

THE 3D PROJECT

DIAGNOSIS

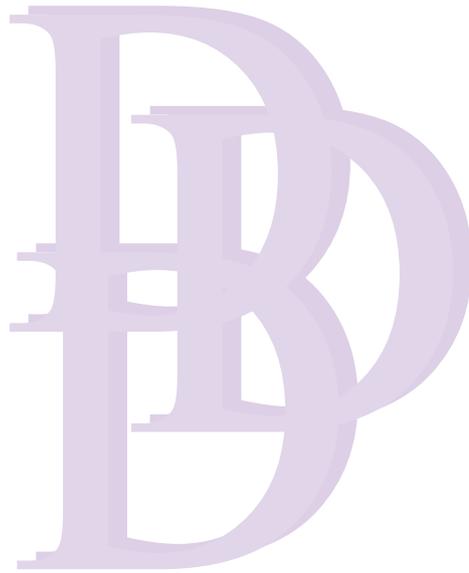
DISCLOSURE

DISCRIMINATION &

LIVING WITH -HEPATITIS C



MAX HOPWOOD
CARLA TRELOAR



THE 3D PROJECT

**DIAGNOSIS, DISCLOSURE, DISCRIMINATION
AND LIVING WITH HEPATITIS C**

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NATIONAL CENTRE IN HIV SOCIAL RESEARCH

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INTRODUCTION

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.

Reaction to hepatitis C infection from across a range of health and social domains has been characterised by confusion since the virus was first identified. While evidence for its existence can be traced back hundreds of years, hepatitis C has only recently become a public health and community concern, and relatively little is understood about the impact of infection on the lives of affected people. For many, the hepatitis C virus is enigmatic. A positive diagnosis often creates confusion as an individual begins to make sense of how they became infected, the changes that they may need to make in order to live with the virus, and their long-term future. The confusion has been exacerbated by differing medical and scientific opinion regarding how transmission occurs, the likelihood of infecting others, and the impact of disease on health-related quality of life.

Recent investigation has revealed a range of social issues salient to affected people. The 3D Project aimed to contribute to this budding social literature. The following pages represent the experiences of one group of people with hepatitis C infection. To some practitioners working in the field, many of the issues discussed will be familiar. For others, we hope this report will provide an insight into the epidemic, as for now and in the years ahead, prevention of viral transmission and quality of life issues will be paramount for those with hepatitis C infection and the general community.

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, in-depth 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. There remains a need for broad-based dissemination of information on a range of issues among people with hepatitis C infection.

HEPATITIS C TREATMENTS, HEALTH AND WELL BEING

A majority of participants had not received treatment for their infection. Around 10–11% had ever received treatment, and these participants were more likely to be older (>45 years) and had their infection for more than a decade. Ex and current injecting drug users were less likely to have received treatment than people who had not injected ($p<.001$). A majority (56.8%) reported their current health status as 'poor' or 'fair'. Participants who earned more than 30,000 dollars per year were more likely to report 'good–excellent' health ($p<.001$) than those earning less. Approximately one in five participants reported that their infection had recently limited their physical, social and work activities 'a lot of the

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 hepatitis C infection were less likely to report a positive future outlook than those who had received at least a partial explanation ($p < .05$).

identified as, or assumed to be, injecting drug users. Reports suggested that infection control procedures were at times inadequate and may be used by some healthcare workers to discriminate against people with hepatitis C infection. These factors have the potential to alienate large numbers of people with hepatitis C from a range of health and information services, and impede attempts to prevent the further spread of infection.

INFECTION CONTROL

Our qualitative data provide evidence that infection control procedures within healthcare were sometimes used to protect workers from the risk of infection without regard for the risk to patients. Reports suggest that at least some healthcare workers assume their patients will disclose infection and rely on patient disclosure before implementing infection control procedures. Patients who are known to healthcare workers as having hepatitis C infection were routinely placed at the end of surgical lists. Reports indicated that infection control procedures were at times implemented by healthcare workers to discriminate against patients.

CONCLUSION

People with hepatitis C infection often do not receive sufficient information about their condition or referral to appropriate services following diagnosis. Participants accessed information about hepatitis C from a variety of sources. However, evidence suggests that there exists a need for broad-based dissemination of information on a range of issues among people with hepatitis C infection. Participants experienced a range of negative reactions and outcomes from disclosing their infection. Hepatitis C-related discrimination occurs in a variety of social domains and is especially salient for people

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 fatty tissue (Dolan, 1997). Viral hepatitis is a term used to describe inflammation of the liver that is caused by a virus and can evolve into one of two forms: acute or chronic hepatitis. Acute hepatitis is a term to describe a disease that evolves in a short period of usually about four weeks, then recovers. Acute hepatitis rarely results in long-term damage to the liver. The second and more problematic type of hepatitis is chronic hepatitis. This is an acute hepatitis that does not recover but persists for more than six months. Only acute hepatitis B, C and D can become chronic. Chronic hepatitis causes a persistent liver injury that if not treated can lead to scarring of the liver tissue (cirrhosis) and to primary liver cancer (hepatocellular carcinoma) (Everson and Weinberg, 1999).

Hepatitis C

Since the early 1970s there had been evidence of a viral cause of hepatitis that was not attributable to hepatitis A or to hepatitis B virus. For nearly twenty years, infection with this virus was referred to in medical literature as 'non-A non-B hepatitis' (Hepworth and Krug, 1999). The hepatitis C virus was discovered in 1988 and a diagnostic test to detect antibodies was developed and available in Australia in February 1990 (Crofts, Louie et al., 1997). The hepatitis C virus circulates in extremely low concentrations in the blood of infected people yet it is highly infectious, virulent and resilient. Even small amounts of the virus can cause major illness and be very difficult to eradicate once contracted. Hepatitis C is classified as an RNA - its genetic material consists of ribonucleic acid in contrast to more genetically stable viruses made up of DNA (deoxyribonucleic acid), such as HIV and the other hepatitides A, B, D and E. Due to their instability RNA viruses often mutate rapidly and evolve into different strains.

The World Health Organisation estimates that currently there are 170 million chronic hepatitis C carriers worldwide (about 3% of the world's population) (Crofts et al., 2001; Everson and Weinberg, 1999). The hepatitis C virus causes an acute hepatitis in approximately 25% of people infected and a chronic infection in up to 75% of people (ANCHARD, 2002). Among a sub-group of people chronically infected with hepatitis C, long-term end-stage liver disease, such as cirrhosis and primary liver cancer occurs after some 10 to 40 years from the time of infection (Crofts, Louie et al., 1997).

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

carcinoma, and around 1000 cumulative hepatitis C-related deaths (ANCHARD, 2002). Projected estimates suggest that if recent trends in injecting drug use continue, there will be around 500,000 people (lower and upper limits of 321,000 and 836,000) living with hepatitis C infection in Australia by 2020 (Law, 2003, May). The combination of a significant pool of infected people and the long duration of illness associated with hepatitis C infection indicates that the overall health and economic costs to Australian society in the years ahead will be substantial (Crofts and Wodak, 2001; Brown and Crofts, 1998; Wodak, 1997). The growing public health significance of the epidemic is evidenced by the implementation of the National Hepatitis C Strategy 1999-2000 to 2003-2004, an initiative aimed at promoting and supporting treatment measures, support and care (Commonwealth Department of Health and Aged Care, 2000).

Genotypes and subtypes of hepatitis C

The genetic constitution of the hepatitis C virus varies and much of the variability is linked to geographic area. Currently, six major genotypes of the hepatitis C virus have been identified throughout the world (Dolan, 1997; Sherman, 1997) with indications that more strains exist (Everson and Weinberg, 1999). Within these six major genotypes there are over thirty variant subtypes of the virus, each have specific characteristics but all broadly behave in similar ways (Dolan, 1997). In Australia, genotypes 1 and 3 are the most commonly diagnosed but there is evidence for the existence of other genotypes in smaller proportions. Fifty-five percent of all hepatitis C infections in Australia are genotype 1, a further 38% of infections are genotype 3 and 7% are genotype 2 (McCaw, 1997). Types 1a and 1b account for more than 60% of all infections in North America, with genotype 4 common in the Middle East and central Africa but rarely found in Europe. Genotype 5 is found mainly in South Africa and genotype 6 occurs mostly in Asia

(Sherman, 1997). Specific genotypes are associated with how an infection is acquired. For example, those people who became infected through blood transfusions are more likely to have genotype 1b (Sherman, 1997) and younger people (those aged between 21 and 40 years) tended to have genotype 3, which appears to be associated with injecting drug use (McCaw, 1997). Response rates to treatment with interferon also differ according to the genotype of the hepatitis C virus (Treppo, 2000). People chronically infected with genotype 1b respond less well to treatment with interferon (Pianko and McHutchison, 2000; Soriano et al., 1999; Vogel et al., 1996) than those people infected with genotypes 3 and 4 (Sherman, 1997). While the condition remains acute all genotypes respond equally well to interferon treatment (Jaekel et al., 2001; Vogel et al., 1996).

Transmission of hepatitis C virus

The hepatitis C virus is predominantly transmitted via blood-to-blood contact. Apart from contracting infection from injecting drug use and medical blood products or procedures, other routes of transmission include the use of non-sterile skin penetration instruments for tattooing, skin and ear piercing and acupuncture, and needle-stick and 'sharps' injuries. Sharing toothbrushes and razors also provides conditions sufficient for the transmission of the hepatitis C virus (Sladden et al., 1997). Patient-to-patient transmission via contaminated anaesthetic circuitry and surgeon-to-patient transmission via percutaneous injury have both been established (Sladden et al., 1997). Mixed findings have fuelled an ongoing debate regarding sexual transmission of hepatitis C infection, however, currently this mode of transmission is thought to be low. The risk does increase when blood is present, for example, during menstruation or anal sex (Terrault, 2002; Kaldor et al., 2000; Leruez-Ville et al., 2000; Everson and Weinberg, 1999; Rooney and Gilson, 1998). Vertical transmission appears to be low

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 current injecting drug users (ANCHARD, 2002). Sharing injecting equipment is clearly the most effective means of transmitting hepatitis C. This virus is extremely infectious under these conditions. Infected blood remaining in a needle or a syringe is sufficient to transmit the hepatitis C virus to the next user of the equipment. Contamination also occurs when people who inject drugs assist each other with administering injections. Microscopic amounts of infected blood on a hepatitis C positive user's fingers or hands can come into contact with another's injection site or skin lesion. Infected blood can contaminate swabs, water, spoons, tourniquets and other injecting equipment (Wodak, 1998). The risk of becoming infected with hepatitis C from sharing needles and syringes with an injecting drug user who has hepatitis C is much greater than the risk of acquiring HIV from sharing equipment with an injecting drug user infected with HIV (Wodak, 1998).

