

# Living with Hepatitis C : a psychosocial exploration of hepatitis C infection and its treatment

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# *LIVING WITH HEPATITIS C*

A psychosocial exploration of  
hepatitis C infection and its treatment



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## PROEFSCHRIFT

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Prof. mr. G.P.M.F. Mols  
volgens het besluit van het College van Decanen  
in het openbaar te verdedigen  
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# *CHAPTER 1*

Thesis overview

## INTRODUCTION

The aim of this thesis is to explore the psychosocial aspects of living with hepatitis C infection and how it impacts on the health and quality of life of affected individuals. This thesis comprises aspects of both the interpretive and critical theoretical perspectives used in the social sciences (Sarantakos, 1993). Social research according to the interpretive perspective seeks to understand the reasons for people's actions and how people construct meaning in order to make sense of the world. This perspective eschews general laws of a restrictive nature. Similarly, the critical perspective seeks to explore below the surface of life to problematise common assumptions and beliefs about society and to expose social relations. The critical perspective is particularly useful for analysing systems of power and the structures that reinforce social inequalities and oppress people. This thesis deploys a mixed-method research design to investigate psychosocial phenomena pertaining to living with and receiving treatment for hepatitis C infection. The work is informed by the academic discipline of social psychology in the applied context of public health; it assumes an ecological transactional approach to health and risk that is, positive health outcomes are mediated by behavioural and environmental interactions (Green & Kreuter, 1999).

This thesis emphasises the distal determinants of health and quality of life like social conditions and social policy. In the context of a framework for health education and promotion the findings inform the five assessment phases of the PRECEDE-PROCEED model for health promotion planning and evaluation (Green & Kreuter, 1999). In this model the social assessment (Phase one) dimension comprises an evaluation of quality of life via social indicators such as alienation, anomie, discrimination and illegitimacy, which are acknowledged as significant determinants of individual health and quality of life. These indicators are recurrent themes throughout this thesis. Data obtained using a cross-sectional questionnaire of 504 people and in-depth interviews with 45 people explore these social indicators, their impact on quality of life, and the limitations infection imposes on the aspirations of people living with hepatitis C in New South Wales, Australia. The findings and conclusions presented here may be used to inform the epidemiological assessment (Phase 2) of the PRECEDE-PROCEED model with regard to the prevalence, incidence, distribution and duration of vital health and quality of life indicators such as disability, discomfort, fitness and morbidity among people living with hepatitis C infection. The findings of this thesis also inform Phase 3 of the PRECEDE planning process for example in relation to factors which impede adherence to hepatitis C treatment; a matter of considerable therapeutic importance. Phase 3 of this model is concerned with analyzing the behavioural and environmental determinants of health and quality of life in the form of personal and collective actions as well as an analysis of the immediate environmental circumstances that may constrain adherence to therapy. Behavioural indicators such as consumption patterns, the quality of an individual's coping strategies, their crisis-prevention activities and approaches to self-care can be assessed for their contribution to successful adherence outcomes. Environmental indicators like economic status, availability of health and social services and individuals' access to services are assessed

during this phase. This thesis contains data regarding these behavioural and environmental indicators that provide insights relevant to the improvement of adherence and quality of life during treatment.

Any plan to influence health-related behaviour such as treatment adherence must consider three sets of causal factors: predisposing factors, as in individuals' knowledge, attitudes, beliefs, values and confidence; enabling factors like availability and accessibility of health resources and governmental and community laws, priorities and commitment to health; and reinforcing factors such as family, peers, employers and health care providers. An assessment of the relative importance and changeability of these factors allows for a prioritization of the causes of health behaviours and this comprises Phase 4 of the PRECEDE planning process; an educational and ecological assessment. This thesis includes information and insights regarding individuals' knowledge and beliefs about hepatitis C treatment and their attitudes to treatment. The findings about treatment adherence in relation to participants' health-related skills and their acquisition of support from family and friends are relevant to this phase of the health promotion planning model. Finally, data presented throughout this thesis can inform Phase 5 of the model which is concerned with an assessment of organizational and administrative capacity for developing and implementing a health promotion programme. This thesis reviews and assesses a sample of health care facilities' policies about approaches to pre-treatment evaluation for patients commencing hepatitis C treatment. The studies also present insights regarding nurses' and allied health professionals' management of the regimen. Together these findings can inform evaluation protocols and management policies to improve treatment adherence. Indeed, the data reported throughout this thesis are instrumental in generating hypotheses to ultimately inform health promotion planning with regard to the impact of hepatitis C-related discrimination, morbidity and treatment on health and quality of life.

## THE HEPATITIS C EPIDEMIC

In the eighteen years since the first reports of the identification of the hepatitis C virus (Choo et al., 1989) little development has occurred in understanding the psychological and social impact of infection on affected individuals' quality of life. While virologists have made significant improvement in the efficacy of treatment for hepatitis C during this time they have been unable to develop broadly efficacious treatments and a vaccine remains elusive. In 2007 social research is still primarily focused on prevention of infection; an observation made in a sociological review of the scholarly literature more than three years earlier (Hopwood & Southgate, 2003). Labels applied over the past decade to describe the profile and nature of the epidemic continue to be relevant today: hepatitis C remains a 'neglected epidemic' (Standing Committee on Social

Issues, 1998) and a 'silent epidemic' (Silberbogan et al., 2005). With regard to the diffusion of community awareness and understanding of the impacts of hepatitis C infection on health and quality of life, the epidemic is in its infancy.

Hepatitis C is also an epidemic of difference (NCHSR, 2001): affected people come from a broad range of ethnic and class backgrounds and the modes of acquisition of infection are diverse. A significant minority of Australians contracted hepatitis C via non-injecting means such as medical procedures, tattooing, skin-piercing, accidental household and workplace transmissions or following mass vaccination programmes in countries outside Australia. On the other hand, a majority of affected people are those who have a history of injecting drug use. Some of these people injected once or twice decades before discovering their infection while others are current injectors and include those who are drug dependent. People who have ever injected do not comprise a homogeneous group instead they inhabit a variety of social spaces. Evidently, people with hepatitis C are culturally and geographically diverse and perform a variety of social roles. These differences affect the way people cope with hepatitis C infection, their access to health and social services, how they experience hepatitis C-related discrimination, their power to respond to stigmatisation, and how health promotion and planning needs to proceed in order to prevent further infection and improve the health and quality of life of affected individuals.

