receiving 'no explanation' about hepatitis C from their doctor than men ($p < .05$). Following diagnosis, 137 participants (32.9%) reported that they had been given no information or advice about conventional treatments, natural therapies, referral to a specialist, counselling, information about how the virus might affect health or information about support groups. Participants who reported receiving none of the above following diagnosis were more likely to be current injecting drug users, or diagnosed from 1989 to 1996 ($p < .05$). Participants who were referred to a specialist were more likely to be older (>45 years) ($p < .01$).

DISCLOSURE

Most participants had disclosed their infection to a doctor, another healthcare worker, partner, family and friends, and many had experienced 'bad' reactions from disclosing their infection. In all, 189 participants (37.5%) said that they regretted telling someone about their infection. Over a third of participants (36.7%, n=185) reported that information about their hepatitis C

infection had been told to someone without their permission. The most common sources of unauthorised disclosure included friends (15.9%, n=80) and doctor or other healthcare worker (13.5%, n=68). Sixty participants (11.9%) reported that they had been pressured into disclosing their infection.

DISCRIMINATION

Reports of hepatitis C-related discrimination were common throughout the study and involved a variety of sources. In relation to healthcare, over a quarter (27.8%, n=140) of all survey participants reported experiencing discrimination from a healthcare worker other than a doctor, and 65 participants (12.9%) from a doctor. In all, 64 participants (12.7%) reported that they had been refused medical treatment because they have hepatitis C infection. Compared with participants who did not inject drugs, current injecting drug users were more likely to report: refusal of medical treatment because they had been injecting at the time ($p<.001$); IDU-related discrimination from their doctor ($p<.01$), family ($p<.01$) and from friends ($p<.05$). A reduced regression model contained four variables that predicted discrimination when other variables were taken into account. These were: currently injecting drugs; knowing others with hepatitis C; pessimism regarding future health; and having limited time with social and familial support networks because of ill health associated with hepatitis C infection. A total of 227 participants (45.0%) reported that discrimination had negatively affected their emotional health and 180 (35.7%) reported that their physical health had been adversely affected by discrimination. In all, 108 participants (21.4%) reported that discrimination had a negative effect on their employment and 134 participants (26.6%) reported that discrimination had adversely affected their personal relationships.

HEPATITIS C INFORMATION AND SERVICES

Participants accessed information from multiple sources, including the Hepatitis C Council of NSW, doctors, other healthcare workers and the internet. Many incorrectly answered questions about risks for hepatitis C transmission. Participants' responses to hepatitis C knowledge questions were associated with mode of acquisition of infection, gender, ethnicity, income, sources of information and contact with other people with hepatitis C infection. For example, women were more likely than men to correctly answer specific questions about hepatitis C prevention ($p<.01$) and health impacts ($p<.05$). Participants reported that they wanted more information about treatments, prognosis, pregnancy and where to access 'hep C-friendly' doctors. A small proportion of participants belonged to a support group. Most reported that their support group served multiple functions, like providing information and emotional support.

time'. The most frequently reported impact of infection was fatigue. Gender, current health status, income and doctors' explanation of hepatitis C infection, significantly affected participants' future outlook. For example, participants who reported that their doctor did not explain to them what it means to have

CHAPTER 1

BACKGROUND AND LITERATURE REVIEW

BACKGROUND

Viral hepatitis

The liver performs a vital role in regulating, synthesising, storing and secreting many important proteins and nutrients in the body. The liver purifies, transforms and clears toxic or unneeded substances from the system. Damage to the liver can occur as a result of inflammation and 'hepatitis' is a broad term used to describe inflammation of the liver. Hepatitis has numerous potential causes such as viruses, bacteria, fungi, or protozoa. Exposure to toxins like alcohol and other drugs or chemical poisons are also significant causes of hepatitis. Occasionally, autoimmune hepatitis develops when the immune system attacks and destroys portions of the liver by incorrectly reacting against its own cells.

The most common cause of hepatitis is viral (Everson and Weinberg, 1999). Viruses are the most fundamental type of living organism and in the case of hepatitis C are simply pieces of protein encased in a lipid envelope.

LITERATURE REVIEW

A review of the hepatitis C literature reveals several prominent areas of research and discussion (Hopwood and Southgate, 2003). These include: the epidemiology of the hepatitis C virus; conventional Western medical treatments; physical and psychological impacts of interferon treatments on health related quality of life; alternative and complementary treatments; the medicalisation of people with hepatitis C; and the meaning of support for affected people. This report begins by providing a background to the hepatitis C epidemic. The sociological literature regarding living with hepatitis C is then reviewed.

Background to the global hepatitis C epidemic

By the time the hepatitis C virus had been identified in 1988, millions of people throughout the world were infected - many via medical interventions involving contaminated blood products and therapeutic injections with reused equipment. Most people infected do not know that they have hepatitis C (Everson and Weinberg, 1999). Symptoms usually do not present until many years, even decades, after infection occurs.

The epidemiology of the hepatitis C virus varies widely within and between countries and continents, revealing multiple patterns of epidemics. Generally speaking, in countries such as Australia and the USA, the epidemic is most evident among people aged 30 to 49 years and is largely attributable to an increase in the prevalence of injecting drug use over the last 30 years. In developing regions, the epidemic is found among older people and appears to be the result of unsafe therapeutic injections and use of contaminated medical blood products. A similar epidemiological profile is evident in some developed countries, such as France, where nosocomial transmissions are apparent. Across Europe to Asia, average prevalence rates range from very low in Greenland and Norway to higher

in France (1.15%) and Italy (>2.0%) and still higher in parts of Russia (3.8% in Siberia) and up to 10.7% in Mongolia (Crofts, 2001). Similarly, prevalence rates vary widely throughout Africa (for example, Tunisia 0.7% and Egypt 22.5%) and throughout Asia (up to 4.0% in China and >20.0% in parts of Japan) (Crofts, 2001). The USA has an average hepatitis C prevalence of 1.8%, with around 2.7 million people chronically infected. Hepatitis C infection is the leading cause of liver transplantation and is implicated in about 40% of chronic liver disease in the United States.

Background to the hepatitis C epidemic in Australia

Law (2003, May) places the number of people infected in Australia at around 210,000 (lower and upper limits of 157,000 and 252,000). Approximately 90,000 of these reside in the most highly populated state of New South Wales (ANCARD, 1998; ANCHARD, 2002). Currently, hepatitis C is the most frequently reported notifiable infection in Australia. Around 16,000 new hepatitis C infections occur annually in Australia with about 91% of new infections happening among injecting drug users (National Centre in HIV Epidemiology and Clinical Research, 2002). Epidemiological research indicates that the majority of people contract hepatitis C through sharing contaminated injecting drug use equipment (MacDonald et al., 2000; Freeman et al., 2000; Crofts, Jolley et al., 1997; Carruthers et al., 1997; MacDonald et al., 1996). Approximately 5-10% of all prevalent hepatitis C infections in Australia are the result of blood transfusions or the use of blood products prior to 1990 when screening was introduced (Law, 2003, May).

Among Australians with hepatitis C infection, current estimates suggest that in 2001 approximately 6,500 people were living with cirrhosis, there were 175 cases of hepatitis C-related liver failure, 50 cases of hepatocellular

with an approximate 6-7% chance of transmitting the virus from mother to child during delivery when the possibility of blood being intermixed is greatest (Kaldor et al., 2000; Everson and Weinberg, 1999). Some studies indicate that a number of people report no known vector of transmission to explain their infection (Abraham et al., 1999; Sladden et al., 1997). Hepatitis C is not transmitted through sharing household items like cutlery and crockery, nor through sharing toilet or laundry facilities (Harvey, 2000-2003; Sladden et al., 1997).

Around 80% of people infected with hepatitis C in Australia are either past or 2ed

In this study many people reported no change in their life since a positive diagnosis while others reported a significant deterioration in circumstances and well being. Fatigue was the symptom most cited and this affected several aspects of participants' daily lives. Stereotyping, isolation, stress and discrimination at work were reported as well as concerns about commencing personal relationships. Sexual contacts decreased and fatigue, nausea and insomnia were reported to affect work performance. Some people improved their diet following a hepatitis C diagnosis (Sladden et al., 1998). Similarly, Gifford et al. (2001) found that after women were diagnosed with hepatitis C, 76% of those who drank alcohol had reduced or stopped their consumption.

Other than a small amount of empirical research, sources of information on the impact of a positive diagnosis include such publications as newsletters produced by injecting drug user associations, a state drug and alcohol authority magazine, hepatitis C websites, brochures from national and state hepatitis C councils, and parliamentary reports (Harvey, 2000-2003; Lowe and Cotton, 1999; Standing Committee on Social Issues, 1998; Wood, 1997). In addition to these, several books written by people with hepatitis C have been published giving voice to people's experiences of diagnosis (Everson and Weinberg, 1999; Dolan, 1997; English and Foster, 1997).