Studies analysing the prevalence and incidence of hepatitis C virus infection among injecting drug users have pointed to several significant predictors of risk behaviour that lead to hepatitis C infection. A US study found that hepatitis C seroprevalence is independently associated with the reuse of syringes, being initiated into injecting by someone older, the injection of specific drugs especially cocaine or

a mix of cocaine and heroin, and at least a two year history of injecting (Garfein et al., 1998). Similarly, in a recent Australian study that reported an apparent decline in the prevalence of hepatitis C among injecting drug users in Australia, major predictors of hepatitis C infection included having been imprisoned, having a history of methadone treatment, being aged 25 years or more, having injected drugs for more than five years and reporting daily or more frequent injection (MacDonald et al., 2000). Many studies have found that the strongest predictor for risk of infection with hepatitis C is the duration of injecting drug use. The older one is and the longer one has injected the more likely they will have been infected with the hepatitis C virus (Carruthers et al., 1997; MacDonald et al., 1996; Chetwynd et al., 1995; Crofts et al., 1993).

Symptoms of chronic hepatitis C infection

Often people with chronic hepatitis C are asymptomatic and discover that they have the infection through a routine medical examination. About fifty percent of those infected seek medical attention as a result of experiencing symptoms (Ware et al., 1999). The most common range of symptoms of chronic hepatitis C include: fatigue; irritability; insomnia; nausea; muscle ache; headache; joint pain; abdominal discomfort; right upper-quadrant pain; and emotional disturbances such as depression, anorexia and stress. The intensity with which people experience these symptoms varies widely (Ware et al., 1999; Sladden et al., 1997). Many people with hepatitis C have extensive tooth decay and general poor oral health that cause difficulties with eating, swallowing and speech and contribute to pain and lethargy (Coates and Logan, 1999, August). Even when cirrhosis of the liver is absent, people with hepatitis C report poor health and well being (Bonkovsky et al., 1999; Foster et al., 1998). When compared with other disease conditions, people

with hepatitis C report more distressing symptoms than those with type 2 diabetes or hypertension (Koff, 1998).

People with hepatitis C are more likely to be either current or past injecting drug users, come from a low socioeconomic background and have a history of blood transfusions (Bonkovsky et al., 1999). People with a history of injecting drug use often present with more severe symptoms than those who have never been injectors (Foster et al., 1998).

Living with hepatitis C

While the sociological literature on living with hepatitis C is relatively scant, popular and scholarly authors as well as government reports allude to a number of key socio-cultural issues. These include: the social and psychological implications for people diagnosed with a contagious and potentially life-threatening illness; outcomes from disclosing hepatitis C infection; experiences of discrimination resulting from infection with a stigmatised virus; the impact of treatments on quality of life; and the medicalising process that accompanies people's entry into the realm of medical monitoring and treatment for a chronic illness.

Diagnosis

People newly diagnosed with hepatitis C often describe a sense of being perceived differently by those around them at a time when they are also experiencing changing perceptions of themselves. A positive test result often means people will transform areas of their lives and it is usually throughout this transitional stage that they fall prey to the medicalising discourses while looking for ways to 'make sense of the new conditions in which the self exists' (Hepworth and Krug, 1999, p.244). People's relationships, sexual practices, consumption of alcohol and other drugs may become closely self-monitored.

A positive diagnosis often brings into the present 'selves' that belonged to the past. For example, experimental drug use in a person's earlier years, rape, violent assault, or trauma that required a blood transfusion are old issues and regrets that are often 'relived' following diagnosis (Hepworth and Krug, 1999; Krug, 1995). Emotional responses such as fear and apprehension regarding the future, feelings of being flawed, alienated, different or set apart from others are also reported (Hepworth and Krug, 1999; Burrows and Bassett, 1996; Krug, 1995). These findings are supported by an Irish study (Glacken et al., 2001) and by observations reported in publications for popular consumption such as magazine articles (Wood, 1997) and 'survivor's guides' (Everson and Weinberg, 1999; Graham, 1998; Dolan, 1997; English and Foster, 1997). These publications also note that family and friends are involved in a redefinition of the hepatitis C positive person and this can create friction within these networks.

While some people respond to a positive diagnosis by making changes to improve their health, others may react differently. A study of current injecting drug users from Perth, Western Australia, found that participants who tested positive for blood borne viruses, including hepatitis C, on the whole did not change their risk taking behaviours in relation to injecting (Loxley et al., 2000). Similarly, those who tested negative did not change their risk taking behaviour. The authors posit that those who tested positive believed that their seroconversion related to an extraordinary event and not their usual injecting practices. Those who tested negative did not change their behaviour as a negative test result was seen to confirm respondents' behaviour as safe. The authors conclude that the testing situation that currently exists in Australia is not a means by which to promote behaviour change.

Sladden et al. (1998) highlight the diverse responses people have to hepatitis C infection.

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

to a positive person, either as a family member or work colleague, often means that people with hepatitis C withdraw socially or are re-positioned outside of family, friendship and occupational networks (Hepworth and Krug, 1999). This isolating of the 'contagious' body has varying outcomes. Some individuals withdraw from social interactions, some become more reckless due to despair around being infected and increase their risk-taking, while others make positive changes to their lifestyle and outlook. The issue of disclosure requires further research in order to gain a more comprehensive understanding of the range and effect of possible outcomes.

Hepatitis C-related discrimination

Stigmatisation and discrimination of people with hepatitis C infection is alluded to in the scholarly and popular literature as well as in government reports. Reports of hepatitis C-related discrimination indicate that it occurs at a governmental, institutional and inter-personal level (National Centre in HIV Social Research, 2001; Puplick, 2001; Crofts, Louie et al., 1997; Burrows and Bassett, 1996). In Australia, hepatitis C has not received the same level of concern or input regarding policy as that which enabled a successful response to the HIV epidemic (Hulse, 1997). It has been suggested that this is because injecting drug users are perceived by the health bureaucracy as disorganised and do not constitute a 'community' in the same sense as the gay community during the early years of the HIV epidemic (Hulse, 1997). The illegal status of injecting drug use throughout Australia, and inadequate concern regarding the likelihood that hepatitis C could cross-over into mainstream Australia are reasons given for why governments have been slow to respond to a mounting public health crisis. Power for making and informing public health policy concerning hepatitis C has shifted to senior health bureaucrats and away from 'affected' communities (Hulse, 1997). This form of bureaucratic discrimination endangers the

development of policy sensitive to the needs of this diverse population.

Scholarly and popular authors, as well as government reports, have highlighted the discrimination and stigmatisation that people with hepatitis C experience because of the virus' association with injecting drug use (National Centre in HIV Social Research, 2001; Puplick, 2001; ADB of NSW, 2001; Hepworth and Krug, 1997; Crofts, Louie et al., 1997). Nevertheless, empirical investigation into the social dynamics of hepatitis C-related discrimination has been minimal. Several small studies have been conducted, however, they provide limited detail about the extent and nature of discrimination and its effects on people with hepatitis C infection (e.g. Crofts, Louie et al., 1997; Hepworth and Krug, 1997). A hepatitis C diagnosis is often delivered in an insensitive manner by doctors who assume infection was the result of 'deviant' behaviour, with healthcare workers continuing this line of reasoning, resulting in the poor treatment of patients (National Centre in HIV Social Research, 2001). Negative media portrayals of people with hepatitis C have contributed to the stereotyping and discrimination of people with the infection (ADB of NSW, 2001).

The manifestations of discrimination are varied. Stress and isolation at work have been reported (Sladden et al., 1998). Access to health services has often been made difficult and treatments (including pain relief) have been denied to patients because they have continued to inject (ADB of NSW, 2001; Hepworth and Krug, 1997). Discrimination also occurs when consideration is being given to who can afford treatments and who is appropriate for treatment (Hepworth and Krug, 1997). According to one source of popular literature, from the outset research around hepatitis C transmission was slow in being implemented, reflecting an ambivalence towards the population most affected (Wood, 1997).

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.

Psychiatric effects of interferon treatment for chronic hepatitis C

Interferon treatments for hepatitis C infection often produce severe psychiatric side effects in patients. A review of the research literature on the behavioural side effects of interferon

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 hepatitis C infection who are receiving treatment suffer negative impacts on health-related quality of life. Psychiatric and physical side effects from interferon treatment often affect people's well being and compromise their ability to fulfil daily activities. In addition, the association of hepatitis C infection with the illegal and stigmatised activity of injecting drug use has implications for a range of social and health issues. In the minds of many healthcare professionals, having hepatitis C implies that infection occurred as a result of injecting drug use. Comparisons can be made to the experience of being HIV-positive where the HIV virus 'homosexualises' those infected (Hepworth and Krug, 1999; Holt et al., 1998; Malcolm et al., 1998; Ariss, 1997). The social stigma attached to injecting drug use adds another burden for someone coming to terms with hepatitis C infection. Evidence suggests that

some people are not accessing mainstream health services either because they fear discrimination from healthcare workers (ADB of NSW, 2001) or because they have experienced unsatisfactory results from conventional hepatitis C treatments (Dolan, 1997). Many people have turned to complementary and alternative treatments as a means of addressing their health concerns. Popular literature discusses alternative treatments for hepatitis C infection including traditional Chinese medicine, Western herbal medicine, homeopathy and vitamin, mineral and amino acid supplementation (Salmond, 1999, August; Dolan, 1997). Some authors cite exercise, healthy diet and abstinence from alcohol and other drugs as treatment options (Everson and Weinberg, 1999; Dolan, 1997).

Alternative and complementary therapies for chronic hepatitis C

According to several survivors' guides, people with hepatitis C infection have used traditional Chinese medicine and Western complementary medicine in the treatment of the virus. These forms of treatment, while currently having no scientific evidence to support their efficacy, are reported by some people as having significantly beneficial effects for symptoms of hepatitis C infection (English and Foster, 1997; Dolan, 1997). Dolan (1997) suggests that hepatologists may be more accepting of complementary therapy interventions than general practitioners. Many general practitioners are reluctant to utilise multiple treatment approaches. English and Foster (1997) caution against therapeutic involvement with unqualified practitioners. However, they argue that the psychological benefits that are to be derived from 'helping yourself to heal yourself' are often worth the effort. Clinical trials to test the efficacy of alternative forms of hepatitis C therapy are currently being conducted throughout the world (Salmond, 1999, August; Dolan, 1997).