### **Estimates and projections of the hepatitis C epidemic in Australia in 2006**

Highlighting this diversity are the latest estimates and projections of the hepatitis C epidemic in Australia, a four-yearly epidemiological surveillance report (Hepatitis C Virus Projections Working Group, 2006). This report provides a background and a referential point for the quality of life issues raised throughout this thesis. Although reporting a significant decrease in incidence since the previous published report (Hepatitis C Virus Projections Working Group, 2002), approximately 10,000 new infections occurred annually in Australia between 2001 and 2005. As in previous reports around 90 percent of incident infections were due to injecting drug use and people aged 20 to 39 years comprise the majority of these cases. While 65 percent of prevalent infections are among men, young woman are reporting increasingly higher rates of new infections. The decrease in hepatitis C incidence since the previous report period is partially explained by a global shortage of heroin since 2000 and an estimation of a concomitant reduction in injecting. The other major social groupings represented in the incidence figures are those people with hepatitis C infection who had migrated to Australia from countries of high prevalence (accounting for around seven percent of new infections) and those people exposed to hepatitis C via the receipt of contaminated blood products, from unsterile tattooing, and through vertical transmission (combined approximate total of four percent) (Hepatitis C Virus Projections Working Group, 2006).

## HEPATITIS C VIRUS INFECTION

The hepatitis C virus causes a chronic infection in approximately 75 percent of people following exposure. The remaining 25 percent develop an acute infection which is resolved within six to nine months and which usually does not produce significant ill health. On the other hand people chronically infected remain infectious over their lifetime and a significant minority is at risk of life threatening illness (Hepatitis C Virus Projections Working Group, 2006). The most common reported symptoms of hepatitis C infection are physical tiredness, irritability, depression, mental tiredness, and abdominal pain however there are a range of other reported neuropsychiatric, gastrointestinal, algescic and dysethetic (e.g. noise and light sensitivities) impacts (Lang et al., 2006). Of all people with chronic hepatitis C infection about seven percent develop cirrhosis after 20 years and of all people with cirrhosis approximately four percent experience liver failure and around two percent develop hepatocellular carcinoma, a fatal liver cancer (Hepatitis C Virus Projections Working Group, 2006). People infected after 35 years of age appear to have a more rapid disease progression than those infected younger; women have a better prognosis than men and spontaneously clear the virus more often; alcohol consumption exacerbates the damage caused by hepatitis C infection and accelerates disease progression; and co-infection with HIV and/or hepatitis B also accelerates disease progression (St. John & Sandt, 2005). Chronic hepatitis C infection is a slow progressing disease with many vague, non-specific symptoms. It often takes between two and five decades to cause serious illness. Nonetheless, due to the high population prevalence it is estimated that currently more people in Australia die each year from hepatitis C-related disorders than from HIV/AIDS.

Since February 1990, diagnostic hepatitis C testing has been available in Australia. Blood is screened for evidence of antibodies and when two positive results are found a polymerase chain reaction (PCR RNA) test is conducted to ascertain viral load and viral genotype (Ministerial Advisory Committee on AIDS, Sexual Health and Hepatitis, 2006). While people with known risk factors (e.g. any history of injecting drug use, incarceration, and immigration from countries with a high endemic rate of infection) are recommended for testing many people are diagnosed with hepatitis C infection while seeking medical attention for other disorders. It is estimated that a large proportion of people with hepatitis C globally are currently unaware of their infection (e.g., Chou et al., 2004; Clarke & Kulasegaram, 2006; St. John & Sandt, 2005).

Over the past 15 years treatment for hepatitis C infection has improved significantly. Interferon, a powerful anti-viral agent, was used in the early years of the epidemic with only about 20-25 percent of people clearing their infection after 12 months of treatment (Sievert, 2001; Soriano et al., 1999). By the late 1990s interferon was trialled in combination with ribavirin, another anti-viral agent and around forty percent cleared their infection with this regimen (Lai, 2000). Currently a pegylated form of interferon is used with ribavirin and this treatment is effective in approximately 50

percent of people with genotype 1 (a persistent subtype of infection) and up to 80 percent of people with genotypes 2 and 3 are likely to clear their infection after six months of treatment (Manns et al., 2001).

While incidence has decreased in Australia since 2002 hepatitis C prevalence has increased and in 2005 approximately 197,000 Australians were estimated to be chronically infected; this is around one per cent of the total population. Among a total of 400,000 Indigenous Australians about 16,000 were living with chronic hepatitis C infection. Similarly, of around 35,000 people incarcerated throughout Australia up to 11,000 of these people were estimated to have had chronic hepatitis C infection in 2005 (Hepatitis C Virus Projections Working Group, 2006). Rates of treatment for hepatitis C infection have not altered since the last report with about 2,000 chronically infected people seeking treatment annually. In the coming decade the prevalence of people living with chronic infection and the number of people with advanced fibrosis and cirrhosis is projected to increase by about 38 percent. To reduce the occurrence of significant liver diseases in the population the authors of the surveillance report estimate that over the coming years at least six thousand people will need to receive hepatitis C treatment annually in Australia. Since 2001 the criteria for accessing Australian Government subsidised interferon-based treatment for hepatitis C infection has gradually eased in a bid to attract more people toward treatment. For example liver biopsy is no longer an inclusion criterion and current injecting drug users are entitled to access treatment subsidies. However, the likelihood of tripling the current number of people entering treatment is generally accepted to be remote (Dore, 2005).

## THEORETICAL FRAMEWORKS

### Stigma theory

Woven throughout a burgeoning scholarly literature that examines the psychosocial dynamics of hepatitis C infection, and the phenomena of hepatitis C-related discrimination reported by people surveyed and interviewed throughout the studies comprising this thesis is Goffman's (1963) conceptualisation of stigma and the management of 'spoiled identity' (i.e. an identity containing undesired and highly discreditable attributes which represent difference from the norm). The identification of a relatively 'new' and contagious viral infection, the fear and uncertainty that this evokes among society, and the close association that the viral epidemic has with the practice of injecting drugs creates a set of conditions that are given expression in Goffman's theory. The explanatory power and appeal of his work for the psychosocial discursive field of hepatitis C is in the description of stigma as being both visible and invisible when referring to discredited and discreditable identities constructed via attributes that are apparent to others and those which reveal themselves only through intimate examina-

tion or following accidental or intentional disclosure or exposure (Fraser & Treloar, 2006). Indeed, illicit drug use is widely acknowledged as one of the most stigmatised behaviours and illicit drug users, particularly those who currently inject and embody a visible stereotype, belong to some of the most marginalised populations that are often scapegoated and discriminated against (Gilmore, 1996). Because of the way society views illicit drug use and injecting drug users people are socialised to hold certain beliefs about users and come to question for example their value as members of society, their ability to find and maintain employment, and their capacity to form relationships with family and others (Fulton, 1999; Gilmore, 1996; Marr, 1999; van Ree, 1997). Injecting drug users are assumed to be addicted and to have close ties with crime in order to finance their addiction. People who use drugs are often stereotyped as lacking social worth and a danger to the community because they are likely to spread their negative characteristics, including viral infections, to others (Fulton, 1999).