Disclosure

There is little scholarly research on the psychosocial effects of disclosing a positive hepatitis C status. However, an exploratory study of hepatitis C-related discrimination revealed that disclosure of a positive status often resulted in 'hysterical responses' (Crofts, Louie et al., 1997, p. 90). Similarly, a study by Dunne and Quayle (2002) found that disclosure of hepatitis C infection was a stressful and ongoing process for participants. These findings resonate with those from the Anti-

Discrimination Board of New South Wales' Enquiry into Hepatitis C-related Discrimination (2001). Submissions to the Enquiry revealed that disclosure usually precipitated discriminatory behaviour and that some people avoided disclosing their positive status to avoid discrimination, particularly in healthcare settings. Conversely, Gifford et al. (2001) found that when women with hepatitis C disclosed their status, most of their partners were supportive of them whether the partner had hepatitis C or not. Other sources of information include government reports and health promotion material. These have canvassed the issue in relation to disclosure to family members; highlighting positive people's fear of transmission within families, particularly to partners and children (Harvey, 2000-2003; Lowe and Cotton, 1999; Australian Hepatitis Council and the Australian National Council on AIDS and Related Diseases, 1999; Standing Committee on Social Issues, 1998).

Whereas past research has demonstrated the beneficial psychological health effects of disclosure in relation to chronic illness (Pennebaker, 1995), disclosure of hepatitis C may not have such positive outcomes. The literature concerning disclosure of HIV infection illustrates that revealing a positive diagnosis to others does not always imply a road to improved health and well being (Holt et al., 1998; Malcolm et al., 1998; Ariss, 1997). These sources suggest that while often there are beneficial health outcomes to be gained from disclosing, the experience of disclosure can produce stress in people's lives.

Hepworth and Krug (1999) argue that a moral imperative is placed on people to disclose their hepatitis C infection to others and explain to families, loved ones, casual partners, even sometimes their doctor, the meaning of hepatitis C. Disclosing a positive status can be traumatic. People's reactions are unpredictable and confusion about the implications of being close

The results of one study suggest that participants experience most instances of discrimination from healthcare professionals (Crofts, Louie et al., 1997). Similar findings were recently made by the Anti-Discrimination Board of NSW (2001). These works have documented poor advice given by doctors to people with hepatitis C and illustrate cases of bad treatment by general practitioners, dentists, nurses and other healthcare workers under the guise of infection control. They conclude with a call for discrimination to be acted upon as a prerequisite for controlling the continued spread of hepatitis C infection among injecting drug users. Only through non-judgemental medical services will injecting drug users access appropriate information regarding the prevention of hepatitis C transmission.

Treatment of hepatitis C infection and health-related quality of life

Medical research into hepatitis C treatment constitutes the majority of the scholarly literature on the virus. Conventional medical treatments for people chronically infected with hepatitis C involve either interferon alpha-2b monotherapy or interferon and ribavirin combination therapy (Battaglia and Haggmeyer, 2000; Tripi et al., 2000; Ware et al., 1999). With interferon monotherapy approximately 20-25% of people with chronic hepatitis C achieve a sustained virological response (SVR) (Soriano et al., 1999) that is, following completion of treatment the virus remains undetectable in a patient's blood and liver for a period of six months. However, when interferon is used in combination with ribavirin a SVR is achieved in approximately 30-60% of people chronically infected. Treatment success depends upon a range of variables such as a patient's age and the viral genotype with which one is infected (Hadzijannis, 2000; Barbaro et al., 2000; Di Marco et al., 2000; Lai, 2000; Malnick et al., 2000; Locarnini, 1999, August). Additionally, high doses of interferon alpha-2b

have been used to prevent the onset of chronicity in patients with an acute hepatitis C infection (Jaeckel et al., 2001; Vogel et al., 1996). Results from recently published studies indicate that pegylated interferon monotherapy produces a significantly better SVR than standard interferon alpha-2b monotherapy. When used in combination with ribavirin, even better response rates ensue. (Cornberg et al., 2002; Sobesky and Buffet, 2001; Gervais et al., 2001; Glue et al., 2000).

Medical research has often focused on the efficacy of therapy to ameliorate symptoms of chronic hepatitis C infection. Elimination of the hepatitis C virus from the body does correlate with reported improvements in measures of health-related quality of life or general sense of well being (Ware et al., 1999). Health-related quality of life instruments are widely used to assess the impact of chronic illness (Bonkovsky et al., 1999; Singh et al., 1999; Ware et al., 1999; Foster et al., 1998; Koff, 1998; Owens, 1998; Carithers et al., 1996; Davis et al., 1994). Studies in clinical settings using a range of instruments, including the SF36 Health Survey and the Sickness Impact Profile, reveal that people with hepatitis C infection have reduced physical and social functioning, reduced mental and general health, limitations in physical and emotional roles and reduced energy and increased fatigue (Conrad et al., 2001; Miller et al., 2001; Bonkovsky et al., 1999; Singh et al., 1999; Ware et al., 1999; Bayliss et al., 1998; Koff, 1998; Carithers et al., 1996; Davis et al., 1994). These symptoms show improvement in people who respond to interferon treatment.

limitations in physical and emotional roles and

treatment for hepatitis C reveals major depression, suicidal thoughts, lack of confidence in work, self-blame for contracting the virus, fatigue and amotivation, anorexia, anxiety and paranoia (Dieperink et al., 2000; Kraus et al., 2000; Clemensen et al., 1999; Miyaoka et al., 1999; Maunder et al., 1998; Sasaki et al., 1997). Interferon therapy has long been associated with increased emotional reactions as well as an accentuation of previous symptoms such as phobias, obsessional thoughts and rituals (Maunder et al., 1998). Monji et al. (1998) claim that the most common reason for discontinuing interferon treatment in chronic hepatitis C patients has to do with adverse psychiatric effects for those either on low or high doses of interferon. These symptoms usually disappear soon after cessation of interferon therapy although reports of persistent neuro-toxicity exist (Monji et al., 1998). Clemensen et al. (1999) suggest that assisting patients with managing the behavioural side effects of interferon could improve compliance and overall quality of life.

As these studies document, people with

The medicalisation of people with hepatitis C infection

Medical and scientific discourses inform understandings of new diseases and their impact on people's quality of life. In this report we use the term 'medicalisation' (Broom and Woodward, 1996; Lindenbaum and Lock, 1993) to refer to a tendency for patients, following a diagnosis, to incorporate medical information about their health into a shifting sense of self. Medical test results are often used by patients to reconstruct a new personal health-identity (Krug, 1995). This tendency to recreate one's identity after a diagnosis speaks to the power and influence of medicine in Western societies (Lupton, 1997) and an 'absence of meaning' around hepatitis C infection (Krug, 1995, p.317). The dominance of medical discourses and a relative lack of alternative voices around living with hepatitis C have material effects on the way people experience their infection. For example, Krug (1995) discusses the tendency for people presented with a positive diagnosis to adopt the medical technologies and associated discourses that define the progress of their disease as a reflection of their state of health and therefore 'true' selves. These discourses often present as 'facts' information about hepatitis C that is 'still preliminary and contested' within medical and scientific literature (Krug, 1995, p. 306). Medical diagnoses may become self-fulfilling prophecies for some patients. Such a consequence of medicalisation is illustrated in research by Rodger et al. (1999) who demonstrated the deleterious health effects that knowledge of a hepatitis C positive diagnosis can have on people previously unaware of their infection.

Hepworth and Krug (1999) argue that medical and scientific discourses deny the experience of being hepatitis C positive in a social and cultural context. Issues such as stigmatisation, discrimination, access to health services, changes in one's sense of identity and difficulties

with forming intimate relationships are either denied or played down, yet these issues remain as central themes in the lives of many people affected by the virus. Stories that give back a sense of meaning to life are needed more than medical and scientific information. Access to narratives about people's daily experiences of

to shrug it off as unimportant. He suggests that this has wider ramifications for people with unhealthy lifestyles (for example, in relation to the use of alcohol and other drugs, diet and exercising) than for people with healthy lifestyles. Bayliss et al. (1998) also claim that some doctors have probably under-estimated the impact of hepatitis C infection on the health and well being of their patients. Similarly, Krug (1995) writes that it is common for people with hepatitis C infection to express concern that most physicians, scientists and the state under-estimate the severity of the virus.

Conversely, Owens (1998) writes that doctors may sometimes perceive their patients to be more ill than patients perceive themselves to be. Consequently, some doctors may recommend treatments that patients do not need. The tests that are normally used to assess the impact of symptoms on hepatitis C infected patients' quality of life, such as the SF36 Health Survey, focus on a patient's physical and mental functioning. While these tests show good reliability and validity, Owens calls for a complementary study of people with hepatitis C to assess how bothered patients are by the symptoms that they experience. This would enable people to express how their symptoms impact on their daily life.