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 living with hepatitis C can assist in reducing the sense of isolation that infection with a stigmatised virus may impose and ameliorate a personal sense of worthiness undermined by negative interactions with individuals or services hostile to people with hepatitis C. A need for such narratives is widely recognised for those living with chronic illness (Frank, 1995; Kleinman, 1988). The quarterly magazine of the Hepatitis C Council of New South Wales, *The Hep C Review*, includes readers' contributions to a regular column dedicated to telling the stories of people with hepatitis C. By providing such stories, people can read accounts of others' trials with diet, drug use, treatment experiences and a range of issues specific to hepatitis C infection.

Krug (1995) believes that people want to know whether they as individuals will develop liver cancer rather than the statistical likelihood. People want to know how their lives and interactions with others will change. He calls for less reliance on medical discourse to create meaning for people with hepatitis C infection and for people to reposition themselves among the power discourses around hepatitis C (Krug, 1996). Repositioning oneself as worthy and deserving of good treatment rather than being "a threat to public health and the common good" (Krug, 1997, p.92) will become possible as people share their experience of infection with others and access to a variety of information about hepatitis C improves (Krug, 1996).

In 'The Hepatitis C Handbook', Dolan (1997) writes that upon patients receiving a positive hepatitis C diagnosis many doctors play down the health implications which cause some patients

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 detriment of social, psychological and community understandings of hepatitis C. To date, epidemiology and virology have dominated political and public health debate concerning the virus (Hepworth and Krug, 1997). An exclusively scientific understanding of hepatitis C impedes recognition and interpretation of related issues (like discrimination) because the discursive field of hard science has no language to deal with such issues. The most relevant of all

knowledges concerning hepatitis C, that of actual people living with the infection, is excluded because of an over-reliance and privileging of specific scientific discourses. Hepworth and Krug (1997) argue that issues like discrimination are not explored by epidemiological understandings of the virus, but that such understandings inform all levels of government policy regarding hepatitis C. The dominant discourse around hepatitis C constructs affected individuals as powerless and marginalised 'sick' people who need to be restricted or excluded from making any decisions concerning their own welfare due to their psychological and social impoverishment. However, such opinions and practices waste valuable resources that are to be found among people with hepatitis C infection. These authors argue strongly for this situation to change and for the voice of affected people to be heard in the construction of hepatitis C policy (Hepworth and Krug, 1997). In recent years, the development of the National Hepatitis C Strategy 1999-2000 to 2003-2004 followed a process that included extensive 'hepatitis C community' consultations.

Support groups

In a climate of incomplete medical knowledge regarding hepatitis C, widespread community misconceptions about infection (Watson et al., 1999), far from optimal therapeutic treatments and no vaccine, and discrimination against and stigmatisation of people with hepatitis C infection, support groups can play a significant role in improving the quality of life of affected people. Support groups provide a forum for the latest medical and scientific information (Krug, 1995), or simply for meeting and talking to other people about lifestyle issues. This is said to be helpful on a number of levels, particularly when it comes to making changes such as giving up or drastically reducing drug use (Dolan, 1997) or dealing with the side effects of interferon treatments (Everson and Weinberg, 1999; English and Foster, 1997).

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 support line in NSW, over two-thirds of callers requested information, most of which concerned transmission issues, and the remaining third requested counselling and support (Cregan et al., 1999, August). These findings indicate a need for support groups to fulfil a demand for information. A qualitative study of medical specialists' perceptions of the support needs of people with hepatitis C identified several critical stages where support was necessary. These were: after diagnosis; when failing to meet treatment criteria; when receiving interferon-based treatments; and following failure to respond to treatment (Teague et al., 1999). It is also likely that support services would be required at other stages of living with hepatitis C infection. The paucity of literature concerning support groups, the function they serve and the meaning of support for people with hepatitis C suggests that this is an area requiring significantly more investigation (Campora, 1999, August).

hepatitis C, uptake of treatments, information and support needs and impact of infection on physical and emotional health and well being.

The 3D Project

Given the myriad health and social issues pertaining to living with hepatitis C infection and their relatively scarce exploration from a social scientific perspective, the 3D Project sought to investigate people's experiences of receiving a hepatitis C diagnosis and their concerns about and experiences with disclosing hepatitis C infection. In addition, the 3D Project aimed to explore the impact of hepatitis C-related discrimination, and a range of social and health outcomes of infection. In sum, this report describes participants' characteristics, their experiences of diagnosis, disclosure and hepatitis C-related discrimination, basic knowledge about

CHAPTER 2

METHODS

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* is sent to members of the HCC of NSW who comprise individuals with hepatitis C, general practitioners who are interested in hepatitis C treatment, nurses, hepatologists, gastroenterologists, government and non-government organisations including the peak state injecting drug user group, needle and syringe programs, methadone clinics, liver clinics and a variety of other health related organisations. Most organisations, like needle and syringe programs and liver clinics attached to large metropolitan hospitals, were sent multiple copies of the questionnaire for staff to pass onto those people who fulfilled the inclusion criteria, were interested in being involved and did not subscribe or have access to *The Hep C Review* magazine. In each edition of the magazine in which the questionnaire was inserted, an advertisement gave information about the purpose of the study, who was conducting the study, an outline of the criteria for inclusion in the study (i.e. having hepatitis C infection) and how to participate.

The second strategy for recruitment to this study involved the HCC of NSW Hep C Helpline; a telephone information and counselling service for people with hepatitis C infection in New South Wales. Callers to the Helpline were sent the reply-paid questionnaire as part of a hepatitis C information pack routinely posted to all users of the service. Callers were supplied with information about the study by a telephone counsellor and were encouraged to participate.

The third and final strategy for recruitment to the quantitative arm of this study involved staff from the Resource and Education Program for Injecting Drug Users (REPIDU – a large inner-Sydney needle and syringe program) informing their clients that a study about living with hepatitis C was being conducted on the premises. Clients were informed of the criteria for involvement. Surveys were administered to interested clients during business hours throughout November 2001. The questionnaire was presented to participants in the style of a brochure. The cover was graphically designed and contained the words 'The 3D Project: Diagnosis, Disclosure, Discrimination and People Living With Hepatitis C' written across the front in small but readable print. The reverse side contained the return address. Once completed, the questionnaire was easily sealed and ready for posting.

The questionnaire contained 58 items that enquired into: participants' experience of hepatitis C diagnosis; disclosure of hepatitis C infection; hepatitis C-related discrimination; knowledge of hepatitis C infection; use of conventional and complementary/alternative treatments; current state of health; future outlook; support needs; alcohol and other drug use; and demographic characteristics.

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 grounded theory approach (Glaser and Strauss, 1967). Audio taped recordings were transcribed and checked for accuracy. Participants were assigned pseudonyms. Two researchers worked independently, closely reading the interview transcripts. The emergent themes were identified, compared and discussed until agreement was reached. The themes were assigned codes and then applied to interview transcripts. Coded data were then entered into qualitative software package, QSR NVivo 2.0. The analysis describes themes within the interviews that emerge as significant or important to participants. Results from the qualitative analyses are used throughout this report to illustrate and reinforce findings from the quantitative data.

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 returned: 450 from *The Hep C Review* and telephone helpline recruitment strategy, and 54 were completed by clients at REPIDU needle and syringe program (N=504).

Gender and age

Participants in the survey arm of the study were almost equally divided between men and women (Table 1). A total of 254 men (50.4%) and 244 women (48.4%) completed the questionnaire. One participant in this arm of the study (0.2%) identified as transgender. Five (1.0%) gave no response to this item. The age of participants who completed the questionnaire ranged between 18 and 77 years with a mean age of 42 years (SD 10.4) (Table 1).

Education

Participants reported a broad range of educational experience (Table 1). Eleven participants (2.2%) left school following completion of primary education. A further 87 (17.3%) left school before the completion of Year 10, and 122 (24.2%) reported Year 10 as their highest level of education. A further 95 participants (18.8%)

reported their highest level of education as a diploma or trade certificate, and 49 (9.7%) reported that the NSW Higher School Certificate was their highest level of education. In all, 50 participants (9.9%) reported that they had completed an undergraduate degree and a further 43 (8.5%) reported that they held a postgraduate qualification.

Mode of acquisition and time since infection

A majority of participants (57.5%, n=290) reported that they had contracted hepatitis C infection through injecting drug use (Table 1). Seventy-four (14.7%) reported that they had acquired their infection from medical blood products. Very few cited tattooing (3.8%, n=19), sex (3.0%, n=15), or body piercing (0.8%, n=4) as the source of their infection. Finally, 44 (8.7%) cited 'other' sources besides those mentioned as the reason for their infection and 46 participants (9.1%) gave multiple responses indicating uncertainty about the origins of their infection. A majority of participants (66.3%, n=334) reported that they had contracted their infection between either 11 to 20 years ago, or more than 20 years prior to being surveyed.

Income

A substantial number of participants (n=184, 36.5%) reported that their annual gross earnings were less than 10,000 dollars per year (Table 1). A further 92 (18.3%) reported that they earned between 10,001 dollars and 20,000 dollars per year and 120 participants (23.8%) reported earning between 20,001 dollars and 50,000 dollars per year. Only 55 (10.4%) reported earning more than 50,000 dollars per year.

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).

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

Characteristic	n	%
Self-reported time since infection (n=490)		
Within the last year	12	2.4
Between 1 and 5 yrs ago	67	13.3
Between 6 and 10 yrs ago	82	16.3
Between 11 and 20 yrs ago	199	39.5
Over 20 yrs ago	130	25.8
Income per year (n=448)		
< \$10,000	184	36.5
\$10,001–\$20,000	92	18.3
\$20,001–\$30,000	58	11.5
\$30,001–\$40,000	29	5.8
\$40,001–\$50,000	33	6.5
\$50,001–\$60,000	30	6.0
Over \$60,000	22	4.4
Employment (n=494)		
Unemployed	91	18.1
Employed full time	93	18.5
Employed part time	50	9.9
Self-employed	35	6.9
Pension	160	31.7
Student	13	2.6
Mix of work/study/pension	52	10.3
Sexual identity (n=494)		
Heterosexual	403	80.0
Gay/queer/homosexual	40	7.9
Bisexual	44	8.7
Other	7	1.4
Injected in the last month (n=496)		
Yes	138	27.4
No	358	71.0
Country of birth (n=499)		
Australia	401	79.6
Other	98	19.6
Ethnicity^b (n=323)		
Anglo	186	36.9
European	59	11.7
'Aussie'	59	11.7
ATSI	16	3.2
Asian	5	1.0
Arabic	2	0.4
Other	12	2.4
Living arrangements^b (n=498)		
Live alone	117	23.2
With friend	55	10.9
With mother and/or father	38	7.5
With partner	231	45.8
With children	156	31.0
With other	47	9.3
Prison in 2000 (n=495)		
Yes	63	12.5
No	432	85.7
Treatment ever (n=500)		
Yes, interferon	58	11.5
Yes, interferon & ribavirin	54	10.7
Yes, multiple (i.e. alt. and con. Tx)	11	2.2
Yes, other	52	10.3
No treatment	325	64.5

^a Proportions do not add to 100% due to missing data

^b Categories are not mutually exclusive

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 infection from a doctor. On receipt of this diagnosis, most reported being ‘shocked’ (48.7%, n=203), with many also reporting being ‘worried’ (39.6%, n=165), ‘scared’ (34.1%, n=142) and ‘confused’ (33.3%, n=139) by their hepatitis C diagnosis. When asked if their doctor had explained what it means to have hepatitis C infection, 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’, and 116 (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 (35.4% v 23.7%, p<.05) (Table 3). Participants diagnosed from 1997 to 2001 were more likely to report receiving an explanation about hepatitis C than those diagnosed from 1989 to 1996 (37.5% vs 23.0%, p<.01) (Table 3).