This perspective contributes to the emergence of a discreditable as well as a discredited identity as results of blood tests and elevated liver function tests can be used by the health professions to identify, reconstruct and redefine individuals as deviant. Building on this part of Goffman's (1968) theory Scambler and Hopkins (1986) articulated an affective dimension called 'felt' stigma, or an expectation of negative judgement, which is in contrast to 'enacted' stigma, the experience of being negatively judged. 'Felt' stigma involves the perception that people have about their own discreditable condition(s) and the ways that others respond to this while 'enacted' stigma pertains to negative responses as a function of the visible discredited dimension within Goffman's conceptualisation. 'Felt' stigma describes an expectation and a fear of discrimination that may cause people to behave in ways to reduce the possibility of 'enacted' stigma, or the direct experience of negative judgements (Fraser & Treloar, 2006; Malcolm et al., 1998). In the context of hepatitis C infection 'felt' stigma implies that due to the fear of negative consequences people might often withhold disclosure of their positive sero-status and/or injecting drug use from those who may be in a position to 'enact' a negative judgement. However when clinical markers like hepatitis C antibodies are present in the blood of a patient, affected individuals lose the facility to manage 'spoiled identity' and 'felt' stigma often becomes enacted, as the discreditable becomes discredited. Scambler and Hopkins' addition to Goffman's work accounts for the distinct and debilitating effects of fear which can arise from withholding disclosure or exposure of a stigmatising attribute and the anxiety which arises from the direct experience of being negatively judged and discriminated against.

Both Goffman (1968) and Scambler and Hopkins' (1986) formulations of stigma are evident throughout the data presented in this thesis. Almost two-thirds of participants in a sample of over 500 people living with hepatitis C – reported in Chapter 4 – claimed ever experiencing discrimination, most of which occurred in healthcare settings. Also many participants had been refused medical treatment either because they had or were assumed to have hepatitis C or were injecting drug users, or were assumed to be currently injecting. According to participants reported in Chapter 4

discrimination occurred in a variety of other domains including within the family, in the workplace, from insurance companies and from friends, and often impacted negatively on participants' lives. Factors which precipitated enacted stigma and the ensuing discrimination included the disclosure of hepatitis C infection. Younger participants living with hepatitis C were more likely to report experiencing discrimination than older participants. Indeed, young injecting drug users are often easily visible either through the way they present or as some research suggests they might be less concerned about disclosing stigmatised identity and practice (D'Augelli & Dark, 1994). Similarly, 'felt' stigma may account in part for an association between higher levels of discrimination and pessimism about one's future health; fearing future discrimination from doctors and nurses can inhibit people from seeking appropriate healthcare. Trying to avoid others' negative perceptions also has implications for garnering support to cope; disclosure of infection and its treatment is less likely to occur and isolation is more likely to compound the negative impacts of chronic illness.

While Goffman articulated the fundamentally social nature of stigma contemporary scholars have highlighted the situational dimension of stereotyping and prejudice (Heatherton, Kleck, Hebl & Hull, 2003). Depending upon social context an attribute may be stigmatised in one setting and not in another, or at one moment in history but not at an earlier or later period. The following section outlines a second theoretical framework used throughout the thesis. It highlights how in certain contexts stigmatised individuals are able to use experiences of marginalisation and discrimination to bring about positive outcomes.

## Resilience theory

A majority of people with hepatitis C in the Australian population are living in socially and economically marginalised circumstances and include former or current injecting drug users, people who are incarcerated or those who have been in custodial settings, ethnic minority communities, Indigenous Australians and youth. Many of these marginalised social groups experience ongoing stigmatisation and discrimination and many individuals suffer from the effects of being devalued, stereotyped and targeted by prejudice. As described above stigma often negatively impacts on one's opportunities for garnering support, feelings of health and wellbeing, and one's sense of self. Nonetheless some stigmatised and marginalised individuals become adept at managing 'spoiled identity' and can mobilise their 'strengths' in order to achieve positive outcomes (Dovidio, Major & Crocker, 2003). Accounting for such phenomena is a theoretical framework pertaining to the paradox of positive adaptation to adversity. While informed by the corpus of literature from the past three decades of developmental psychology, the theory of resilience and resilient coping has been applied in this thesis for the first time to a clinical context of managing complex therapeutic regimens; namely interferon-based treatment for hepatitis C infection. Resilience as defined by seminal authors in the field (e.g., Bonanno, 2004; Luthar, 2003; Masten, 2001) and as used throughout this thesis describes a process that is inferred from the

coexisting conditions of risk and positive outcomes. The theory predicts that people from marginalised and stigmatised social groups develop effective coping styles often by incorporating responses to past adverse experiences and utilising accessible resources. Chapter 8 explores participants' methods for ameliorating the impacts from treatment. It identifies the protective individual and social factors ranging from dispositional traits like optimism and determination to broader social processes like knowing how to use the health and social services which were available in participants' local communities. Emerging from these data were detailed descriptions of resilient coping which lead to positive outcomes; defined here as successfully adhering to and completing hepatitis C treatment.

Taking these resilient coping narratives as a lead, a method of estimating individuals' strengths is considered in Chapters 6 and 8 as a strategy which might assist people to better withstand the side effects of treatment and increase the likelihood of completing the regimen. Assessing strengths is posited in Chapter 6 as a complementary approach to the currently deployed deficits-based approach to treatment preparation and management. In recent years there has been a growing interest in quantitatively and qualitatively measuring and assessing the factors which contribute to the development of adaptive outcomes among people who are routinely exposed to adverse circumstances (Epstein & Sharma, 1998; Moos et al., 1994) and part of this thesis considers a framework for evaluating and fostering resilience called strengths-based assessment. This framework is discussed in Chapter 6 and we conclude by considering the efficacy of such an assessment strategy for minimising dose reduction and treatment discontinuation. Drawn from research into children growing up in poverty in inner-urban areas (e.g., Masten 2001), strengths-based assessment is an outgrowth of resilience theory that might significantly contribute to the health and quality of life of people receiving treatment for hepatitis C infection.