In addition to constructing individual identities, medical and scientific discourses inform government policy. Governments have a strong tendency to privilege scientific and medical models of disease in their formulation of policy and implementation strategies to the

Some research findings show that healthcare professionals cannot be relied on to provide information about hepatitis C (Gupta et al., 2000; Smyth et al., 1999; Crossen et al., 1999, August; Crofts, Louie et al., 1997; Krug, 1995). In a study of five thousand caller records to a community based hepatitis C telephone information and

QUESTIONNAIRE – SAMPLING AND PROCEDURE

Study participants were men and women with hepatitis C infection living in New South Wales. Participants were recruited between March 2001 and August 2002 using convenience sampling, including snowballing. Three strategies were used for recruitment to the quantitative arm of this study. The first method consisted of inserting a reply-paid copy of the 3D Project questionnaire into the March and June 2001 editions of *The Hep C Review*, a quarterly hepatitis C news and information publication produced by the Hepatitis C Council of New South Wales (HCC of NSW). *The Hep C Review*

INTERVIEW – SAMPLING AND PROCEDURE

Interview participants were men and women living in New South Wales who had tested positive for antibodies to hepatitis C virus infection. Interview participants were recruited via an advertisement positioned at the end of the questionnaire asking for volunteers to take part in an hour-long interview. Out of a total of 19 interview participants, all except one were recruited this way. The final interview participant directly approached the principal investigator at REPIDU needle and syringe program and requested to be interviewed.

Interviews were conducted in an informal setting such as a cafe or restaurant, a park, or in a private residence if preferred by the participant. Several chose to be interviewed at the National Centre in HIV Social Research. Before the interviews commenced, participants were given an information sheet about the study, which included an outline of procedures for making complaints, for following up the progress of the study and/or obtaining a report of the study. Participants then signed a consent form and chose a pseudonym to preserve their anonymity throughout the tape-recorded interview. Interviews took on average 45 to 60 minutes to complete. As with the questionnaire, no financial incentives were offered for participation in the interview arm of the study. Participants were offered coffee, tea and cake as a sign of appreciation for their time.

The interview schedule contained semi-structured, in-depth question areas that focused broadly on participants' experiences of hepatitis C diagnosis, disclosure and discrimination. In addition, participant accounts of their backgrounds, including alcohol and other drug use, involvement with support groups, general physical and psychological well being, experience with treatments and opinions

regarding hepatitis C service provision were sought. The semi-structured nature of the schedule enabled discussion of issues deemed important by individual interviewees. Issues raised by participants were explored for their relevance to the focus of the study.

QUANTITATIVE AND QUALITATIVE ANALYSES

Quantitative data were analysed using SPSS 10.0 software. Most of the findings presented here are descriptive (frequency and chi-square statistic) and designed to explore aspects of a population that prior research has not investigated. Inferential analyses (multiple linear regression) were conducted with regard to hepatitis C-related discrimination.

Analysis of qualitative data involved a that prior research v0683sgc.392tdfiuredvestigadiscren25 le linear

CHAPTER 3

CHARACTERISTICS OF SAMPLE

The following section reports on the characteristics of participants in the survey arm of the study, with figures presented in Table 1. The sample characteristics of the interview participants are presented in Table 2.

QUESTIONNAIRE

Response rate

A total of 6,000 questionnaires were printed and distributed via *The Hep C Review*, the Helpline and direct recruitment. Over the course of eight months, 504 completed questionnaires were

Employment

When participants were asked about their current employment, 93 (18.5%) reported that they were working full time and 50 (9.9%) reported working part time (Table 1). In total, 91 participants (18.1%) reported that they were unemployed and 160 (31.7%) reported receiving a pension at the time of completing the questionnaire. Finally, 35 (6.9%) reported that they were self-employed, 13 (2.6%) were students and 52 (10.3%) received an income from a mix of work, study and pension. The four most commonly cited categories of employment of those 197 participants (39.1% of the total sample) who reported currently having a job were, healthcare (18%), administration (11%), labouring (10%) and education (9%).

Sexual identity

A total of 403 participants (80.0%) reported that they were heterosexual or 'straight' (Table 1). A further 44 (8.7%) identified as bisexual, 40 (7.9%) identified as either 'homosexual, gay or queer', and seven participants (1.4%) reported their sexuality as 'other'.

Injecting drug use

Participants were asked if they had injected any drug in the month prior to being surveyed (Table 1). Over a quarter (27.4%, n=138) had injected at least one drug during this time. Of those who reported that they were currently injecting, the most commonly injected drugs were heroin (61%), amphetamine/speed (41%) and cocaine (33%).

Country of birth and ethnicity

The majority of participants were born in Australia (Table 1). In total, 401 (79.6%) were Australian born. Of 323 participants (64.1%) who reported their ethnicity, 304 (94.2%) said that they were Anglo, European or 'Aussie'. Among the remainder, five were Asian, two were Arabic and 12 reported their ethnicity as 'other'. In all, 16 participants (3.2%) reported that they were Aboriginal or Torres Strait Islanders.

Living arrangements

Nearly half of all participants (45.8%, n=231) who completed the questionnaire reported that they lived with a partner, 156 (31.0%) lived with children, 117 (23.2%) lived alone, 55 (10.9%) lived with a friend (or friends), 38 (7.5%) lived with their mother and/or father and 47 (9.3%) lived with 'other' (Table 1).

Prison experience

A total of 63 participants (12.5%) reported that they had been in prison in 2000 (Table 1). Of those who reported being in prison during 2000, 28 (46%) said that they had injected a drug while there.

Treatment for hepatitis C infection

Participants reported receiving a range of treatments for hepatitis C infection (Table 1). Fifty-eight (11.5%) had received interferon monotherapy, 54 had been on interferon and ribavirin combination therapy, 11 had tried multiple therapies including conventional western medicine, alternative and complementary treatments, and 52 cited 'other' treatments for hepatitis C infection. Nearly two-thirds (n=325, 64.5%) reported having no treatment.

Finally, with regard to the geographical spread of the sample recruited for this study, 214 different postcodes from urban, suburban and regional areas throughout NSW were represented in the data.

INTERVIEWS

Participants

Of the 19 participants who were interviewed, 12 were women (63%) and seven were men (37%) (Table 2). The age of the interview participants ranged from 22 to 72 years with a mean age of 45 years. In all, 11 out of 19 participants who were interviewed were born in Australia. The remainder reported that they were born in England

(n=2), New Zealand (n=2), Canada (n=1), Holland (n=1), Cambodia (n=1) and Uruguay (n=1). A majority of participants were employed (n=9), 6 were unemployed, one described her employment as unpaid and three were retirees (Table 2). This arm of the study did not enquire into the sexual identity. Among the 19 interview participants, 11 reported that they did not live with a partner and 12 reported that they lived in a household with children. Four participants had attended university, two reported that they had left school before Year 10, five reported leaving school after Year 10 and one participant left school after completing Year 12. The remaining interview participants either did not recall their education or were educated overseas and could not give a clear indication of educational achievement equivalent to the NSW system. None had attended university. Most (n=12) had not been treated for their infection (Table 2). Six had either completed treatment or were undergoing treatment at the time of interview. Finally, almost half of the interview participants had acquired their infection through injecting drug use (n=8), six had medically acquired infections and five were unsure of the source of their infection (Table 2).

| Characteristic | n | % |
|---|---|---|
| Self-reported time since infection (n=490) | | |
| Within the last year | | |
| Between 1 and 5 yrs ago | | |
| Between 6 and 10 yrs ago | | |
| Between 11 and 20 yrs ago | | |

Table 1: Characteristics of survey sample (N=504)^a

| Characteristic | n | % |
|--|-----|------|
| Gender (n=499) | | |
| Male | 254 | 50.4 |
| Female | 244 | 48.4 |
| Transgender | 1 | 0.2 |
| Age (n=472) | | |
| 18–30 years | 65 | 12.9 |
| 31–50 years | 334 | 66.3 |
| 51–77 years | 73 | 14.5 |
| Education (n=495) | | |
| Up to and including Year 12 | 269 | 53.4 |
| Diploma/degree | 183 | 36.2 |
| Postgraduate | 43 | 8.5 |
| Self-reported source of infection (n=494) | | |
| Injecting drug use | 290 | 57.5 |
| Medical blood products | 74 | 14.7 |
| Tattooing | 20 | 4.0 |
| Sex | 15 | 3.0 |
| Body piercing | 5 | 1.0 |
| Other | 44 | 8.7 |
| Multiple responses | 46 | 9.1 |

Table 2: Characteristics of interview sample (N=19)

| Characteristic | n | % |
|---------------------------------|----|----|
| Gender | | |
| Male | 7 | 37 |
| Female | 12 | 63 |
| Employment | | |
| Unemployed/pension | 6 | 32 |
| Employed full time | 7 | 37 |
| Employed part time | 2 | 11 |
| Unpaid work | 1 | 5 |
| Retiree | 3 | 16 |
| Treatment for hep C | | |
| Currently in Tx or completed Tx | 6 | 32 |
| Terminated Tx | 1 | 5 |
| Untreated | 12 | 63 |
| Mode of acquisition | | |
| Medical | 6 | 32 |
| IDU | 8 | 42 |
| Unsure | 5 | 26 |

DISCUSSION

This sample is not representative of all people in NSW with hepatitis C infection, and this is evident from a comparison with known attributes of the 'hepatitis C community' in Australia. For example, around 58% of our sample reported contracting their infection from injecting drug use and this compares with estimations that 80% of all hepatitis C infections in Australia are explained by injecting drug use. Our sample contained about 50% males and 50% females; this is an over representation of female participants. Around 35% of all hepatitis C diagnoses in Australia are among women (ANCAHRD, 2002).