Table 3: Received explanation of hepatitis C infection from doctor at diagnosis^a

	Yes n (%)	No n (%)	Partly explained n (%)	Total n (%)
Gender*				
Male	65 (32.8)	47 (23.7)	86 (43.4)	198 (100)
Female	51 (24.1)	75 (35.4)	86 (40.6)	212 (100)
Diagnosed**				
1989–1996	62 (23.0)	87 (32.3)	120 (44.6)	269 (100)
1997–2001	54 (37.5)	36 (25.0)	54 (37.5)	144 (100)

^a Only significant results presented

*p<.05 **p<.01

Following diagnosis, 137 (32.9%) participants reported that their doctor had not given them any information or advice about conventional treatments, natural therapies, referral to a specialist, post-test counselling, information about how the virus might affect health or information about support groups (Table 4).

Table 4: Received from doctor at diagnosis (n=409)

Received from doctor:	Yes n (%)	No n (%)
Advice on natural therapies	23 (5.5)	386 (92.6)
Counselling	37 (8.9)	372 (89.2)
Information about support groups	53 (12.7)	356 (85.4)
Pamphlets with information about hep C	119 (28.5)	290 (69.5)
Referral to a specialist	123 (29.5)	286 (68.6)
Information on health effects of hep C	133 (31.9)	276 (66.2)
Information about hep C treatments	78 (18.7)	331 (79.4)
Other	42 (10.1)	367 (88.0)
I was given nothing at diagnosis	137 (32.9)	272 (65.2)

Participants who reported receiving none of the above from their doctor following diagnosis

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 have received information about hepatitis C treatments (24.5% vs 16.2%, $p < .05$), advice regarding natural therapies (9.1% vs 3.8%, $p < .05$) and pamphlets containing information about hepatitis C (39.2% vs 23.7%, $p < .01$) from their doctor than those diagnosed from 1989 to 1996 (Tables 6, 7 and 8 respectively). The year a participant was diagnosed did not appear to significantly affect doctors' provision of post-test counselling, information about support groups, information about how hepatitis C might affect their patients' health, or referral to specialists. Those participants who were referred to a specialist were more likely to be older (i.e. >45 years) (41.9% vs 25.5%, $p < .01$) (Table 9).

Table 5: Received 'nothing' from doctor at diagnosis^a

	Yes n (%)	No n (%)	Total n (%)
Current IDU*			
Yes	45 (42.9)	60 (57.1)	105 (100)
No	90 (30.2)	208 (69.8)	298 (100)
Diagnosed*			
1989–1996	100 (37.6)	166 (62.4)	266 (100)
1997–2001	37 (25.9)	106 (74.1)	143 (100)

^a Only significant results presented
* $p < .05$

Table 6: Received information about hepatitis C treatment from doctor at diagnosis^a

	Yes n (%)	No n (%)	Total n (%)
Diagnosed*			
1989–1996	43 (16.2)	223 (83.8)	266 (100)
1997–2001	35 (24.5)	108 (75.5)	143 (100)

^a Only significant results presented
* $p < .05$

Table 7: Received advice on natural therapies from doctor at diagnosis^a

	Yes n (%)	No n (%)	Total n (%)
Diagnosed*			
1989–1996	10 (3.8)	256 (96.2)	266 (100)
1997–2001	13 (9.1)	130 (90.9)	143 (100)

^a Only significant results presented
* $p < .01$

Table 8: Received pamphlets from doctor at diagnosis

	Yes n (%)	No n (%)	Total n (%)
Diagnosed*			
1989–1996	63 (23.7)	203 (76.3)	266 (100)
1997–2001	56 (39.2)	87 (60.8)	143 (100)

^a Only significant results presented
* $p < .01$

Table 9: Received referral to a specialist from doctor at diagnosis^a

	Yes n (%)	No n (%)	Total n (%)
Age*			
18–45	69 (25.5)	202 (74.5)	271 (100)
46–77	49 (41.9)	68 (58.1)	117 (100)

^a Only significant results presented
* $p < .01$

Following diagnosis, a majority of participants (66.7%, $n=278$) reported that they were given no advice regarding whom to tell about their infection. Conversely, 17 (4.1%) were advised to tell no one about their infection. Participants were asked who had given them the most support following their hepatitis C diagnosis. Partners (18.9%, $n=79$) were reported as the people who had given the most support following diagnosis. When asked to describe the impact of infection on participants' lives, 198 (47.5%) reported that their life had become 'worse', 159 (38.1%) reported 'no change' in their life since diagnosis and 46 (11.0%) reported that life had become 'better' since their diagnosis.

Finally, participants were asked to report how many other people they knew with hepatitis C infection. In all, 160 (38.4%) reported knowing more than 10 people with hepatitis C, however, 65 (15.6%) reported knowing no other people with the infection.

EXPERIENCES OF DIAGNOSIS

The experience of diagnosis was a primary focus of the in-depth interviews. In all, 16 participants received their diagnosis from a doctor or a specialist, with the remaining three diagnosed in prison, at an IVF clinic and a methadone clinic. Most participants had been diagnosed with hepatitis C infection from 1989 to 2001. Two had been diagnosed with non-A non-B hepatitis during the 1970s. Three major themes emerged from the interview data regarding diagnosis and these centred on healthcare workers' interactions with newly diagnosed hepatitis C patients. These themes were: information provided at diagnosis; healthcare workers' knowledge of hepatitis C virus infection; and healthcare workers' reactions to a positive diagnosis.

Information provided at diagnosis

Interview participants' experiences of diagnosis supported the findings from the survey data. Most participants reported that their doctor had explained to them what it meant to have hepatitis C infection or were given reliable information that addressed and satisfied their concerns:

I saw a specialist who's been pretty good, as much as a specialist can be with their limited social skills and stuff. He had a lot of information and a lot of facts and was able to tell me what was going on. (Deb, 40 years old)

However, in some cases, often the only information provided was the diagnosis. In such instances, participants reported feeling 'shrugged off':

[M]y local GP ... did a blood test and said I had a virus, that was it, nothing else. So no advice on anything to try. This other fellow I saw in late '97, the gastroenterologist ... he just said 'Oh, you've got hep C' and I didn't have any idea what it was ... and that's all he said. (Keith, 70 years old)

When I went back to my doctor to get the diagnosis, or the result of the blood test, he said 'Oh, you've got hep C. Just go home now and forget you've got it' and that was the only help I got from him! But fortunately, his secretary (or receptionist, really) said 'I think we've got some forms here from the Hep C Council'. So she gave me one. (Mavis, 70 years old)

The lack of information and referral to support services provided at the point of diagnosis had a significant emotional impact on some participants. Claris received her diagnosis in 1997, indirectly via her husband. She received no other information.

[The doctor] told my husband I had hep C and I'd never heard of it. So my husband and I sat outside and cried because we thought we were going to die; that I was going to die within the next couple of weeks. Because, as I've never ever heard of it. I'd heard of A and I'd heard of B but I'd never heard of C and I

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 to your mind ... and it's just that I was scared to touch anything. If I was doing anything with the grandchildren, like pick them up or anything, I was sort of scared. (Claris, 57 years old)

The lack of information about hepatitis C infection provided at diagnosis and thereafter, made some participants frustrated and angry:

I was just so tired all the time and frustrated because trying to get knowledge [about hepatitis C] is like trying to get gold out of Russia, I'd say. For about a year, when I first found out, I was as angry as a bear. You feel like punching holes in doors all the time because you just can't see any light or way out. You ring up [a large Sydney hospital] and go and see a specialist out there. I rang [another specialist] and they all talk to you but never tell you anything. (Keith, 70 years old)

Two participants had been diagnosed prior to 1989 with non-A non-B hepatitis. In these cases, there was some confusion and difficulty reported in finding out the implications of a subsequent hepatitis C diagnosis:

I got a bit stropky and [the doctor] got a bit stropky, over this question of non-A non-B being hep C and so on. Because ... most of us ... were told ... we've got this non-A non-B

and that's good. You've had it you've cleared it, that's OK, it will never worry you again, the same as hep B and that's what everyone thought 'Oh well, no problem'. But, at the end of this conversation, I said to this doctor 'Well, what do you mean by "this is going to cause you problems?"' and he said to me: 'Well, if I was you I wouldn't make any plans for much past 50'. (Sebastian, 42 years old)

Healthcare workers' knowledge of hepatitis C infection

Some participants were ambivalent about the extent and quality of the information they were given, recognising that they received little information due to either a lack of knowledge existing at the time or a lack of specialist knowledge on the part of a general practitioner. Generally, participants reported their doctor had little knowledge of hepatitis C infection. One reasoned this was due to his doctor's low caseload of patients with the infection:

People don't know that much about it. Even my doctor, because I've asked him questions about it and he'd say 'Look, that's not my area'. I'd say: 'If someone comes in with hep C, what do you do?' He'd say 'Just send them up to the liver clinic'. And that's what they do ... I mean, he's just a GP ... he said he had one patient who was diagnosed with hep C and went on the old monotherapy for a year. That was the only experience he had with it ... it's just one guy doing a specific job and he doesn't specialise in that sort of thing. (Geoff, 54 years old)

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)

DISCUSSION

The experience of receiving a diagnosis of hepatitis C infection can be a shock for many people and even more harrowing when little advice and reliable information about one's prognosis is forthcoming from doctors and other healthcare workers. While most participants indicated that they did receive at least some information about their infection, many others did not. Findings from both the survey and interview data indicate that many participants received either partial or no explanation about hepatitis C infection from a doctor at diagnosis.

More women than men in the survey arm reported receiving no explanation about their infection at diagnosis. Previous research has indicated women's dissatisfaction with the level of information received in medical settings.