While the theoretical frameworks of stigma and resilience underpin the research presented in the thesis, discussion of theory is designated a low priority in many journals. We wrote these articles for specific audiences of health professionals like nurses, general practitioners, alcohol and other drug workers and public health policy bureaucrats. Therefore, while not a salient feature of the published articles theory is nonetheless inextricably linked to the study findings providing a framework to enhance meaning.

## THESIS AIMS

The next section explains the aims of the thesis and provides background information that led to the formulation of research questions presented throughout this body of research.

## Literature review

Chapter 2 of this thesis commences with a sociological review of literature pertaining to living with hepatitis C infection. The literature reviewed throughout this chapter comprises scholarly research from epidemiology, public health, medicine and clinical sciences, government publications of reports enquiring into the epidemic, articles found in popular culture magazines, survivor's guides, and information pamphlets. Hepatitis C-related literature from sociology and psychology remains under developed in 2007 and still primarily focuses on prevention of infection for example among people with a psychiatric illness or injecting drug users from a range of ethnic and geographic backgrounds. This work says little with regard to living with or being in treatment for hepatitis C infection.

A catalyst for this thesis was the finding of the review that a majority of research and writing about the epidemic was from medicine, virology and epidemiology. There was a dearth of literature about the lived experience of hepatitis C infection. Among the few examples were several information resources for injecting drug users which briefly discussed hepatitis C testing, prevention and living with hepatitis C as well as information pamphlets from emerging state-based hepatitis Councils that sited stigmatisation and discrimination as a significant problem. However a report of the Anti-Discrimination Board of New South Wales' (ADB of NSW) Enquiry into Hepatitis C-related Discrimination (2001) contained useful leads for research and policy; for example it recommended investigation of people's experiences of pre and post test discussion and counseling and of receiving a hepatitis C positive diagnosis.

A lack of non-medical voices in the discursive field of hepatitis C was observed in Hepworth and Krug's writings from the mid to late 1990s which identified an 'absence of meaning' in relation to living with hepatitis C. The medicalisation of affected people had privileged bio-scientific understandings and subdued knowledge of the social and cultural dynamics and impacts of hepatitis C infection upon people's daily lives. Following a review of the epidemiological data which establishes the hepatitis C epidemic both globally and in Australia as one of the most significant challenges for public health in recent times, Chapter 2 reviewed published information about all available experiences of hepatitis C diagnosis, disclosure, discrimination and treatment and set a research agenda for exploring these issues from a socio-cultural perspective.

## Diagnosis

Following the review reported in Chapter 2, we aimed to explore people's experiences of receiving a hepatitis C diagnosis particularly focusing on the provision of information, advice and referral from general practitioners at the time of diagnosis. The report of the ADB of NSW Enquiry had highlighted doctors' lack of engagement with some patients following a positive diagnosis. To explore this finding Chapter 3 sought to

compare participants' self-reports with regard to the information they received from their doctor at the time of their diagnosis. Diagnosis was explored according to gender, current injecting drug use and in relation to different temporally defined stages of the epidemic.

## Discrimination

Around the time of the ADB of NSW Enquiry into discrimination we surveyed a sample of people with self-reported hepatitis C infection and conducted interviews with an aim of exploring a variety of health and quality of life issues. The salience of discrimination as an issue had been highlighted by the Enquiry and during 2002 it had become a common topic for discussion on email lists and Internet sites for people living with hepatitis C throughout Australia. Anecdotal evidence pointing to an epidemic of discrimination had been accumulating since Crofts and colleagues (1997) had reported that the phenomenon might be widespread especially within healthcare. Using a convenience sample Chapter 4 reports on a study that we conducted which sought answers to the following research questions: (i) Who experienced discrimination because they had hepatitis C or had been injecting drugs? (ii) What impact had discrimination had on their quality of life? (iii) What factors predicted reports of high level discrimination? Chapter 4 aimed to explore the manifestation of stigma and who it most affected.

## Hepatitis C treatment experiences

During the 1990s and into the early part of the current decade interferon was trialled as a monotherapy and in combination with other antiviral agents. As a monotherapy its therapeutic efficacy was poor; in combination with ribavirin response rates improved significantly; and in trials of pegylated interferon and ribavirin these response rates improved again. However all regimens were associated with significant decrements in scores on health-related quality of life instruments reported in the clinical literature but little was known regarding the implications for those patients experiencing reductions in social, physical and emotional functioning during treatment. One aim of the thesis was to explore the experience of treatment side effects and their impact on quality of life by reporting findings from our study of a sub-sample of participants who had received interferon-based therapies. Interview data was collected from a sample of nineteen participants some of whom had received treatment for their infection. From this initial investigation emerged an interest in gathering further data to explore in more detail a range of issues which had arisen throughout interviews. The findings are reported in Chapters 6, 7, and 8 of this thesis.

## Health professionals' perspectives on hepatitis C treatment

Given the increasing number of treatment-related reports appearing in the clinical literature and anecdote regarding the difficulties associated with side effects from interferon-based treatments, and given the common need to reduce therapeutic doses or discontinue administering treatment completely, we sought to explore the experience of hepatitis C treatment from the perspective of both health professionals and a larger group of people receiving treatment in several major facilities in Sydney Australia. Health professionals were asked about the process of treatment preparation in order to document the approach used by clinical nurse consultants and social workers. They described the psychosocial issues they encountered among patients, their patients' concerns regarding treatment, and the information they provided to patients who were entering treatment. Similarly, the study aimed to identify and describe the policy, philosophy and approach underlying the management strategy used by health professionals during hepatitis C treatment. This was to see whether the findings suggested a complementary method of assessment and management that might contribute to ameliorating the impact of side effects and reduce the need for dose reductions and treatment continuations. Indeed, the data did point to an approach which could form the basis of further research into health professionals' preparation and management practices. This is discussed in Chapter 6.