An explanation for the low response rate of the quantitative arm of the study involves two issues, beginning with the initial recruitment strategies used. We sent multiple copies of the questionnaire inserted in *The Hep C Review* to organisations with the aim that they would be passed onto appropriate clients or patients of their services. It may be that potential participants did not access many of these questionnaires as service providers were limited in the time that they had to promote the study and to distribute the questionnaires to clients and patients.

A second explanation for the low response rate may involve participants' concerns with confidentiality and anonymity. The authors noted that a substantial number of questionnaires (around 10%) were returned either inside stamped envelopes or with the words 'hepatitis C' obscured from the study title. Often the returned survey form would be heavily taped closed and/or with staples attached to the perimeter, even though the adhesive substance bordering the questionnaire worked effectively. Presumably this was done to disguise handwriting or personal information that may be recognised by family and friends, or perhaps identified by postal staff in small town offices. In sum, it is likely that our poor response rate may have at least partly resulted from an over-reliance on busy organisations to distribute questionnaires, and participants' fear of being identified while either filling out the questionnaire, having it in their possession or while posting it.

CHAPTER 4

DIAGNOSIS

Most survey participants were diagnosed with hepatitis C infection between 1992 and 1999 (mode=1995). A total of 71 (14.9%) were diagnosed with non-A non-B hepatitis before 1988 (i.e. prior to the virus being identified as hepatitis C). For the purposes of analyses of quantitative data conducted throughout this chapter, only those participants (n=417) who received a hepatitis C positive diagnosis (i.e. those diagnosed since 1988) have been included. Because of a cumulative increase in medical knowledge about hepatitis C throughout the 1990s, and the establishment of state and national hepatitis C councils by 1997 — thus enabling doctors to refer patients for information and support — the experience of participants diagnosed from 1989 to 1996 is compared with those diagnosed from 1997 to 2001.

Of participants diagnosed from 1989 to 2001, a majority (78.2%, n=326) first learnt of their

were more likely to be current injecting drug users (42.9% vs 30.2%, $p < .05$), or more likely to be diagnosed from 1989 to 1996 (37.6% vs 25.9%, $p < .05$) (Table 5). Participants diagnosed from 1997 to 2001 reported that they were more likely to

*thought we were ... it made us
frightened. We just thought that I'd
be dead, you know ...yeah. By the
sound of it, I thought I was finished.
You know, just thoughts that come in*

Some participants reported that the information they were given at diagnosis was wrong. Several participants reported receiving inaccurate information regarding transmission and lifestyle practices. Misinformation had implications for participants' future trust in their doctors' expertise, it perpetuated stereotypes and clouded the real issues:

It seems that there are so many doctors who know nothing about hep C. They don't always admit it and then they just give you the wrong information because they think 'Oh, that will keep her quiet' but it doesn't if she already knows he's not telling her the truth. You need to be able to have confidence in your medical practitioner. (Mavis, 70 years old)

So that was my initial diagnosis. She referred me to a specialist from there. So it was pretty negative and there was very little information. She didn't know very much about it. She told me ... I would have got it from my husband because he's African and, of course, African people have all these dreadful diseases. So it was, you know 'You got it through sexual intercourse and you got it through your husband', so that was very upsetting for him at the time. She was like 'You've got a terminal disease and I don't know much about it but here's a specialist to talk to'. So it was pretty horrendous at the time. (Deb, 40 years old)

Misinformation, or statements made by health professionals that lacked clarity, contributed to the confusion, distress and sense of isolation reported by several participants following their hepatitis C diagnosis:

[H]e said he didn't know much about it and he sent me down to Dr L and what he said to me was 'Ooh, they're going to like you down there. You've never smoked and you've never drunk and you've got hepatitis C. They'll like you down there'.

What do you think he meant by that?

I thought that he meant that ... if you don't smoke or drink, you don't get hepatitis C, you know? I thought I was one of the few. (Claris, 57 years old)

Healthcare workers' reactions to a patient's positive diagnosis

Several participants reported that their diagnosis was accompanied by either moral indignation or a lack of concern from their doctor, or both. These participants believed healthcare workers were uninterested in treating them, doctors stereotyped them as 'junkies', and held them personally responsible for their infection:

[The medical staff] didn't explain anything about it and the doctor ... it seemed to me that what he thought was we all had it [hepatitis C] and we were all junkies, and it was a part of his job to refer us to a specialist ... (Gloria, 45 years old)

Participants were often concerned about healthcare workers' assumptions. Some participants reported that doctors assumed that their hepatitis C infection was the result of injecting drug use. Conversely, as illustrated below, one specialist assumed that his patient was not an injecting drug user. The participant felt that it was an inappropriate judgement for a specialist to make:

[E]ven the specialist that I went to, I can remember feeling quite offended that ... like, we had a pleasant conversation and when he said 'How did you get this?' and I said 'Well, I've taken drugs and all that'. He said 'You don't look like a drug addict'. (laughs) 'Well, thank you!' ... And that's a guy that deals with [hepatitis C] all the time. (Helen, 44 years old)

drug use. These results are in keeping with the findings of the Anti-Discrimination Board of NSW's enquiry (2001), and may partially be explicated by recent research in naturalistic settings into discrimination against people in stigmatised roles, which demonstrates that while overt or formal discrimination may not transpire, stigmatised people are responded to significantly more negatively in interpersonal ways (Hebl et al., 2002). Some of these ways include shorter interpersonal interactions, less words spoken during interactions and less adherence to common courtesies. In the present study, some participants who acquired their hepatitis C infection from injecting drug use, or were currently injecting, may have received no explanation or information about their infection from their doctor because of a tendency for some doctors to shorten consultation times and engage less with these patients. This form of interpersonal discrimination may be enacted to communicate a doctor's disdain regarding the source of a patient's infection and/or their current injecting, and in some cases to discourage the patient from returning for further treatment. More research into clinical interactions is required.

Older participants in the survey phase of our study were more likely to be referred to a specialist following diagnosis. Older participants in the interview phase of our study reported being referred to a specialist often because the diagnosing doctor knew little about hepatitis C infection. The lack of information provided by some doctors at diagnosis was a concern for several older interviewees, and caused distress, frustration and uncertainty about their prognosis, often prompting a referral.

It is encouraging to find in our survey data that participants diagnosed from 1997 to 2001 were more likely to receive an explanation about hepatitis C infection from their doctor, and be given pamphlets about hepatitis C, advice

regarding natural therapies and information about treatments. However, doctors' provision of information about support groups, information about how hepatitis C might affect their patients' health, post-test counselling and referral to specialists appears to have not changed from the reported low rates from 1989 to 2001. Having access to a range of information from an agency like a state hepatitis C council, or support group, can help people learn how to cope with their infection; especially when doctors may be unable, or unwilling, to provide it.

In summary, these results regarding diagnosis of hepatitis C infection are consistent with findings outlined in the literature. These results have a range of implications for hepatitis C patients. Evidence presented here suggests that since the latter part of the 1990s, hepatitis C patients received more information about their infection at diagnosis than in previous years.

However, patchy and inconsistent provision of comprehensive and detailed information about hepatitis C infection and support services, as reported by our participants, appear at odds with the diagnostic procedures recommended by the National Health and Medical Research Council guidelines (NHMRC, 1997) and the practices recommended in the general literature on clinical interactional skills (Smith and Norton, 1999; Enelow et al., 1996; Gordon, 1995). In recent years, efforts have been made to ameliorate hepatitis C patients' negative experiences of healthcare in NSW. The NSW Hepatitis C Strategy 2000-2003 recognises that education and training of healthcare workers is necessary to improve the quality of health services for people with hepatitis C infection, to improve the effectiveness of prevention programs and to reduce hepatitis C-related discrimination within the health sector (2000). These strategies have been designed to achieve an increase in the quality of medical

Australasian Society of HIV Medicine (ASHM) (n.d.), with a similar aim, has developed a HIV and hepatitis C continuing medical education program for general practitioners.