Sometimes this is explained by doctors' underestimation of female patients' ability to comprehend medical information (Oakley, 1993). The amount of information considered appropriate to give to patients is contested among doctors in a range of fields. For example, in the context of cosmetic surgery the biomedical conception of femininity as 'irrational' and 'emotional' presents barriers for explanation to female patients by male doctors (Fraser, 2003). An alternative explanation may be related to the differences in patterns of men and women's health seeking behaviours (Smith et al., 1999). In our study, some men may have been less engaged or concerned with their diagnosis than some women, who may have expected and demanded more information from their doctors following diagnosis.

The survey data from this study indicated that many participants reported receiving no written information in the form of pamphlets or advice on the impact of hepatitis C infection on health, nor did many participants receive information about available treatments from their doctor at the point of diagnosis. There was a lack of evidence that pre and post-test counselling occurred, and that information about support groups and referral to appropriate support agencies were provided. These findings were reflected in the interviews. Several interviewees commented on some healthcare workers' lack of concern for participants' well being following a positive diagnosis.

Our survey data show that current injecting drug users were more likely to report receiving no information regarding hepatitis C, no information about treatments and no advice, counselling or referral at diagnosis than participants who were not current injectors. Our interview data supports these findings in as much as it documents reports of some doctors' hostility towards and disengagement from patients who had acquired hepatitis C infection from injecting

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 care to people with hepatitis C. Since 1999, the

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 (%)	Total n (%)
Gender*			
Female	194 (79.8)	49 (20.2)	243 (100)
Male	171 (67.9)	81 (32.1)	252 (100)

^a Only significant results presented
*p<.01

Table 11: Disclosure of hepatitis C infection to doctor^a

	Yes n (%)	No n (%)	Total n (%)
Gender*			
Female	196 (80.7)	47 (19.3)	243 (100)
Male	182 (72.2)	70 (27.8)	252 (100)

^a Only significant results presented
*p<.05

Of the 143 (28.4%) participants who reported that they either worked fulltime or part time, 83 (58%) reported disclosing their infection to their 'boss'. Similarly, 87 (61%) reported that they had told their 'workmates' about their infection. We did not enquire into how many participants had casual sex partners, however, 96 (19.0%) reported that they had disclosed their hepatitis C infection to their casual sex partners. Finally, 13 participants (2.6%) reported that they had told 'no one' about their hepatitis C infection.

Table 12: Disclosure of hepatitis C infection and subsequent 'bad' reactions (N=504)

Disclosed to:	Disclosure		Reacted 'badly'	
	n	% ^a	n	% ^b
Wife/husband/partner	369	73.2	63	17.1
Family (i.e. parents/siblings)	359	71.2	81	22.6
Children	143	28.4	14	9.8
Doctor	383	76.0	44	11.5
Other healthcare worker(s)	331	65.7	54	16.3
Casual sex partner	96	19.0	26	27.1
Flatmate	90	17.9	17	18.9
Friend(s)	348	69.0	68	19.5
Boss	83	16.5	14	16.9
Workmate(s)	87	17.3	12	13.8

^a Percentage of total sample.

^b Of those who had disclosed, the percentage of people who had experienced a bad reaction.

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, I'm not sure whether I would let the same people know. But it dates back from the time when I didn't think it was really that important ... I feel obliged to tell doctors and health practitioners. I'm obliged to tell them, I feel. You don't expect someone to treat you where there are dangers involved without disclosing those sorts of things ... Oh, any close links. Family don't necessarily need to know.

Angus, 41, equates a loss of control with disclosing hepatitis C infection. He implies that his personal health information is not for public consumption and he fears that he would become a target for discrimination if he were to become an advocate for people with hepatitis C infection, which he states he has no wish to do:

So you haven't disclosed your hep C status to anyone?

No. Mind you, in saying that, I didn't disclose I was HIV positive for over a year. Again, it's just being proactive, taking control over my life and trying to get on with it and organise it and not bother too many people ... I have no intentions of

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.

How did you feel at the time of telling them?

I remember telling my dad, because he didn't know that I'd used drugs. Mum had always said not to tell dad. Then I thought 'Well, he's a big boy now. If he can't cope with that, then too bad.' And he did, he was fine. He bought a book about it and everyone worried and fretted for a while. Then no one talks about it now, not because it's taboo but because there's no new news. There's nothing to discuss; it's just in the background.

Mary, 28, reported withholding disclosure in social contexts. She discusses the implications of hepatitis C disclosure for the initiation of long term, intimate relationships. Her fears of rejection are clearly articulated:

Who do you tell that you have hep C?

No one. I tell no one, except the doctors ... But no, I wouldn't tell people.

Does not disclosing your status to people prevent you from getting close?

Oh, for sure. I met someone just recently and ... he comes from [Queensland] but it was just more like a friendship type of thing but it could have eventuated into something more. But, I thought if it gets to the point where the relationship eventuates, or becomes deeper, I thought 'Well, how are you going to sit down and tell this person? Will he

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

know! So, I think, well don't even entertain going down that avenue because you know – well, 'irrationally' I know that it's not going to come to fruition, that we won't go on a date or whatever, because he's a doctor. He wouldn't want to be partners with, you know, someone with hep C ...

Keith, 70, is unique among the interviewees in his approach to disclosure. He is very selective about to whom he discloses his hepatitis C infection, and has developed an alternative strategy for explaining his symptoms to people he is less familiar with:

Who do you tell that you have hep C?
Who would you confide in?

... Close friends, real close friends, I tell but generally because you read such ... how people are so anti it, I don't tell it generally, I just tell them I've got chronic fatigue. I think that's simpler, it's very acceptable ... You're not proving anything, just poking a stick in your eye really, telling people, because they don't understand. So I don't broadcast it fully, but I don't care. If someone knows, well that's OK, I don't hide it, but I don't feel it's worth broadcasting either, you know, because there is such terrible discrimination.

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 disclosure of hepatitis C infection – a worrying result given that health professionals are often the first people one turns to when ill. These findings support those of the qualitative study by Crofts et al. (1997) and the Anti-Discrimination Board of New South Wales' (2001) enquiry, where negative reactions from healthcare professionals, partners and families to disclosure of hepatitis C infection were commonly reported. Similar patterns of findings have been reported in previous studies into disclosure of HIV infection (Ariss, 1997; Gilmore and Somerville, 1994; Malcolm et al., 1998). Efforts to improve healthcare workers' understanding of hepatitis C infection and to reduce the likelihood of negative reactions to patients' disclosure are needed if the public health system is to avoid alienating many people from health services.

Bad reactions were reported to have occurred in similar proportions among participants' friends, employers and flatmates. Reactions to disclosure of hepatitis C infection to casual sexual partners were reported as negative in over a quarter of

instances. In the present study, over a third of participants regretted telling someone about their infection illustrating the risks associated with disclosing personal health information. Healthcare workers were reported to have spread personal health information without permission and to have pressured patients into disclosing their hepatitis C infection. Both practices are clearly unethical and compromise patients' right to confidentiality, and for many may initiate a loss of trust and faith in the health system. Government departments were also reported as pressuring people to disclose their infection. Such practices illustrate an important need for people to be informed of their legal obligations with regard to disclosing personal health information to bureaucracies.

Our findings illustrate that investigation of hepatitis C disclosure patterns and outcomes is important for reasons that concern both the public health system and the well being of individuals. Disclosure of hepatitis C infection to healthcare workers is unlikely to occur again if it has previously been associated with negative outcomes for a patient. This scenario could lead to a situation where many people with hepatitis C infection avoid seeking appropriate advice and treatment. An understanding of the barriers and incentives to disclosure in healthcare settings may assist to minimise the risk of nosocomial transmission, given that universal infection control procedures are not always applied (ADB of NSW, 2001). Regarding individual well being, past literature shows that disclosure is important for coming to terms with having an infection and may be a marker of self-acceptance following diagnosis (Pennebaker, 1995). For many, disclosure is necessary for acquiring social support to assist in the continuation of one's physical and emotional health. Finally, issues pertaining to disclosure are likely to vary according to one's ethnic and cultural background. More research on the experience of disclosure of hepatitis C

infection in Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities could assist in the production of public health programs and campaigns specific to these populations. Generally, further research is needed to describe in more detail the dynamics of disclosure as it specifically relates to the diversity of people with hepatitis C infection in Australia.

CHAPTER 6

DISCRIMINATION

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 of NSW, 2001; Puplick, 2001; Crofts, Louie et al., 1997; Hepworth and Krug, 1997). The evidence indicates that hepatitis C-related discrimination occurs either because of the association of the infection with injecting drug use or because of an irrational fear of infection due to an inadequate knowledge about modes of transmission.

Reports of hepatitis C-related discrimination were common throughout the present study and involved a range 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. Approximately 64 (12.7%) reported that they had been refused medical treatment because they have hepatitis C infection. Other sites of hepatitis C-related discrimination included friendship networks (11.1%, n=56) and insurance companies (12.7%, n=64).

When survey participants were asked if they had ever experienced discrimination because they were perceived as being an injecting drug user, 140 (27.8%) reported that healthcare workers other than a doctor had discriminated against them, and 115 participants (22.8%) said a doctor had discriminated against them because they were thought to be currently injecting. In all, 27 participants (5.4%) reported that they had been refused medical treatment for hepatitis C because they had been injecting at the time. A total of 98 (19.4%) reported that friends had discriminated against them because they were injecting and 81 (16.1%) said that their family had discriminated against them for this reason.

Compared with those who reported that they had been infected with hepatitis C through medical blood products, sex, tattooing, piercing or some other means, participants who reported that they were infected with hepatitis C from injecting drugs were more likely to report that a healthcare worker (besides a doctor) had discriminated against them (34.7% vs 25.0%, $p < .05$) because they were assumed to be current injecting drug users (Table 13). Compared to participants who did not acquire their infection through injecting drug use, those who did were more likely to report having being refused treatment because it was assumed that they were current injectors (8.5% vs 2.6%, $p < .05$) (Table 14). 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 (14.2% vs 2.7%, $p < .001$) (Table 14); IDU-related discrimination from their doctor (35.1% vs 20.9%, $p < .01$) (Table 15); hepatitis C-related discrimination from their family (12.9% vs 5.5%, $p < .01$) (Table 16); and from friends (18.2% vs 9.7%, $p < .05$) (Table 17).