## Illicit drug use and hepatitis C treatment

Investigation of illicit drug use during receipt of treatment for hepatitis C infection is an issue which is muted in the clinical literature. While highlighting a debate among clinicians regarding the 'value' of treating current injectors this literature does not explore the larger picture of patients' illicit drug use during treatment and its risks and benefits in relation to treatment outcomes. Reports of health professionals' negative attitudes to patients' illicit drug use led to my decision to write about patients' use of illicit drugs during treatment, particularly regarding concerns with current injecting drug users. As with the approach taken to treatment preparation and management Chapter 7 explores several hypotheses with significant implications for health care practice which require further investigation.

## Resilience and coping

The final four chapters of this thesis weave a thread through people's experiences of interferon-based therapies for hepatitis C infection. The main issues include the impact of side effects, health professionals' perspectives on the way treatment is conducted, aspects which affect the health and well being of people receiving treatment and finally the coping strategies deployed by patients in a bid to maintain a satisfactory quality of life in order to complete treatment. The health professionals' perspectives are balanced in the final chapter by reporting patients' approaches to coping

with treatment. The aim of Chapter 8 was to document narratives regarding the strategies, either medical or personal, that people found had improved their quality of life during treatment. This information is useful because the currently high rate of hepatitis C treatment discontinuation is a concern for people considering treatment, for the health professionals at clinics who administer treatment and for public health policy and the systems that aim to minimise future hepatitis C-related morbidity and mortality among affected populations. Making current treatments more tolerable through improved methods of managing side effects is an area where social research can make a significant contribution to the clinical sciences.

## METHODS

### Quantitative method

Quantitative methods were used in two chapters presented here. A questionnaire was devised to explore the experience of receiving a hepatitis C positive diagnosis and to describe the factors which predicted hepatitis C-related discrimination in a sample of affected people.

By the beginning of this decade a government enquiry, some nascent qualitative research and anecdote had established that receiving a hepatitis C diagnosis was for many people fraught with difficulty (e.g., Glacken et al., 2001). We analysed the diagnosis experiences of people who had been tested since the identification of the virus in response to a perceived need for quantifiable information regarding the impact of a positive diagnosis. This included investigating doctors' explanation of hepatitis C infection and provision of further information, advice and referral during post-test discussion. A convenience sampling frame was used because it was considered that obtaining a random sample of all people with hepatitis C infection who were living in New South Wales would be problematic; theoretically, because many people remain unaware of their infection, and pragmatically because we had no access to medical databases of people who had been diagnosed hepatitis C positive.

Similarly, an analysis of hepatitis C-related discrimination was partly in response to a publication by Day and colleagues (2003) which described discrimination among a sample of injecting drug users, some of whom had hepatitis C infection. In their article the authors called for further quantitative research using a sample of people living with hepatitis C. The need for further quantitative analysis of the dynamics of discrimination using samples of people with hepatitis C infection was evident. The ADB of NSW Enquiry (2001) report also provided a rationale for quantitatively describing discrimination by asking question such as: who does discrimination most affect, from where does it originate and what are the likely outcomes of discrimination. The

two recruitment strategies deployed, that is via the Hepatitis C Council of New South Wales and a large inner-Sydney needle and syringe programme (NSP) outlet, provided convenient samples of both people living with hepatitis C and current injecting drug users. The latter sample was included to ensure that the number of people who were currently injecting would be sufficient in order to compare and contrast the experiences of current injectors with former injectors and those participants who had acquired their infection through other means.

## Qualitative method

In contrast to the preceding issues of diagnosis and discrimination, the psychosocial experience of interferon-based treatments had received no scholarly attention. Medical and psychological online databases contained relative large numbers of articles reporting impacts of hepatitis C treatment on health-related quality of life, a quantitative measure of physical and cognitive functioning. However these articles revealed no published accounts of patients' perspectives of treatment. In an effort to address the dearth of vital experiential information which could potentially illuminate interventions and approaches to facilitate hepatitis C treatment uptake, adherence and completion we formulated a general research question informed in the main by a review of the clinical literature but also aided by anecdotal evidence from colleagues working on trials of interferon-based therapies. An analytical induction method as described by Minichiello and colleagues (2000) was deployed. This is a method which is used to construct general rules from observation of specific phenomena and it is a useful method for building theory from data. Cases are examined and where appropriate phenomena are redefined and hypotheses are reformulated until a widely applicable relationship is described (also see Silverman, 2001). Initial exploratory interviews were conducted with people who had had experience of interferon-based treatments. Using concepts, sentences and themes as the principle elements a content analysis of these early interviews uncovered reports related to the treatment experience and from which propositions emerged to be tested during subsequent data collection. The nature of the information obtained from this initial foray was compelling (Hopwood & Treloar, 2005) in as much as it revealed thick descriptions (Patton, 2002) of several psychosocial issues. These data instigated further data collection based upon a theoretical sampling frame; that is, recruitment of people in treatment and the health professionals responsible for managing treatment regimens. Over the course of the subsequent interviews many of the early propositions appeared to be validated by an ongoing iterative analytical process. When we identified that a saturation of themes had been achieved (Patton, 2002) and that this procedure had informed an adequate level of explanation of the phenomena being investigated data collection and analysis ceased.

Similar approaches to collecting and analysing qualitative data has been described by contemporary theoreticians of methodology and method (e.g., Crotty, 1998; Grbich, 1999; Minichiello et al., 2000; Rice & Ezzy, 1999; Silverman, 2001). In Silverman's

discussion of generating a research problem (Silverman, 2001) he claims that qualitative researchers often fall into a trap when seeking to explore social problems like homelessness as defined for example by political debates which commonly appear in the media; the scope may be too broad, or the work may serve vested interests, for instance. Silverman argues rightly that research problems are distinct from social problems. In accordance with this distinction the qualitative enquiries throughout this thesis have, as one outcome, articulated a range of hypotheses which form a basis for further investigation. The generation of these testable propositions which are embedded in analyses of research data are concerned with investigating social problems, rather than born of them.

## STUDY FINDINGS AND RECENT LITERATURE

This final section presents an overview of findings reported throughout the thesis. These findings will be viewed through the prism of Goffman's (1968) theory of stigma and using the developmental psychology framework of resilience. Literature that is relevant to living with hepatitis C and which has been published since our review article (Chapter 2) will also be highlighted and integrated.

### Literature review

Our sociological review of literature pertaining to living with hepatitis C is the first of its kind to appear since the identification of the infection (Hopwood & Southgate, 2003). The review which became a blue-print of the areas this thesis explored highlighted concerns about receiving a positive diagnosis, disclosure of infection, and stigmatisation and discrimination against people living with the virus. The review argued for an expanded socio-cultural understanding of hepatitis C to account for the material effects of medicalisation, stigmatisation and discrimination and the socio-cultural impact of treatment on the lives of people with hepatitis C infection. While several commentators have published work on these issues over the past three years we argue that today there remains an 'absence of meaning' (Krug, 1995; 1997) around living with hepatitis C that is not despairing and stigmatising.