Similarly, there has been a steady increase over the last decade in the availability of information and support for people with hepatitis C infection in Australia. Throughout the early to mid 1990s, state hepatitis C councils began to emerge and in 1997 the Australian Hepatitis Council was incorporated as the national body of hepatitis C organisations. Ever since, these councils have been working to inform affected people and the community about hepatitis C infection. Publications from these organisations include magazines and information pamphlets aimed at keeping people affected by the epidemic abreast of research related to new treatments, the prevention of transmission and a range of social issues. Doctors need to be aware of the key agencies that provide information and support to hepatitis C patients and refer their newly diagnosed patients to them.

All health professionals urgently need to be informed about hepatitis C infection, as inadequate provision of information to patients, disengagement with patients and a lack of referral to relevant support services for hepatitis C infection at the point of diagnosis will obstruct efforts to prevent the further spread of the virus among the community.

CHAPTER 5

DISCLOSURE

Disclosure of hepatitis C infection can result in unpredictable reactions, and confusion about the implications of being close to a person with hepatitis C has led to acts of discrimination (ADB of NSW, 2001). The widespread confounding of injecting drug use with hepatitis C and a lack of accurate information circulating in the community concerning the virus has contributed to the stigma associated with hepatitis C infection. A majority (52.0%, n=262) of participants in the study reported that they had encountered a 'bad' reaction to disclosure of their hepatitis C diagnosis.

When asked to whom did survey participants *first* disclose their hepatitis C infection, the most common response was 'wife/husband/partner' (45.4%, n=229), 'family' (18.3%, n=92) and 'friends' (15.1%, n=76). Participants were asked to nominate to whom they had ever disclosed their infection from a list of social categories (Table 12). Many had disclosed their infection to their doctor (76.0%, n=383), partner (73.2%, n=369), family (71.2%, n=359), friends (69.0%, n=348) and another healthcare worker (65.7%). Women were more likely than men to have disclosed their hepatitis C infection to their partner (Table 10) (79.8% vs 67.9%, $p < .01$) and doctor (Table 11) (80.7% vs 72.2%, $p < .05$), however, no other gender differences in relation to disclosure were found.

Table 10: Disclosure of hepatitis C infection to partner^a

| Yes n (%) | No n (%) |
|--------------|-------------|
|--------------|-------------|

Participants were asked who had reacted 'badly' to disclosure of their hepatitis C diagnosis (Table 12). Interestingly, 41.9% (n=211) of the total sample reported that 'no one' had reacted badly to disclosure of their hepatitis C diagnosis. One in six women (16.6%, n=31) reported that their partners reacted badly when they disclosed to them.

In all, 189 participants (37.5%) said that they regretted telling someone about their infection. Over a third (36.7%, n=185) reported that information about their hepatitis C infection had been told to someone without their permission. Of these cases, a common source of unauthorised disclosure included friends (43%, n=80) and doctor or other healthcare worker (37%, n=68). Finally, 11.9% of all participants reported that they had been pressured into disclosing their infection and of these 60 people, 31 (51.7%) reported that a healthcare worker had pressured them into disclosing and 17 (28.3%) reported that a government department had pressured them into disclosing their hepatitis C infection.

EXPERIENCES OF DISCLOSURE

This section reports on disclosure of hepatitis C infection from the perspective of interview participants. Eighteen of the nineteen interview participants discussed disclosure. Some had disclosed widely while others had not disclosed their infection to anyone. Two participants reported that they had not told anyone about their infection prior to being interviewed. The issues pertaining to disclosure covered during the interviews included: people to whom participants disclose; reasons for disclosure; reasons for non-disclosure; reactions to disclosure from healthcare workers, family, friends and partners; and impacts of disclosure on intimate relationships. Presented below are interviewees' thoughts and experiences of disclosure.

Claris, 57, appears fearless in her resolution to disclose, however, she reports that she has experienced bad outcomes. Many participants, like Claris, nominated people to whom they would not disclose and the reasoning behind this:

Yes. I'm not worried about telling anybody. I don't give a damn

OK, so you don't worry about who you tell ... What about your friends? Do you ever talk about it amongst friends?

Well, I would have told my friends. I had a friend before and we were pretty good friends but all of a sudden she stopped talking to me. She was having a baby and that might have been the cause; that's what I put it down to ... There's one person I wouldn't tell and that's the landlord. Because I feel that, if he found out, he might chuck me out or something. That worries me.

What makes you think he would be like that?

Oh, he might not understand. They're young people.

Like several participants, Clint, 38, associated disclosure of hepatitis C infection with a fear of discrimination, and he reports a need to be judicious about who is privy to such information. He also alludes to the ease with which his personal health information can become common knowledge among his social networks:

So what about telling people that you have hep C?

Oh, I only told my family. I actually don't go telling everyone, just in case I do get discriminated against.

Your wife and children, or your brothers and sisters?

Brothers and sisters ...

And how have they been with it?

Yeah, they've been OK about it; they're quite good. But you've got to watch who you're telling. You've got to tell them at the same time not to tell everyone else, because you tell someone and they tell someone else and they tell someone else. So you have to tell them before you say anything and say 'Keep this to yourself. Don't tell anyone else that I've got hep C because they'll spread it around to people you don't even know!'

But so far you don't think that's happened?

No. Maybe a couple of close friends but ... Oh, I've told one or two. They weren't very worried about it either, I don't think.

Below, Deb, 40, highlights people's responses to an unfamiliar epidemic. She briefly charts her initial approach to disclosure and how this has changed over the course of the epidemic:

I would like to move on to disclosure, like who you tell, why you tell people and what their reactions are like?

OK. When I first found out, back in probably '89 or whenever, I did tell work in '89 or '90 and they didn't understand the disease either and they got me to get a letter from my GP saying that I wasn't going to contaminate people at work ... With medical profession, I always believed that I should disclose my history with them ... I told most of my family. Initially I didn't because I didn't understand it myself but, in time, they all came to know. Mum had the classic mum-reaction ... With friends, there were some people whom I had told who were really concerned about it, who had probably heard negative media. So I got a mixed reaction ... I used to be pretty open about it and I felt if they had a reason why they would need to know or ... sorry, if they were friends or whatever, I wouldn't hesitate, but nowadays I'm much more selective about who I would disclose that to and I would only do it if I felt I was putting them at risk or ... that would be it, I suppose.

Gloria, 45, reported that during her twenties she was continually discriminated against by healthcare workers and others while on a methadone programme. That experience has affected her profoundly and now she sees no reason to disclose her hepatitis C infection to anyone:

So that brings us up to disclosure. Who do you tell?

Nobody, tell nobody. Often I would change doctors as often as I could to avoid telling them that I had hepatitis C ...

And what about [disclosing] to other people?

No, it's so no. It's often a topic of conversation and I've got lots of friends that I've known for ten years and that I wouldn't tell.

Some participants reported that they had only disclosed their infection to very select people, and some expressed relief at being able to talk about hepatitis C in the context of an interview. Justine, 31, only discloses her infection to other people with hepatitis C. She highlights the nexus between injecting drug use and hepatitis C in her refusal to disclose to her family, the impact of disclosure on close relationships and the denial of infection she sees among her drug-using network:

Well I haven't told many people, and the people I do tell is people that have it themselves and I probably only told three or four people, and I wouldn't tell my family because they don't know anything about my drug use. I wouldn't tell anyone I met unless I started seeing them so yeah bit of a taboo subject and I don't like to tell people if I can avoid it ... it's good to talk about it with someone else ... a lot of people even if they do have it pretend that they don't have it.

Susie, 54, alludes to her changing perspective on disclosure and her regrets about disclosing her infection widely when she was younger. She also briefly discusses her notion of obligation to disclose to healthcare workers:

Who have you told that you have hep C?

I think just about all my friends know. Some people I work with know but, if I were given my choices now,

being out and proud and potentially putting myself up against verbal abuse and discrimination.

Several participants, like Helen, 44, discussed their relatively positive experiences of disclosing hepatitis C infection. As well, Helen discusses a commonly reported reaction to disclosure, that is, being judged as 'guilty' of her infection because it was contracted via injecting drug use. She also reveals her trepidation at disclosing hepatitis C infection to her father because of its association with injecting drug use:

I've told my mum and dad, my brother, my husband, my step-kids, and my step-kids have told the world! Everyone at their school knew. But I didn't cop any flak from anyone ever. Another girl in the country that I knew had had it and she was quite angry and felt that people had discriminated towards her, so I was expecting it but I didn't have it ... The only times I find discomfort is when people talk about their health – they've got a cold or they might have whatever it is and you can't talk about [hepatitis C]. And if I've attempted it there's just a cold silence. That would be the worst ever that I've found, nothing worse than that.