Table 13: IDU discrimination from a healthcare worker (besides a doctor)^a

	Yes n (%)	No n (%)	Total n (%)
Mode of acquisition*			
IDU	94 (34.7)	177 (65.3)	271 (100)
Other	45 (25.0)	135 (75.0)	180 (100)

^a Only significant results presented

* $p < .05$

Table 14: IDU discrimination and refusal of medical treatment^a

	Yes n (%)	No n (%)	Total n (%)
Mode of acquisition*			
IDU	23 (8.5)	248 (91.5)	271 (100)
Other	4 (2.6)	151 (97.4)	155 (100)
IDU**			
Current IDU	19 (14.2)	115 (85.8)	134 (100)
Non Current-IDU	8 (2.7)	285 (97.3)	293 (100)

^a Only significant results presented

*p<.05 **p<.001

Table 15: IDU discrimination from doctor^a

	Yes n (%)	No n (%)	Total n (%)
IDU*			
Current IDU	46 (35.1)	85 (64.9)	131 (100)
Non-Current IDU	67 (20.9)	253 (79.1)	320 (100)

^a Only significant results presented

*p<.01

Table 16: Hepatitis C discrimination from family^a

	Yes n (%)	No n (%)	Total n (%)
IDU*			
Current IDU	17 (12.9)	115 (87.1)	132 (100)
Non-Current IDU	18 (5.5)	311 (94.5)	329 (100)

^a Only significant results presented

*p<.01

Table 17: Hepatitis C discrimination from friends^a

	Yes n (%)	No n (%)	Total n (%)
IDU*			
Current IDU	24 (18.2)	108 (81.8)	132 (100)
Non-Current IDU	32 (9.7)	297 (90.3)	329 (100)

^a Only significant results presented

*p<.05

Survey participants were asked if hepatitis C-related discrimination had had any bad effect on their lives. A total of 227 (45.0%) reported that discrimination had negatively affected their emotional health, with 180 (35.7%) reporting that their physical health had been affected negatively by discrimination. In all, 108 participants (21.4%) reported that discrimination had a detrimental affect on their employment and 134 (26.6%) reported that discrimination had a bad effect on their personal relationships.

Two items in the questionnaire were used as a scale to measure participants' experiences of discrimination: 'Have you ever been discriminated against by any of the following people because you have hep C?' and 'Have you ever been discriminated against by any of the following people because they thought you were an injecting drug user?' The response categories for these two items were: my doctor; other healthcare worker(s); a landlord; my family; my flatmate(s); my friend(s); my workmate(s); an insurance company. A response to either question was counted as evidence of hepatitis C-related discrimination based on the assumption that people with hepatitis C often do not know the precise reason they are being discriminated against (i.e. whether because of being considered an infectious risk or being an injecting drug user, or both). A scale ranging from one to nine was developed where one indicated low level discrimination from one category of people and nine represented high level discrimination, or discrimination from all nine categories of people. A reliability analysis indicated that the discrimination scale has a Cronbach alpha of 0.65. Although this scale does not indicate the absolute number of people that participants report experiencing discrimination from, it does capture the breadth of hepatitis C-related discrimination.

In bivariate analyses, widespread discrimination was associated with participants being male, on a lower income, diagnosed early

(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 linear regression model contained four variables that predicted wider discrimination when other variables were also taken into account: injecting drugs in the month prior to being surveyed; knowing many others with hepatitis C infection; being pessimistic about one's future health due to hepatitis C infection; and, being limited in time spent with family, friends, neighbours or groups because of hepatitis C infection. In total, these four variables accounted for 23.1% of variation in scores on discrimination.

EXPERIENCES OF HEPATITIS C-RELATED DISCRIMINATION

The interview data contained evidence of hepatitis C-related discrimination from healthcare workers, often manifested through the quality of interpersonal communication, implementation of infection control procedures and quality of medical treatment. Interviewees were often unsure whether the discrimination they experienced was related to a fear of infection or a disdain for injecting drug users. For example,

Susie, 54, discussed the treatment she received in hospital:

The only time I've really noticed [hepatitis C-related discrimination] has been when I've been in hospital, being treated by some nurses. Then I found it quite bad. And whether that is because of hep C or whether that's an indication that I was a junkie, I don't know. But even as recently as two or three years ago, I have been treated very badly by some nurses.

Gloria, 45, discusses the confounding of hepatitis C infection, the socially ubiquitous hostility towards injecting drug users and her strategy for avoiding further discrimination:

I know people equate hepatitis C with injecting drug use and I know that is where the discrimination comes from and I know that if you are a known injecting drug user that you will not get a job, or a house or a partner or anything so it's important to keep it very quiet ... my experiences of being on methadone taught me never let anyone know ... because the discrimination's so horrendous that you can't live with it.

Some participants did not always understand the reasoning behind hepatitis C-related discrimination, however, several felt that they were being 'judged' and 'categorised', and held personally responsible for their infection by healthcare workers.

One commonly reported manifestation of hepatitis C-related discrimination involved placing people known to have hepatitis C infection last on day-surgery lists. It was common

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 practices everyone should be treated in a certain way, they are not. If you've got that sticker in your file, you do get a degree of paranoia coming from the people that are dealing with you. Most of them have very little knowledge too of the illness. Certainly that dentist demonstrated that he didn't know what was going on ... I felt like taking him out and buying him a coffee and explaining it to him and saying 'Anyone in your surgery could be in the same state ...'

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:

I went to the dole office ... the sheila came out about work experience and started talking to me in a crowd when I wanted a bit of me own confidentiality because I had hep C and she started talking to me about it in the middle of a crowd ... If you go to the job centre, they ask

'would you like your prospective employer to know you've got hep C?' Well, I certainly wouldn't because he'd tell his co-workers and when you have lunch, you're the only one who's going to be sitting over there in a corner by yourself.

Family members and friends with hepatitis C infection were sometimes excluded from normal interactions and social activities. Claris, 57, describes restrictions that her ex-daughter-in-law placed on Claris' interactions with her grandchildren:

... [my ex-daughter-in-law] told [my son] that he wasn't to let me near the children and they said this and it was written in a letter that I wasn't to touch the children because of the hepatitis C ... so I haven't seen the children, I haven't seen them for three years.

Similarly, Deb reported that her personal relationships were affected by discrimination following disclosure of her infection. This was particularly evident with regard to her relationship with her husband:

With friends, there were ... very mixed reactions. I think one of the most severe reactions came from my husband in that I was contagious and he just freaked out at first and didn't give me support. He just went off 'How did you get this?' and he associated it with AIDS at the time too. He couldn't see the difference and then he thought I got it sexually transmitted.

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 of hepatitis C-related discrimination. Dependent users in a chaotic stage of their drug use careers are often visible targets for discrimination. As well, many current injecting drug users belong to extensive networks of people who inject. Being in daily contact with other marginalised users with hepatitis C and sharing their experiences can highlight the ubiquitousness of discrimination. Similarly, when limited in the time spent with family, friends, neighbours or groups because of ill health caused by hepatitis C infection, users may become isolated and

unable to benefit from the support and positive reinforcement that family, friends and other networks can provide. This can contribute to a general disaffection with life and pessimism regarding the future likelihood of a cure or improved treatment for their infection.

CONCLUSION

Information about hepatitis C infection is scant in the community and our data provide evidence that at least some of the hepatitis C-related discrimination results from misinformation or inadequate information about the virus. As predicted by social identity theory, some uninformed sections of the community react to people with hepatitis C in discriminatory ways in order to preserve social distance between them. Some participants were barred from interacting with loved ones, friendships were re-evaluated and financial opportunities were affected. In order to prevent social exclusion some participants either withheld disclosure or lied to avoid a perception that they were an infectious risk.

Whether discriminatory responses occur due to fear of viral transmissibility or a profound dislike of people who inject drugs, they reflect attempts to establish and maintain distance from the threat of disease and to uphold what are seen as important community values. Social identity theory highlights the cognitive process of social categorisation that people use to identify risk and/or to reinforce a moral and social superiority over marginalised groups, in the present case, people with hepatitis C infection and injecting drug users. These processes are vulnerable to stereotyping and bias, and some individual perceptions of risk have worrying implications, especially for infection control within healthcare. The application of universal infection control procedures has to be reinforced to replace individual healthcare workers' assessments of

infectious risks. Similarly, access to healthcare services is compromised when people with hepatitis C infection are subjected to ongoing discriminatory treatment. It is only through the provision of non-judgemental medical services that injecting drug users will access appropriate information regarding the prevention of hepatitis C transmission. Respectful treatment of all people with hepatitis C infection within healthcare is needed to reduce the impact of morbidity.

Continued discrimination and stigmatisation of people with hepatitis C will obstruct efforts to prevent the further spread of the virus among the community. Addressing community ignorance of the virus will assist to ameliorate some people's experiences of discrimination, however, increased knowledge alone will not be sufficient to address hepatitis C-related discrimination within all domains. Legislative change may be the first step in a process to counter discrimination of people with hepatitis C infection. Drug law reform would pave the way for broader changes in the attitudes and social norms that currently inform and give legitimacy to discriminatory practice.

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

Table 21: People with hep C should always wear a condom^a

	Correct n (%)	Incorrect n (%)	Total n (%)
Sources of hep C info*			
Includes doctor	75 (32.3)	157 (67.7)	232 (100)
Other	104 (41.9)	144 (58.1)	248 (100)
Know others with hep C*			
Yes	144 (35.2)	265 (64.8)	409 (100)
No	35 (49.3)	36 (50.7)	71 (100)
Income**			
<\$30,000	108 (33.5)	214 (66.5)	322 (100)
>\$30,000	58 (54.2)	49 (45.8)	107 (100)

^a Only significant results presented

* $p < .05$ ** $p < .001$

A substantial minority of participants (28.6%) believed that hepatitis C may be transmitted via kissing. A sizeable number chose not to answer this question. However, over two-thirds of participants' responses reflected the public health information regarding transmission, which reports that kissing is not a risk for hepatitis C infection. Participants whose sources of hepatitis C information include their friends were more likely to report that hepatitis C can be transmitted by kissing (42.3% vs 27.4%, $p < .01$) than participants whose sources of information do not include friends (Table 22).

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-term, monogamous sexual relationships are a low risk for transmitting hepatitis C infection to a hepatitis C-negative partner (Terrault, 2002).

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)
Other	292 (72.6)	110 (27.4)	402 (100)
Sources of hep C info			
Includes The Hep C Review**	249 (72.8)	93 (27.2)	342 (100)
Other	88 (63.8)	50 (36.2)	138 (100)

^a Only significant results presented

*p<.01 **p<.05

There was some gender difference associated with knowledge about hepatitis C infection. Women were more likely than men to give correct answers to items about hepatitis C prevention and health impacts. For example, women were less likely than men to report that all people with hepatitis C will eventually need a liver transplant (2.1% vs 5.7%, p<.05) (Table 23). Similarly, women were less likely than men to report that there is a vaccine against hepatitis C infection (3.3% vs 9.7%, p<.01) (Table 24).