One recent investigation into the daily lives of people living with hepatitis C is from Gifford and colleagues (2003; 2005). In two articles focused separately on women and men with hepatitis C similar conclusions were reached: the health and social needs of affected people are considerable however many do not engage with health services. Most men and women surveyed had not accessed primary and specialist healthcare for hepatitis C because of barriers like stigma and discrimination. The authors concluded that gender has an important influence on the health seeking behaviours of

people with hepatitis C with men being particularly vulnerable due to their tendency to dismiss symptoms of disease for a range of reasons (Gifford et al., 2003 and 2005). An article by Faye and Irurita (2003) typify people living with hepatitis C infection as feeling condemned and suggest that widespread dissemination of non-stigmatising information about infection and its transmission, focusing on blood awareness rather than injecting per se, might assist in reducing transmission rates and help to fill a void in meaning. Similar to Faye and Irurita (2003), concern was expressed by Fraser and Treloar (2006) pertaining to affected people's 'sense of despair and absolute contamination' at receiving a hepatitis C positive diagnosis. They discussed the negative impact of a positive diagnosis on identity and how this might contribute to a disregard for adhering to messages about safer injecting. These authors exhort the need for a careful non-stigmatising approach to health prevention campaigns so as to prevent further marginalisation of people. Similarly, Crockett and Gifford (2005) report young women's concerns with stigma and the meaning of hepatitis C. While discussing the limitations of the biomedical model of treatment and care, Harris (2005) describes how healthcare fails to provide a roadmap for those living with chronic illness like hepatitis C infection.

Indeed, a majority of hepatitis C-related literature continues to be medical and epidemiological in focus. Psychosocial research continues to report an absence of positive meaning for people affected by hepatitis C. Concerns are focused on stigmatisation and its impact, confusion regarding viral transmission and a need for non-stigmatising media and other education campaigns to better inform the public and health professionals of the epidemic (e.g., Conrad et al., 2006; Korner & Treloar, 2006; Faye & Irurita, 2003; Paylor & Orgel, 2004; Rhodes et al., 2004; Smith et al., 2006; Southgate et al., 2005; Treloar & Hopwood, 2004; Waller, 2004). Waller (2004) in giving a personal perspective of diagnosis and living with hepatitis C describes her journey from self-loathing to a role of advocate for other affected people. Advocacy was a way of deriving meaning from the author's experiences. However the research literature indicates that the meaning of hepatitis C remains in the sphere of bio-medicine: for example affected people are current injecting drug users who need to confront and change their pathology; they are characterised as addicted; they experience psychiatric illness; they are to be herded into treatment; they are opportunities for primary prevention; or missed opportunities for primary prevention; and they are targets of behaviour modification programmes. While emerging literature may yet create new possibilities for a non-stigmatised and meaningful identity for people living with hepatitis C infection, currently affected people are still characterised as a risk to the community because of the likelihood they could spread their negative characteristics to others (Acker, 1993; Edlin et al., 2001).

## Diagnosis

Until recently the experience of receiving a hepatitis C-positive diagnosis was unreported in the scholarly literature. Some early Australian and international research,

gray material and anecdote from health professionals working in viral hepatitis had indicated that people who tested positive commonly received no pre or post-test discussion and counselling with their diagnosis. From our cross-sectional survey of over four hundred people who had been given a hepatitis C positive diagnosis since 1989 (as opposed to a diagnosis of non-A non-B hepatitis pre 1989), almost a third of participants reported receiving no explanation about their infection (Hopwood & Treloar, 2004). A third of participants also reported receiving no information about conventional treatments, advice regarding natural therapies, referral to a specialist, pamphlets with information about hepatitis C infection, counselling, information about how the virus might affect health or information about support groups. Our review article reported in Chapter 2 (Hopwood & Southgate, 2003) stated that injecting drug users' access to healthcare and information on reducing transmission (a major component of pre and post-test counseling) were two important areas that were poorly understood. My subsequent analysis reported in Chapter 3 revealed that current injecting drug users were significantly less likely to report receiving post-test counselling than those who were not currently injecting. Similarly, participants who reported receiving no information, advice, referral, counselling, or information about support groups were more likely than not to be currently injecting. This chapter highlighted concerns that some doctors might not have enough knowledge about hepatitis C infection to conduct appropriate pre and post-test counseling while others might assume that current injecting drug users are not interested in information, advice and referrals. While the transition from a 'virtual identity' to an 'actual identity' as described by Goffman (1968) may cause some doctors to reclassify patients following a hepatitis C positive test result, we did not explore stigma in the context of diagnosis. Nonetheless there may be a relationship between a discredited identity (following a positive diagnosis) and injecting drug users' reduced likelihood of receiving post-test counselling and explanation about their infection. This has been observed and reported elsewhere (e.g., ADB of NSW, 2001).

Few articles pertaining to diagnosis experiences have been published in recent years. However in one study of general practitioners Gupta and colleagues (2006) found that 76 percent of respondents had managed just one patient with hepatitis C during the previous year and only around 39 percent reported being likely to discuss psychosocial issues as part of an initial patient management. A similar proportion of general practitioners reported that they found it difficult to play a role in the medical and psychosocial care of people with hepatitis C infection. In another study focusing on diagnosis Minuk and colleagues (2005) reported that newly diagnosed people are concerned with a variety of issues but most notably disease progression, premature death and infecting family members. These concerns were consistent across demographic groups. It appears that when receiving a hepatitis C-positive diagnosis, newly diagnosed people desire reliable information that will help them to prevent further transmission and to satisfy a common human need for knowledge about the status of one's health and any likely impact on quality of life.

## Hepatitis C-related discrimination

Following a diagnosis of chronic illness people often embark on a process of self-reconceptualisation whereby their new condition in life is considered in relation to family, friends, and employment (Bury, 1982). When the diagnosis involves a stigmatised infection like hepatitis C there is an added reconfiguring especially if the stigma is perceivable and one's social identity is aligned with a stereotype. This is the subject position according to Goffman (1968) of the 'discredited'; those whose 'undesired difference' is immediately evident or known to others. On the other hand some people with hepatitis C are able to exercise information control over their social identity and they constitute the 'discreditable'; those people whose stigma is not immediately recognisable or known about and information pertaining to its existence may usually only surface at the determination of the bearer. Deciding to disclose one's 'blemishes of individual character' is an important step towards garnering emotional and social support and for ultimately achieving 'acceptance' from others (Goffman, 1968).