What did you think caused that cold silence?

It's possible that it's drug-related. That they think 'Well, you caused it. It's your problem, you silly bitch', something like that.

want nothing to do with me?’ ... It’s just a huge, huge kind of spanner in the whole works. It’s just like some huge complication ... you might see someone and like that person but that’s as far as it goes because you play the scenario in your head. It’s only going to go to that point anyway, when you have to disclose that you’ve got hep C and you think when will be the right time? At the beginning of the relationship or twelve months down the track when you decide to take the relationship to that next level, when you’ve got to really tell them. Well, yeah, it’s like what’s going to happen then? ... all this kind of goes on in your head.

Do you feel very isolated as a result of that?

Oh, yes, I think so. I mean, I have friends and stuff but the quality of the relationship, you know, intimate relationships for me is just like ... I might like someone and then I think ‘hey, how far is this gonna go, and when do I tell them about the hep C?’ ... an example being there was this guy, and he’s a doctor, and I can kind of tell that he’s kind of interested but he hasn’t gone any further. I mean, you know when someone likes you, you kind of pick up the ... I mean, I’m thinking I’m not going to do anything because he’s a doctor and, if I tell him, he’ll say ‘Ah, you’ve got hep C ugh.’ Shit, you

CONCLUSION

As is evident from the survey data and interview extracts, participants' experiences of disclosing hepatitis C infection vary widely, yet there appears to be a broad awareness of the stigma associated with the infection and the need to be wary about to whom one discloses, a finding echoed in a recent international study (Dunne and Quayle, 2002). Some of our participants reported their preparedness to disclose in all situations, some were more discerning, while others were extraordinarily cautious. Our findings indicate that women are more likely to disclose in certain contexts than men. In relation to disclosure of health information, this finding has been reported previously (d' Agincourt-Canning, 2001). Disclosure appears to be a gendered activity and women's socialisation may explain the greater tendency for women to disclose health information.

Several participants were concerned about losing control over personal health information that they divulged to others, and some have changed their attitude to disclosure over a period of years. Several described an obligation to disclose to healthcare workers, while others acknowledged that disclosure of hepatitis C infection revealed their past as injecting drug users. This acted as a disincentive to disclosure and some resisted telling others, such as family, about their infection.

There is a social pressure placed on people to disclose their hepatitis C infection to others, and explain to families, loved ones, casual partners, even sometimes their doctor, the meaning of hepatitis C infection (Hepworth and Krug, 1999). This is reflected in the present study, as more than half of the survey participants indicated that they had disclosed their infection to at least four categories of people, and about a third had disclosed more widely – from five to eight categories of people. The majority of

participants had disclosed their hepatitis C infection to their wife, husband or partner, to their parents or siblings, to their doctor or to another healthcare worker.

A 'bad' reaction to disclosure was reported in nearly a quarter of cases where participants had disclosed to their family (i.e. parents and siblings). Almost one in five of participants' partners were reported to have reacted badly to disclosure of hepatitis C infection. Our finding that a minority of women reported receiving a bad reaction following disclosure of infection to their partners is corroborated by Gifford et al., (2001) finding that the overwhelming majority of partners of women with hepatitis C infection were reported to be supportive following the women's disclosure. A substantial minority of participants reported that doctors and other healthcare workers reacted badly following

In recent years, government enquiries and a nascent social research have found that discrimination is a salient issue for people with hepatitis C infection (Treloar et al., 2002; ADB

(i.e. between 1970 and 1992), infected with hepatitis C from injecting drug use, currently injecting drugs, pessimistic about one's future health with hepatitis C infection, feeling tired because of hepatitis C infection, unemployed, identifying as non-heterosexual, and experiencing negative reaction from partners and family members following news of participants' hepatitis C infection. Experiencing wider discrimination was also associated with knowing a greater number of people with hepatitis C and reporting greater limitations in the time spent with family, friends, neighbours and groups due to participants' hepatitis C infection.

The phrase 'discrimination by wider categories of people' and 'wider discrimination' is used to refer to those people who scored higher on this scale compared with those who scored lower. A type 1 error rate of 0.05 was used to determine statistical significance. A reduced

for interview participants to report that they were made to wait for day surgery, often for a considerable time, after they had disclosed their infection to a doctor or nurse, or because their infection had been previously documented in their medical records:

I was at [a large Sydney hospital] a little while ago and there's no risk in the world that it wasn't because of the hep C that I was left ... being first in and last out and everyone else had gone home even ... This was about six or eight weeks ago ... I mark [the admission form] that I've got hep C and it wasn't that mind-boggling but I was just a lot longer there than most of the other people. (Keith, 70)

Infection control procedures were often implemented by healthcare workers following a participant's disclosure of infection. In some cases, this involved healthcare workers performing procedures that appeared to be aimed at publicly humiliating patients. Such experiences influenced participants' subsequent decisions to withhold disclosure in healthcare settings in order to avoid a repeated enactment of discrimination. Although disclosure of hepatitis C infection was described by several participants as a part of their approach to healthcare, some had decided not to disclose in future because of the discrimination that they had previously experienced. For example, Deb, 40, claimed that she had 'always believed in notifying people' but following an experience at the dentist she has changed her opinion and practice:

A few years ago I went to a dental surgery and disclosed. I will never tell another medical professional as long as I live. They only had to do some routine stuff and first of all they

came in geared up like they were about to land on Mars and the guy was really nervous. He was terrified. Then while I was standing there waiting to pay the account, he had everyone from the whole surgery in there, scrubbing down the walls, cupboards, everything – all gowned up the lot of them. Everyone in the waiting room could see this. The greatest over-reaction. I mean anyone could have been in that surgery carrying a virus that they needed to be protected against. It was so directed at me. They didn't wait until I left the premises, they didn't wait for anything, they just did a big show ... Don't come back, I think that was the message ... So I think now I will be very hesitant to go in and tell somebody. If the procedures are in place which they have to follow, then why should I even go through that again? I never will. Like to me, I always believed in notifying people but now I really don't. Certainly you will get treated different. Although in medical

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Such practices have implications for infection control within our healthcare services. It appears that infection control procedures are not applied universally, rather, many healthcare workers rely on patients' disclosing their infection before the necessary procedures are implemented.

Hepatitis C-related discrimination occurred in contexts apart from healthcare. These included government agencies, insurance companies, family and friendship networks and within intimate personal relationships. Helen, 44-years-old, discusses her experience with an insurance company after disclosing her infection:

*I suppose where you notice
[hepatitis C-related discrimination] is
when you apply for life insurance.
My husband and I both applied for
life insurance and his was back in a
flick but mine has been months now
and they're still going through
doctors and what-not and, you know,
you realise then that things are
different.*

Similarly, several interview participants reported that they had experienced problems with the government employment agency, Centrelink, while looking for employment. Clint, 38, characterised the staff's lack of adherence to his right to confidentiality as hepatitis C-related discrimination:

Interview participants commonly expressed fear of experiencing further discrimination. Such fear inhibited disclosure of infection in a number of contexts like healthcare, employment and among family and social networks. Some participants felt that disclosing their infection could disqualify them from employment opportunities and others felt it could lead to termination of their intimate personal relationships. Many participants protected themselves from experiencing further hepatitis C-related discrimination by adopting a blanket policy of non-disclosure.

DISCUSSION

Findings from this study confirm previous reports that hepatitis C-related discrimination is experienced in a variety of social domains such as government agencies, private sector organisations, family and friendship networks and healthcare. Participants reported that the effects of discrimination are far-reaching, adversely impact on one's quality of life and influence decisions regarding disclosure, employment, access to health services, opportunities for financial security and intimate personal relationships. Our data confirms previous suggestions that inadequate knowledge of the virus and a disdain for injecting drug users inform many of the reported discriminatory practices.

Social identity theory (Sears et al., 1991; Tajfel, 1981) suggests that discrimination may serve a socially adaptive function for members of certain groups by reinforcing cultural norms and values that are at odds with people who belong to, or are perceived to belong to affected groups. Many of our survey participants had no tertiary education, were unemployed and current injecting drug users, a constellation of factors that make them vulnerable to discrimination from powerful social groups as diverse as insurance companies, government agencies and healthcare

workers. Our data provides evidence that people with hepatitis C infection are often assumed to be either ex or current injecting drug users and therefore, according to social identity theory, members of an inferior out-group with irrational values, needs and lifestyle practices foreign to the mainstream. Some perceive people with hepatitis C infection as an immoral and contagious threat to the health of society's majority. Participants' reports of being refused medical treatment illustrates the creation of boundaries that social identity theory predicts will occur when specific groups or practices are deemed incompatible with the mainstream or perceived to threaten hegemonic group values and safety.