Table 23: All people with hep C will eventually need a liver transplant

	Correct n (%)	Incorrect n (%)	Total n (%)
Gender*			
Female	231 (97.9)	5 (2.1)	236 (100)
Male	233 (94.3)	14 (5.7)	247 (100)

^a Only significant results presented

*p<.05

Table 24: There is a vaccine against hep C^a

	Correct n (%)	Incorrect n (%)	Total n (%)
Gender*			
Female	231 (96.7)	8 (3.3)	239 (100)
Male	223 (90.3)	24 (9.7)	247 (100)
Source of hep C info**			
Includes The Hep C Review	333 (96.0)	14 (4.0)	347 (100)
Other	119 (85.6)	20 (14.4)	139 (100)

^a Only significant results presented

*p<.01 **p<.001

Other differences in levels of knowledge regarding hepatitis C infection were evident among the survey participants. Participants who reported that they did not contract hepatitis C infection from injecting drug use were more likely to correctly report that the infection can be transmitted by sharing a toothbrush with an infected person (93.5% vs 84.7%, p<.01) than those who contracted their infection from injecting (Table 25). One item revealed evidence of a difference in knowledge levels as a function of ethnicity. Participants who identified as non-European or non-'Aussie' were more likely to incorrectly report that people with hepatitis C infection can always be cured if new treatments are taken early (16.7% vs 4.7%, p<.05), than those who identified as European or 'Aussie' (Table 26). Finally, participants whose sources of hepatitis C information include *The Hep C Review* were less likely to incorrectly report that there is a vaccine against hepatitis C (4.0% vs 14.4%, p<.001) (Table 24), and that hepatitis C infection can be transmitted via kissing (36.2% vs 27.2%, p<.05) (Table 22), than those who do not cite this magazine as a source of information.

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

	Correct n (%)	Incorrect n (%)	Total n (%)
Mode of acquisition*			
IDU	243 (84.7)	44 (15.3)	287 (100)
Other	188 (93.5)	13 (6.5)	201 (100)

^a Only significant results presented
*p<.01

Table 26: New treatments always cure hep C if taken early^a

	Correct n (%)	Incorrect n (%)	Total n (%)
Ethnicity*			
European/Aussie	282 (95.3)	14 (4.7)	296 (100)
Non-Euro/Aussie	15 (83.3)	3 (16.7)	18 (100)

^a Only significant results presented
*p<.05

INFORMATION AND SERVICES FOR HEPATITIS C

Survey participants were asked to nominate hepatitis C information and services that they would like to be able to access, and they could choose from a range of categories (Table 27). Over half of the participants indicated that they wanted more information regarding conventional medical treatments and alternative therapies for hepatitis C, and information about how their health is likely to be affected by hepatitis C infection. Almost half wanted information about accessing hepatitis C-friendly doctors. Over a third wanted more access to information about transmission of the virus, and just under a third wanted to know about how to get counselling for hepatitis C-related matters. A large proportion of participants wanted information about pregnancy and hepatitis C infection.

Table 27: Information and services for hepatitis C (n=461)^a

Information and services	n	%
How to get counselling	145	28.8
Information about how to avoid passing on hep C	171	33.9
Information about medical treatments for hep C	292	57.9
Information about alternative therapies for hep C	277	55.0
Information about how my health is likely to be affected	276	54.8
Information about finding 'hep C-friendly doctors'	228	45.2
Help with drug and alcohol issues	108	21.4
Information about pregnancy and hep C	98	19.4
Help with finding a support group	111	22.0
Other	68	13.5

^aMissing data = 43

SUPPORT GROUPS

Participants were asked if they belonged to a support group. In all, 58 (11.5%) reported that they were in a support group. Of the 56 participants who answered the follow-up question: 'Is your support group helpful?' 54 (96.4%) reported that their hepatitis C support group was 'helpful'. We asked what participants wanted *most* from their support group. The results of this question are reported in Table 28.

Even though this question aimed to identify the single most important function of a hepatitis C support group for its members, participants' responses indicated that their support groups had multiple important functions. Participants nominated the provision of 'up to date information about hepatitis C' as the most important function of their support group.

Table 28: Function participants wanted most from their support group (n=55)^a

Function	n	Valid %
Knowing that there are others like me	4	7
Help in making decisions about treatments	1	2
Help with coping on a day to day basis	4	7
People who will listen to my story	2	4
Up to date information about hep C	18	33
Information about how to stay healthy	3	6
Other	3	6
Multiple responses	20	36

^a Missing data=3

CONCLUSION

While participants accessed information from a variety of sources, responses to basic questions regarding hepatitis C prevention, lifestyle implications, treatments and health impacts revealed some gaps in knowledge. While most participants answered most of the questions accurately, some in this study remain unsure about important issues, such as prevention of viral transmission. Because people with hepatitis C infection who read or had access to *The Hep C Review* constituted the majority of the study's sample, it might be anticipated that participants would be knowledgeable about hepatitis C, relative to the general community. Still, these results highlight the need for further broad based dissemination of information among people with hepatitis C infection, including where to access non-judgemental and non-discriminatory healthcare.

CHAPTER 8

TREATMENTS, HEALTH & WELL BEING

While not a primary focus of the study, we sought basic information regarding participants' experiences of treatments: conventional, complementary and alternative. We also enquired into participants' physical health and well being by asking whether and how hepatitis C infection limited daily work, social and domestic life. To gain a sense of emotional health and well being, we enquired into the recent (i.e. in the last month) general impact of infection on participants. In addition, one item asked about participants' future outlook with regard to their health.

HEPATITIS C TREATMENTS

Survey participants were asked if they had ever had any treatment for their hepatitis C infection. A majority (64.5%, n=325) reported that they had not had any treatment. A further 58 (11.5%) reported that they had been treated with interferon monotherapy, 54 (10.7%) had been treated with a combination of interferon and ribavirin, and 52 participants (10.3%) had been treated with other hepatitis C therapies such as traditional Chinese medicine (TCM). Eleven participants (2.2%) gave multiple responses to this question, indicating that they had received a range of interferon therapies and/or complementary and alternative treatments.

Participants who estimated that they were infected with hepatitis C less than a decade before completing the survey, were less likely to report ever having treatment (21.4% vs 42.0, p<.001) than those who reported longer infections (Table 29). Participants aged more than 45 years were more likely to report ever having treatment (46.5% vs 30.1%, p<.01) than those who were younger (Table 29). Participants who contracted hepatitis C infection from injecting drug use were

less likely to report ever having treatment (28.7% vs 44.6%, p<.001) compared with those who acquired their infection from non-injecting means (Table 29), and current injecting drug users were less likely to report ever having treatment (14.7% vs 42.7%, p<.001) than those who are not currently injecting (Table 29). There were no gender differences in relation to ever having treatment.

Table 29: Hepatitis C treatment ever^a

	Yes n (%)	No n (%)	Total n (%)
Time since infection*			
0-10 years	34 (21.4)	125 (78.6)	159 (100)
>10 years	140 (42.0)	193 (58.0)	333 (100)
Age**			
18-45	98 (30.1)	228 (69.9)	326 (100)
46-77	66 (46.5)	76 (53.5)	142 (100)
Mode of acquisition*			
IDU	83 (28.7)	206 (71.3)	289 (100)
Other	90 (44.6)	112 (55.4)	202 (100)
Current IDU*			
Yes	20 (14.7)	116 (85.3)	136 (100)
No	152 (42.7)	204 (57.3)	356 (100)

^a Only significant results presented

*p<.001 **p<.01

With regard to current treatment, 436 (86.5%) reported that they were not receiving any treatment. Two participants (0.4%) reported that they were currently on interferon monotherapy, 26 (5.2%) reported that they were currently on interferon and ribavirin combination treatment, and 36 participants (7.1%) reported that they were currently on 'other' forms of hepatitis C treatment.

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'.

Table 30: Current state of health (n=495)^a

Health status	n	%
Excellent	49	9.7
Good	160	31.7
Fair	212	42.1
Poor	74	14.7

^a Missing=9

These four categories were collapsed into 'Poor-Fair' and 'Good-Excellent' for further analysis. Participants who earned more than 30,000 dollars per year were more likely to report that their health is 'Good-Excellent' (62.8% vs 35.8%, $p < .001$) than those earning less than 30,000 dollars per year (Table 31). There were no significant gender or age differences in relation to self-reported current health status. Similarly, current injecting drug users reported no difference in health status from those not currently injecting and mode of acquisition of infection did not affect self-reported health status.

Table 31: Self-reported health status^a

	Good-excellent n (%)	Fair-poor n (%)	Total n (%)
Income/yr*			
<\$30,000	117 (35.8)	210 (64.2)	327 (100)
>\$30,000	71 (62.8)	42 (37.2)	113 (100)

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

Three questions asked participants to describe how often their hepatitis C infection had limited them over the month prior to being surveyed with regards to: everyday physical

activities; doing their job; and spending time with family, friends, neighbours and groups. In relation to everyday physical activities such as walking, climbing stairs, carrying groceries or playing sport, 91 participants (18.1%) reported that they had been limited 'a lot of the time' in these activities because of their hepatitis C infection. Thirty-seven participants (7.3%) reported that they had been limited 'a lot of the time' in doing their work because of their infection. Finally, 70 participants (13.9%) reported that they had been limited 'a lot of the time' in social activities with family, friends, neighbours and groups because of their hepatitis C infection.

Participants were asked about their perception of the general impact of hepatitis C infection on health and well being over the month prior to the survey. Seven statements reflecting the possible effects of hepatitis C infection were presented, and participants were instructed to nominate the statements that resonated with their experiences. The results are presented in Table 32 below. The most frequently reported impact of infection was tiredness ($n=272$, 54.0%), with many other participants claiming that they were 'worried' ($n=194$, 38.5%) about having hepatitis C.

Table 32: Impact of hepatitis C infection over the month prior to survey^a (n=491)^b

Self-reported impact of hepatitis C infection	Agree n	%
In the last month hep C has not affected me	121	24.0
In the last month hep C has weighed me down	143	28.4
In the last month having hep C has made me want to get healthy	166	32.9
In the last month having hep C has caused me to worry	194	38.5
In the last month having hep C has stopped me from doing the things I like to do	145	28.8
In the last month having hep C has made me feel very tired	272	54.0
In the last month having hep C has made me take control of my life	68	13.5

^a Categories are not mutually exclusive
^b Missing=13

FUTURE OUTLOOK

To explore beliefs regarding the long-term future impact of hepatitis C infection on health and well being, participants were asked to complete a statement by selecting from a list of predetermined responses. The results (Table 33) indicate that nearly a third believed that in the future, treatment of hepatitis C infection will make living with the virus easier. Others, however, were less optimistic with almost a fifth reporting that they believed their infection would make them 'really sick' in the future.