This thesis comprises a set of analyses from cross-sectional data (Chapter 4) which investigated some of the impacts of stigmatisation and ensuing discrimination among people living with hepatitis C infection. Almost two-thirds of 504 participants reported experiencing some form of hepatitis C-related discrimination. A worrying aspect to this finding is that discrimination was most commonly reported in healthcare settings. In order to reduce transmission of hepatitis C infection prevention education and testing among former and current injecting drug users is vital. However as inferred by findings from studies in social psychology and sociology (e.g., Goffman, 1968; Scambler & Hopkins, 1986) the feeling that one is being negatively perceived – 'felt' stigma – and is at risk of encountering discrimination (Scambler & Hopkins, 1986), could be a disincentive to engage with those contexts where transmission information and testing is offered. Chapter 4 describes how being younger, reporting fatigue and knowing many other people with hepatitis C predicts self-reports of any discrimination. This implies that being part of a network might sensitise one to stigma and make such healthcare-avoidance behaviour more likely thereby exacerbating personal health problems and minimising exposure to information which might reduce viral transmission. On the other hand, having chronic symptoms of infection that need ongoing healthcare, such as fatigue or depression implies that interaction with health services could lead to a risk of continuing tension and discrimination.

Over the past three years similar findings to those sited in Chapter 4 have been reported in the literature regarding hepatitis C-related discrimination. Disclosure, particularly workplace disclosure, presented a dilemma to most people following a positive diagnosis (Fraser & Treloar, 2006; Platt & Gifford, 2003). Current injecting drug use has been associated with increased reports of hepatitis C-related discrimination in other Australian research (Day et al., 2003). Nonetheless most of this work looks at interpersonal discrimination that is, discrimination which arises from individual prejudice. There remains little investigation of the structural and institutional determinants of stigma and discrimination like healthcare values and norms and the influ-

ence of systems of governance (e.g. the law) on the construction of 'spoiled' identities. Given the findings of this thesis regarding the poor experiences some people have of diagnosis and the fear and enactment of hepatitis C-related discrimination this phenomenon has significant implications for the health and quality of life of affected people. An image emerges of people, often current injecting drug users or those assumed to be currently injecting, coping with a profound realisation that they have a chronic illness that is infectious, virulent and not easily treated. Exacerbating their efforts to cope they flounder without answers to basic questions about symptoms and prognosis; simultaneously avoiding the discriminatory attitudes and practices of doctors, nurses, employers, family and friends.

Returning to the framework for health promotion planning discussed earlier (Green & Kreuter, 1999) and embedding the findings of this thesis pertaining to diagnosis and discrimination, the subjectively defined problems of concern to people living with hepatitis C infection that are evident from social indicators represented in the social assessment (Phase 1) are: (i) difficulty in acquiring reliable information about the health effects of hepatitis C infection from general practitioners and other healthcare workers at the time of receiving a positive diagnosis, and (ii) the negative impact on health and quality of life of stigmatisation including an ongoing fear of discriminatory treatment and the enactment of discrimination from interaction with health professionals. Chapters 3 and 4 provide an epidemiological assessment of these issues and are a basis for informing Phases 3, 4 and 5 of the PRECEDE model which can be used to plan programmes to increase health professionals' knowledge of hepatitis C and to reduce stigma and discrimination within the healthcare sector. These chapters indicate that poor diagnosis experiences and hepatitis C-related discrimination are not uncommon and are potential barriers to blood-borne virus prevention, testing and accessing of healthcare.

This thesis contributes to an emerging literature which has vetted a direction for hepatitis C-related health promotion planning. Other commentators have called for non-stigmatising blood-borne virus prevention education for current injecting drug users and people living with hepatitis C (e.g., Fraser & Treloar, 2006) while we have recommended an urgent need to address the education needs of physicians, medical students and other health professionals regarding hepatitis C and infection control procedures, particularly in a hope to dissuade the use of infection control as a tool for enacting discrimination in hospitals (e.g., Hopwood & Treloar, 2003; Treloar & Hopwood, 2004). This literature is nascent and further research is warranted. Nonetheless the findings reported throughout this thesis on diagnosis and discrimination provides further empirical contribution to health promotion planning efforts. Evidence is accruing where previously anecdote informed our understanding.

### **Side effects of hepatitis C treatment**

A major component of this thesis reports on research into the experience of people receiving interferon-based treatments for hepatitis C and includes health profession-

als' perspectives on the preparation and management of treatment regimens. Two chapters are presented which focus on people's experience of receiving treatment; Chapter 5 explores the physical and emotional impact of side effects and Chapter 8 reviews participants' strategies for coping with side effects and the demands of the regimen.

The emotionless, disengaged tone of the hepatitis C treatment-related clinical literature presented a marked contrast to my experience of interviewing patients during the collection of data which are presented in Chapters 5 and 8. Interviews were often terminated because of participants' treatment-induced distress and resumed once they had regained composure. The first of the four treatment-related chapters is a descriptive account of a variety of reported impacts of therapeutic drugs from compromised heart function to depression and anxiety. Participants described reductions in health and quality of life due to severe and sustained physical and psychiatric side effects which affected their capacity to fulfill social roles. The data also showed that some participants' understandings of diagnostic labels were at times different to clinicians' use of these terms. Further data have emerged since publication of our article (Chapter 5) and the similarities in reported experiences of treatment are notable, particularly in relation to an ongoing need for social support during therapy to improve adherence (Fraenkel et al., 2006; McNally et al., 2006). In this thesis, reports of psychiatric adverse events highlighted potential risks for people who have limited support networks available. This appears particularly so for those who have not disclosed their hepatitis C infection or its treatment and therefore have no support outside the clinic. These findings also raise issues regarding the administration of interferon-based treatment for hepatitis C in rural and regional areas where support and psychiatric counseling services are much less available. Treatment adherence and continuation is affected by levels of support and emergency interventions by health professionals are commonly reported during treatment (see Hopwood, Treloar & Redsull, 2006). Well resourced urban communities present different treatment dynamics to those in isolated geographic areas and the findings presented in Chapter 5 suggest that general practice models of hepatitis C treatment delivery which are proposed for rural and regional areas of Australia may not be productive for health and the quality of life of patients in those regions.