The authors would like to emphasise that people with hepatitis C are more likely to disclose their infection to doctors, dentists, specialists and nurses than in other community or social contexts. The tendency to disclose more often to healthcare workers account in part for the common occurrence of hepatitis C-related discrimination in this context. Healthcare workers who use discriminatory strategies when treating hepatitis C patients appear to be making judgements concerning an individual's moral and personal adequacy via a process of categorisation that positions people with the virus as deviant. Their judgements establish an 'us' and 'them' binary where people with hepatitis C are perceived to belong to a homogeneous out-group that has a lifestyle and value system inconsistent with, and inferior to, healthcare workers and the majority of society. The out-group is characterised as having prioritised pleasure above physical health, compromised their rationality through using drugs, and participated in illegal activities: in essence, 'guilty' victims, responsible for their infection and deserving of discriminatory treatment.

Discriminating against people already vulnerable due to illness can be a profoundly negative experience and one that has material, social and personal costs and effects. To be ill yet considered unworthy of proper medical treatment and care because your disease is associated with a particular lifestyle practice can isolate people who are already marginalised. Disengagement with health services is a likely outcome for some. Health problems may be compounded by the fear that future interactions with the health system will end in bad experiences. Access to information regarding the prevention of transmission is compromised when people fear interaction with health services. Several of our interview participants reported their decision to withhold future disclosure of infection in a variety of contexts, for fear of experiencing further discrimination. Withholding disclosure for fear of discrimination has implications for the prevention of transmission, future social and personal relationships as well as access to medical services and the quality of medical treatment received.

Participants who reported experiencing the most discrimination in this study were current injecting drug users who knew many other people with hepatitis C infection, had recently suffered ill health from their infection and were generally pessimistic about their future living with the virus. Current injecting drug users often bear the brunt

infectious risks. Similarly, access to healthcare services is compromised when people with

CHAPTER 7

HEPATITIS C INFORMATION AND SERVICES

Inadequate knowledge of hepatitis C infection is reportedly a significant cause of hepatitis C-related discrimination among healthcare workers and the general community (ADB of NSW, 2001). The Anti-Discrimination Board of NSW enquiry into hepatitis C-related discrimination documented evidence of confusion, misunderstanding and factual errors related to hepatitis C among a variety of health and social settings where discrimination occurred.

Several recent Australian studies have explored people's knowledge of hepatitis C infection. A telephone survey by Watson et al. (1999) conducted in Victoria using a stratified sampling frame found that many people were uncertain of what constituted a risk for hepatitis C transmission. A large proportion of participants cited contaminated food or water, receipt of a blood transfusion, sexual contact and sharing a household with a person with hepatitis C infection as risks for transmission. Similarly, findings from a study into the level of hepatitis C knowledge among 1330 New South Wales high school students indicated that students generally had a poor knowledge of all the hepatitides (van de Ven et al., 2001). Students confused the various hepatitis infections, some believed they had been vaccinated against hepatitis C and indicated a poor understanding of transmission risks. The international research literature also documents poor levels of understanding of hepatitis C in the general community. Among these findings, differences in knowledge levels based on ethnicity were evident (Buffington et al., 2000).

The above studies indicate that knowledge about hepatitis C infection is sparse within the general community. To gain a better understanding of the circulation of information within the community, the present study asked people with hepatitis C infection about their level

of knowledge and access to information. This chapter reports on our findings regarding participants' sources of information and level of knowledge about hepatitis C. It concludes with a brief enquiry into information and service needs, and functions of support groups for people with hepatitis C infection.

SOURCES OF HEPATITIS C INFORMATION

Participants were asked where they found information about hepatitis C and to nominate as many sources as they used from a range of given categories (Table 18). The majority of participants reported that they accessed information about hepatitis C from the *The Hep C Review* (70.6%). Many accessed information from their doctor (47.8%) and the Hepatitis C Council of NSW Helpline (42.1%).

Table 18: Source of hepatitis C information^a (n=500)^b

| Source(s) of information | n | % |
|-------------------------------|-----|------|
| The Hep C Review (HCC of NSW) | 356 | 70.6 |
| My doctor | 241 | 47.8 |
| The Helpline (HCC of NSW) | 212 | 42.1 |
| Other healthcare workers | 135 | 26.8 |
| Internet | 130 | 25.8 |
| Magazines | 98 | 19.4 |
| Friends | 84 | 16.7 |
| Books | 82 | 16.3 |
| Other sources | 64 | 12.7 |

^a Categories are not mutually exclusive

^b Missing data = 4.

Given that the study was based in NSW and recruited through the state hepatitis C Council, it is not surprising to find that their magazine

and information telephone line were integral to participants' accessing of information. Apart from these two sources, participants used a variety of avenues, including their doctor, another healthcare worker and the internet. Even when participants had received information about hepatitis C infection from their doctor, there was a tendency to look further. This raises concerns regarding the reliability of the information accessed, particularly in situations where this information conflicts with that of a doctor.

SURVEY PARTICIPANTS' HEPATITIS C KNOWLEDGE

One aim of this study was to uncover the level of knowledge regarding hepatitis C infection among the survey participants. Five statements about hepatitis C transmission, three statements about treatments and prognosis and two statements regarding lifestyle were formulated. Participants were asked to nominate 'True' or 'False' for each of these statements. The results are shown below (Table 19).

Table 19: Knowledge of hepatitis C infection (N=504)

| Statement | Correct | | Incorrect | | Missing | |
|---|---------|------|-----------|------|---------|-----|
| | n | % | n | % | n | % |
| 1. People can get hep C from sharing my toothbrush | 438 | 86.9 | 59 | 11.7 | 7 | 1.4 |
| 2. People with hep C can drink as much alcohol as they like | 487 | 96.6 | 12 | 2.4 | 5 | 1.0 |
| 3. All people with hep C eventually need a liver transplant | 469 | 93.1 | 19 | 3.8 | 16 | 3.2 |
| 4. Having a healthy diet is important for people with hep C | 487 | 96.6 | 13 | 2.6 | 4 | 0.8 |
| 5. Hep C can be passed on by an invisible drop of blood | 449 | 89.1 | 41 | 8.1 | 14 | 2.8 |
| 6. You can catch hep C from sharing a tourniquet | 245 | 48.6 | 230 | 45.6 | 29 | 5.8 |
| 7. There is a vaccine against hep C | 456 | 90.5 | 34 | 6.7 | 14 | 2.8 |
| 8. You can't catch hep C from kissing | 340 | 67.5 | 144 | 28.6 | 20 | 4.0 |
| 9. People with hep C should always wear a condom | 181 | 35.9 | 302 | 59.9 | 21 | 4.2 |
| 10. New treatments always cure hep C if taken early enough | 454 | 90.1 | 30 | 6.0 | 20 | 4.0 |

The results reveal both definite patterns of knowledge as well as areas of ambiguity.

Generally, participants answered all questions accurately; items regarding transmission of infection revealed most uncertainty. The statement 'You can catch hep C from sharing a tourniquet' resulted in almost an equal number of participants who answered 'True' (48.6%) and 'False' (45.6%). This item had the highest number of missing data, which suggests that many people were hesitant about committing to an answer and preferred to leave the item blank. Participants who reported that they did not contract hepatitis C from injecting drug use, were less likely to answer correctly that the infection can be transmitted by sharing a tourniquet (41.0% vs 59.2%, $p < .001$) than participants who contracted their infection through injecting (Table 20).

Table 20: You can catch hep C from sharing a tourniquet^a

| | Correct n (%) | Incorrect n (%) | Total n (%) |
|-----------------------------|------------------|--------------------|----------------|
| Mode of acquisition* | | | |
| IDU | 168 (59.2) | 116 (40.8) | 284 (100) |
| Other | 75 (41.0) | 108 (59.0) | 183 (100) |

^a Only significant results presented
* $p < .001$

The item regarding condom use also revealed uncertainty – nearly 60% of participants reported

that condoms should always be used during sex. Participants whose sources of information about hepatitis C infection include their doctor, were more likely to report that people with hepatitis C should always wear a condom for sex (67.7% vs 58.1%, $p < .05$) than those whose sources of information do not include their doctor (Table 21). Conversely, participants who reported knowing no one else with hepatitis C infection were less likely to state that people with hepatitis C infection should always wear a condom for sex (50.7% vs 64.8%, $p < .05$) than those who knew other people with the infection (Table 21). Similarly, participants who earned more than 30,000 dollars per year were less likely to state that people with hepatitis C infection should always wear a condom for sex (45.8% vs 66.5%, $p < .001$) than those who earned less than 30,000 dollars per year (Table 21). This item had the second largest number of missing data, again indicating that many participants were unsure about committing to an answer.¹

¹ Findings from recent research recommend that people with hepatitis C infection use a condom to prevent sexual transmission under certain conditions, for example: for those people who have short-term sexual partners or multiple partners; when other sexually transmissible infections are present; if having sex during menses; or if engaging in sexual practices that might traumatise the genital mucosa. People with hepatitis C who are in longer-

Table 22: You can't catch hep C from kissing^a

| | Correct n (%) | Incorrect n (%) | Total n (%) |
|------------------------------|--------------------------|----------------------------|------------------------|
| Sources of hep C info | | | |
| Includes friends* | 45 (57.7) | 33 (42.3) | 78 (100) |

Table 25: People can get hep C from sharing my toothbrush^a

| | Correct n (%) | Incorrect n (%) | Total n (%) |
|--|--------------------------|----------------------------|------------------------|
|--|--------------------------|----------------------------|------------------------|

SELF-REPORTED CURRENT HEALTH

Participants were asked to describe their current state of health (Table 30). A majority reported their current health as either 'poor' or 'fair'.