Table 33: Future outlook of participants with hepatitis C infection 1 (n=473)^a

In the future I think ...	Agree n	%
I will be cured of my hep C	78	15.5
Hep C will make me really sick	99	19.6
Treatments will make living with hep C easier for me	161	31.9
Hep C will make no difference to me	67	13.3
Other	68	13.5

^a Missing data=31

The responses (reported in Table 33) were collapsed into 'positive', 'neutral' and 'negative' future outlook. Women were more likely to report a neutral future outlook than men (34.5% vs 23.0%, $p<.05$) (Table 34). Participants who reported good-excellent health were less likely to hold a negative future outlook (10.8% vs 28.6%, $p<.001$) than those who reported poor-fair health (Table 34). Participants who earned more than 30,000 dollars per year were less likely to hold a negative future outlook (7.3% vs 25.4%, $p<.001$) than those who earned less than 30,000 dollars per year (Table 34). Participants who reported that their doctor had not explained what it means to have hepatitis C were less likely to hold a positive future outlook (39.0% vs 51.6% and 58.2% respectively, $p<.05$) than those who

reported receiving either an explanation or a partial explanation from their doctor (Table 34). There was no association between mode of acquisition of infection, current injecting drug use and future outlook.

Table 34: Future outlook of participants with hepatitis C infection 2^a

	Positive outlook n (%)	Neutral outlook n (%)	Negative outlook n (%)	Total n (%)
Gender*				
Female	111 (48.5)	79 (34.5)	39 (17.0)	229 (100)
Male	127 (52.3)	56 (23.0)	60 (24.7)	243 (100)
Health status**				
Good-Excellent	105 (51.7)	76 (37.4)	22 (10.8)	203 (100)
Fair-Poor	131 (50.0)	56 (21.4)	75 (28.6)	262 (100)
Income**				
<\$30,000	142 (45.1)	93 (29.5)	80 (25.4)	315 (100)
>\$30,000	68 (61.8)	34 (30.9)	8 (7.3)	110 (100)
Doctor explained hep C*				
Yes	65 (51.6)	37 (29.4)	24 (19.0)	126 (100)
No	57 (39.0)	52 (35.6)	37 (25.3)	146 (100)
Partly explained	114 (58.2)	44 (22.4)	38 (19.4)	196 (100)

^a Only significant results presented

* $p<.05$ ** $p<.001$

Finally, participants were asked to describe their current use of alcohol. Over half (53.0%, $n=267$) reported that they did not drink alcohol. In all, 137 (27.2%) described their current use of alcohol as 'light', 44 (8.7%) described their use as 'moderate' and 17 (3.4%) described their alcohol use as 'heavy'. While there were no gender and age differences associated with drinking alcohol, participants who earned more than 30,000 dollars per year were more likely to report drinking alcohol than those earning less than 30,000 dollars per year (57.9% vs 42.9%, $p<.01$) (Table 35).

Table 35: Alcohol use^a

	Yes n (%)	No n (%)	Total n (%)
Income*			
<\$30,000	142 (42.9)	189 (57.1)	331 (100)
>\$30,000	66 (57.9)	48 (42.1)	114 (100)

^a Only significant results presented

*p<.01

CONCLUSION

The majority of survey participants had received no treatment for their infection. Of those who reported that they had received treatment, most were older (>45 years) and estimated that they had been infected with hepatitis C for more than a decade. Participants who were ex or current injecting drug users reported less experience with any form of treatment for their infection. Of those participants who reported that they were currently being treated, most were receiving something other than a combination of interferon and ribavirin therapy or monotherapy with interferon.

With regard to health status, participants who reported better health were more likely to be higher income earners. Higher income earners were also more likely to have a positive outlook with regard to their future health. In this sample, higher income appeared to be associated with overall well being.

Hepatitis C infection limited some participants' ability to do everyday physical activities, to do their work and to socialise. In accordance with previous quality of life studies, fatigue was reported as the most common physical symptom of infection. Many participants reported being worried about their infection, and a substantial number believed that their future would be affected by illness. However, a majority believed that in the future treatments would make their lives easier.

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

him to me I give blood over at [a large metropolitan hospital] for testing for new diagnoses of haemophilia babies ... but again they don't take any precautions at all because they work on the assumption that babies won't be infected with anything so there's no need to take any precautions. So they'll do it without gloves on so ... they're pretty stupid to themselves and they're compromising the level of care.

In this case Sebastian does not ascribe the discriminatory behaviour of the healthcare workers in terms of power relations between workers and individual patients, but as their attempt to distance themselves from risks of infection. Similarly, Hilda, a 72-year-old woman, reports on her approach to three surgeons to perform elective surgery. Hilda was in a position to accept or reject the healthcare offered depending on her evaluation of the appropriateness of the surgeons' approaches to infection control. Hilda reported that the first surgeon told her that he couldn't perform the surgery because 'it would ruin [his] career'. The second surgeon agreed to do the surgery but in hospital, not in his private surgery. Hilda decided to give 'him the miss' as she felt 'he'd rather put the hospital at risk'. She described the approach of the third surgeon as acceptable and conforming to her view of how infection procedures should be applied:

I went to see him and he didn't talk about [hepatitis C]. He knew I had it, of course, but he didn't even talk about it. Because it's not my responsibility – it's my responsibility to look after my own and so on - but, if I were a surgeon, then it would be my responsibility. It would be:

'alright, [I will assume that everyone has hep C] so I have to clean those special ways. I have to wear double gloves'. So that's when I thought 'I don't go to those [other surgeons] because, if they look at it that way, I don't need that'.

Below, Sebastian describes how difficult it is for a patient to challenge the work practices of healthcare workers in relation to issues like infection control. The incidents that he reports occurred in a general hospital ward rather than in the specialist centre in which he usually receives care for haemophilia:

I've been admitted into hospital a couple of times and [hepatitis C infection] is an issue with them on the wards. It hasn't become a huge problem and because you don't want to rock the boat too much you can't really say too much if you think you're being discriminated against, because there are extra things that have to be done because of the haemophilia. And also, like most of the other blokes, I take morphine on a four-hourly basis and if you upset the nurses they might not...I've seen it happen, they just delay medication like that because they're annoyed. So you can't afford to upset them because they'll get you back somehow.

DOING THE 'RIGHT' THING

Several participants reported their belief that infection control procedures should be applied by healthcare workers in all situations, without the necessity to disclose. However, within

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 for the protection of healthcare workers. Participants saw themselves as partners within a therapeutic relationship and extended notions of care and trust to the healthcare workers involved in their treatment. Interestingly, several participants reported that healthcare workers assumed that patients would disclose their infection and that patients who did not disclose were commonly assumed to be without infection. Such assumptions appeared to at least partly explain the lack of adherence to infection control procedures.

CAUSE AND EFFECT: DISCLOSURE AS A TRIGGER TO INFECTION CONTROL PROCEDURES

In situations where participants did disclose their infection, healthcare workers' reactions varied. In some cases the healthcare worker's response was in accordance with infection control guidelines and provided without reference to social relations. However, commonly our participants were treated differently from other patients following disclosure of infection. Participants who disclosed were placed last on the list for day surgery. For Mavis, 70, this practice created inconvenience and discomfort:

I told the doctor how fearful I was of being shunned because I've got this [hepatitis C] ... He was most discreet about it and had a little word with the nurses. They just quietly said 'We understand' and that's all they said ... but I had to go to theatre last because they don't want you in a bed before anyone else, which apparently is wrong because they're supposed to make it completely sterile for every new patient. But they do do you last. When you're fasting overnight you need to go in early ... I was in [the hospital] before lunch, but [by] 5.40 at night there was just no sign of me going to theatre at all.

And you hadn't eaten since the night before?

No, that was the trouble ... [the surgeon] got through the situation by saying 'It's good being last because I get better at this as the day goes on'. And I said 'Well, that's no good because I'm dying of malnutrition here'.

Indeed, placing participants at the end of the day's surgical list appeared to be a commonly understood expression of infection control (also see Chapter 6). In principle, the surgical environment should be of the same risk in terms of transmission for each patient, regardless of whether the patient before had disclosed a blood-borne infection. Given that an estimated 30–40% of Australians with hepatitis C are unaware of their infection (Delpech et al., 2001; National Centre in HIV Epidemiology and Clinical Research, 2000), non-adherence to universal infection control procedures in our health system

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 infection and therefore our findings cannot claim to characterise all infection control-related

episodes experienced by people with hepatitis C. Yet, these data do provide an insight into how infection control is practiced in some medical settings. These findings may have implications for the education and professional training of healthcare workers.

Decisions by healthcare workers to implement universal infection control procedures should be made independently of the perceived social category a patient belongs to and be solely dependent on the level of risk inherent to the procedure. Universal infection control procedures, by definition, imply that the notion of in-group and out-group differentiation is irrelevant. However, some healthcare workers may regularly make judgements about whether to implement infection control procedures by matching individual patient characteristics against stereotypical representations of group membership, for example, whether or not someone looks like an injecting drug user (ADB of NSW, 2001). Individualist perceptions of risk run contrary to the principles of universal infection control. Reliance on them, whether for reasons of cost cutting or convenience, is innately dangerous to public health.

Participants who believed it was their obligation to disclose hepatitis C infection to their healthcare workers speak to the notion of partnership within a therapeutic relationship. These participants described their perceived 'responsibility' to protect others and to do what was necessary to avoid transmitting infection to healthcare workers. Within this, there was an implicit understanding that their disclosure would be appreciated and held in confidence. Participants did not appear to construct their perceived responsibility to others in terms of social identity and power relations, but rather as a symbiotic relationship where a mutual respect and concern for the well being of all prevails.

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 treatments. To date, most research in this area employs a health-related quality of life approach using quantitative instruments to measure well being. Broadening the theoretical and methodological framework in this area to include approaches such as narrative theories would contribute significantly to our understanding of the experiential aspects of living with hepatitis C. In addition, the role and function of support

groups might also be an area ripe for research particularly given the issue of stigmatisation. Another important area for social research concerns how people with hepatitis C infection negotiate, successfully and otherwise, medical institutions to gain access to treatment.

Several other areas that could benefit from social research include an investigation of the influence of socio-political contexts on the development of hepatitis C policy and historical enquiry into the rise of injecting drug use, the medical use of blood products and the advent of the epidemic. Finally, further educational research into hepatitis C is needed to develop effective strategies to address a variety of issues, such as prevention and treatment, that are relevant to the diverse 'communities' affected by this virus (Dowsett et al., 1999).

As an increasing number of people contract hepatitis C and those who are infected become symptomatic and diagnosed, the need for social research into living with hepatitis C becomes more urgent. A nuanced social research picture of the impact of socio-cultural difference and social systems (welfare, medical and justice, for example) is vital if appropriate policy, health promotion and therapeutic models are to be devised and implemented.

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