FUTURE OUTLOOK

To explore beliefs regarding the long-term future impact of hepatitis C infection on health and well

CHAPTER 9

INFECTION CONTROL

The following chapter discusses findings from the study regarding infection control and hepatitis C. Infection control was not a focus of the study and the survey did not contain items asking participants about their experiences of infection control. However, interview participants spontaneously raised the issue and commonly alluded to concerns they had regarding the implementation of universal infection control procedures.

According to the Anti-Discrimination Board of NSW (2001) enquiry into hepatitis C-related discrimination, and supported by our data, healthcare workers at times make judgements regarding the likelihood of their patients having hepatitis C infection. Sometimes decisions will be made to implement infection control procedures following a visual assessment of a patient, or when information regarding a patient's hepatitis C infection is known. However, such practices run contrary to the principle of universal (or standard) infection control. Universal infection control guidelines were incorporated into professional practice and training models to remove the need for healthcare workers' judgements of risk. Judgements about the use of infection control procedures should be made according to the degree of risk of exposure inherent in a medical procedure rather than based on knowledge or judgements regarding a patient's infection status. The infection control guidelines were designed for all procedures in which there is risk of exposure to any body product with the aim of preventing transmission from patient to worker, from patient to patient and from worker to patient.

In this chapter, we examine interview participants' descriptions of infection control experiences in healthcare settings. This is not to

say that disregard for infection control guidelines is widespread among our hospitals and dental surgeries, rather these examples are given to provide insight into how and why some healthcare workers implement infection control in some situations. We use the theoretical framework of social identity to view decisions made and actions taken by healthcare workers and their patients.

HEALTHCARE WORKERS' USE OF UNIVERSAL INFECTION CONTROL PROCEDURES

Participants provided detailed accounts of instances where they believed they recognised breakdowns in infection control procedures. During his many years of receiving healthcare as a patient with haemophilia, Sebastian, 42, had observed that some healthcare workers implement infection control procedures solely to protect themselves from contracting an infection. Even so, he believes that some healthcare workers miscalculate the risks:

.... most nurses don't bother taking the universal precautions they are supposed to take with every patient. In fact, they only take precautions ... to protect themselves, and they don't actually think about protecting you against other patients in the ward. A nurse will come in with gloves on but they'll go to someone over there with those gloves on, then they'll come over to you with the same pair of gloves on. So it's obvious that they're not worried about transmitting something from

participants' descriptions of interactions with healthcare workers, some believed that disclosing a hepatitis C infection was appropriate and the 'right' thing to do. Susie, 54, reports:

I'm obliged to tell them [that I have hepatitis C], I feel. You don't expect someone to treat you where there are dangers involved without disclosing those sorts of things.

In such cases, disclosure of hepatitis C infection was related to participants' concerns

may have significant implications for viral transmission and containment of the epidemic.

INFECTION CONTROL AND HEPATITIS C-RELATED DISCRIMINATION

As reported by several participants, infection control procedures were often implemented by healthcare workers following a participant's disclosure of infection. In some cases, it appeared that healthcare workers performed procedures to publicly humiliate patients. Such performances influenced participants' subsequent decisions to withhold disclosure in healthcare setting in order to avoid a repeated enactment. Although disclosure of hepatitis C infection was described by several participants as a part of their approach to healthcare, some had decided not to disclose in future because of the discrimination that they had experienced in the past. For example, Deb (see Chapter 6) claimed that she had 'always believed in notifying people', but following a humiliating experience at a dental surgery she had changed her opinion and practice. The discriminatory use of infection control procedures was a means of embarrassing Deb in front of other patients while enabling the dentist to express disapproval of a patient.

CONCLUSION

The sample included a high proportion of people who had medically acquired hepatitis C infection. Some of these participants had familiarised themselves with infection control guidelines since learning of the mode of their infection. In subsequent medical treatment they were observant of occurrences where infection control was compromised. However, our sample is not representative of all people with hepatitis C

Participant reports that healthcare workers often assume that patients will disclose their hepatitis C infection is disconcerting. This assumption is flawed for two reasons: firstly, there are no requirements for patients to disclose infection; and secondly, such assumptions are naive given the reported prevalence of hepatitis C-related discrimination within healthcare settings. Not only is there a risk of transmission to healthcare workers who subscribe to these assumptions, there is an increased risk of nosocomial transmission. Such suppositions are dangerous given that a large proportion of people with hepatitis C remain unaware of their infection.

Similarly, placing patients last on the list for surgical procedures because they have disclosed their hepatitis C infection is a flawed practice. Such practices act as a disincentive to further health disclosures from patients. Making patients wait for lengthy periods without food and often without explanation is an inconvenience to patients and the family and friends who care for them. This practice can be a manifestation of healthcare workers' power to discriminate; it provides them with an opportunity to express their disapproval of patients with hepatitis C. Disrupting a patient's expected timetable for surgery demarcates them as an out-group member, causes physical and emotional discomfort and reinforces the message that they are a danger to the health of others.

In summary, our data provide evidence that infection control procedures are sometimes used as a tool to protect healthcare workers from the risks of infection with little regard for risks to patients. In addition, infection control procedures are at times implemented to express disdain for participants' lifestyle choices and to discriminate between social groups. In this way, the healthcare worker demonstrates a differentiation between acceptable patients and those who are considered or assumed 'dangerous' to the health of others.

CHAPTER 10

FUTURE DIRECTIONS

HEPATITIS C SOCIAL RESEARCH

The literature concerning the hepatitis C epidemic predominantly focuses on medical and scientific aspects of infection. The paucity of research into social issues highlights a significant gap in the literature. Nonetheless, a number of researchers have pointed to key areas for investigation (e.g. Southgate et al., 2002). For example, there is a need for further research into the social and psychological implications for people diagnosed with hepatitis C (Hepworth and Krug, 1999; Krug, 1995). Scant attention has been paid to stigmatisation and discrimination of people with hepatitis C. Discrimination and stigmatisation is mentioned in the context of diagnosis and disclosure and interactions with healthcare professionals, however, further exploration of discrimination is needed (Crofts, Louie et al., 1997; Burrows and Bassett, 1996).

How people cope on a daily basis with at times debilitating symptoms needs further study. The impact of medical treatments on quality of life is an area cited as poorly understood and one that would benefit from social research (Owens, 1998). Several authors have suggested the need for further social research into the medicalisation of people with hepatitis C infection and the personal and social impact of infection with a virus associated with injecting drug use (Hepworth and Krug, 1999; Dolan, 1997).

Furthermore, we would argue that any social scientific investigation of hepatitis C should take into account the heterogeneous groups affected by the virus. For example, the experiences of Aboriginal and Torres Strait Islanders and of people from culturally and linguistically diverse communities warrants further investigation (Sargent et al., 2001), as does the effect of social class, gender and residential location (ie. urban, suburban, and rural). While vector of transmission

is likely to impact upon how someone experiences the infection, we suggest that even those who have contracted the virus from injecting drug use should not be viewed as a homogeneous group. The experiences of ex-injectors may differ dramatically from current users. There are also likely to be differences between the experiences of middle class injectors versus marginalised street-based injectors or prisoners. Examining socio-cultural difference is vital if issues such as disclosure, discrimination and access to treatment and non-judgemental healthcare are to be adequately addressed. Investigating the impact of hepatitis C infection on socially and culturally diverse populations is in line with recommendations contained within the National Hepatitis C Strategy 1999-2000 to 2003-2004 (Commonwealth Department of Health and Aged Care, 2000).

Other fruitful avenues for investigation touched upon in the literature include an analysis of the 'folk knowledges' that surround hepatitis C infection, particularly in relation to understandings of household transmission, prognosis and coping with chronic illness. Uncovering non-medicalised constructions of the 'contagious' and 'chronically ill' self may offer useful and empowering material for health promotion. This includes a comparison of those people not on treatment with those on alternative therapies and those undergoing combination

groups might also be an area ripe for research particularly given the issue of stigmatisation.

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