### **Resilient coping**

Applying an inductive analytical approach we identified in participants' narratives the use of adaptive responses to treatment side effects which were learned from prior adversity and applied the theoretical framework of resilience to explore a nexus between social marginalisation and successful health outcomes in the context of people receiving treatment. Social marginalisation is commonly associated with poor health outcomes for affected people (Wilkinson & Marmot, 2003). However the data presented in Chapter 8 reveal how participants who were living in socially disadvantaged circumstances successfully applied approaches learned from past experiences

of drug dependence, living with symptoms of chronic illness, coping with depression and childhood sexual abuse to cope with severe treatment-related side effects. The phenomena of resilient coping has implications for the clinical management of hepatitis C treatment; namely, the factors and processes that facilitate adaptive coping to adversity associated with social marginalisation and stigmatisation can be assessed for their clinical contribution to coping with treatment.

## Pre-treatment assessment and hepatitis C treatment management

From a review of the clinical literature it was evident that up to a half of people who commence interferon-based treatment for hepatitis C infection in clinical trials discontinued therapy for reasons related to intolerance of adverse side effects. There is an emerging body of literature which considers the evaluation of people's suitability for commencing hepatitis C treatment. However there are few recent studies which discuss assessment strategies and how people are prepared for treatment. In what appears to be a rare article in that it privileges the role of social and family contexts in pre-treatment assessments, psychiatrists Goldsmith and colleagues (2003) discussed the quality of family and environmental support, household incomes, collaboration with social services, and patients' transport needs as well as other more common concerns like psychiatric co-morbidity. Identification of illicit drug use during hepatitis C treatment was not considered to be grounds for discontinuation of treatment. Conversely, Silberbogen and colleagues (2005) recently published a structured interview schedule for evaluating patients' suitability for hepatitis C treatment which assumes that only a homogenous population of deviants has hepatitis C infection and they seek to disrupt treatment protocols whenever possible.

Chapters 6 and 7 of this thesis constitute health professionals' perspectives on the preparation for and management of hepatitis C treatments. Health professionals reported that pre-treatment preparation usually focused on information provision regarding adverse events and the medical strategies that could ameliorate their impact. Evidence of resilient coping suggested the utilisation of strengths-based assessment. Health professionals discussed patients' resilient coping style and the beneficial impact this had on treatment management. However they did not make the link between resilient coping and the deployment of a strengths-based assessment during pre-treatment interviews. While they assessed their patients' vulnerabilities and some supports prior to treatment, for the most part health professionals sought to address patients' problems as they arose during treatment; that is, they applied a common deficits-based approach to managing treatment. We suggest that by exploring patients' past experiences of coping with adversity and making a detailed evaluation of a range of patients' strengths, clinicians might prevent crises from occurring or ameliorate their impact and thereby significantly contribute to the management of hepatitis C treatment regimens. This is fertile ground for further quantitative and qualitative research.

## Illicit drug use during hepatitis C treatment

The risks and benefits of illicit drug use for health, quality of life and adherence to hepatitis C treatment regimens, and the phenomenon of injecting drug use during treatment are some of the issues covered in Chapter 7. Exploration of patients' illicit drug use during treatment is largely absent from the clinical literature. Much of the recent literature is clinically focused (e.g., Matthews et al., 2005; Stoove et al., 2005). Health professionals' engagement with patients' drug use during treatment is contentious yet important for health outcomes given that most people acquire their infection through injecting drug use and anecdotally people continue to inject throughout treatment. Among the findings of Chapter 7, health professionals' described adopting a harm reduction approach to patients' illicit drug use. However, they omitted this information from medical files and when communicating with specialist physicians. In response to these findings several hypotheses are proffered for investigating the extent of illicit drug use during hepatitis C treatment, the risks and benefits associated with their use in this context, and the harms that can befall patients and health professionals from perpetuating a duplicitous healthcare system which denies the common practices of many of its patients.

As was evident in earlier chapters and represented in Chapter 7, the stigma of substance use is confounded with hepatitis C infection and stigma permeates the clinical spaces where treatment is administered and managed. However the difference here is that a collaborative arrangement between illicit drug using patients and the healthcare workers that they are in closest proximity to, and whom are in a position to manage patients' potentially stigmatising information – described in Goffman's treatise as 'the wise' – enabled nurses to protect and conserve the virtual social identity of these patients; that is, as 'reformed' or non-drug users (Goffman, 1968). Through careful negotiation and information management by 'wise' health professionals such as nurses and social workers, the discreditable person passes and conforms to patient-norms as long as visibility is kept in check and no events arise that could highlight a discrepancy between patients' virtual and actual identity.

Referring finally to the health promotion planning framework (Green & Kreuter, 1999), the findings reported in this thesis which pertain to interferon-based hepatitis C treatments form a basis for: an epidemiological assessment (Phase 2) regarding the prevalence of side effects and problems with adherence; a behavioural and environmental assessment (Phase 3) of the personal and collective actions which impact on and determine adherence and quality of life outcomes including the environmental factors that may constrain adherence; an educational and ecological assessment (Phase 4) of the predisposing, enabling and reinforcing factors that have direct impact on behavioural and environmental targets; and finally, an administrative and policy assessment (Phase 5) of organizational capabilities for building and executing health promotion programmes.

Some of the social problems that impact on quality of life reported throughout the latter sections of the thesis might be barriers to the uptake and completion of treatment. For example, the disjuncture between the lives of current injecting drug using patients and the expectations of health professionals, particularly specialist physicians, the ways that patients understand diagnostic labelling in relation to the bodily and emotional changes they experience during treatment, and their capacity for coping with side effects and the demands of treatment. From the health promotion planning assessment phases outlined above a programme may be developed to address the major social impacts reported by our study participants regarding treatment adherence and quality of life.

## CONCLUSION

This thesis depicts an arduous journey; commencing with a hepatitis C positive diagnosis that 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 a new set of health conditions, and uncertainty about their long-term prognosis. The confusion is exacerbated by inadequate information and counseling about the impact of disease on health and quality of life. The next stage of the journey is coming to terms with stigma and the discrimination that accompanies those with an attribute which many consider deeply discrediting. Whether living with medically acquired hepatitis C or a current injecting drug user with infection the impact of stigmatisation is often emotionally debilitating and may present an effective impediment to accessing healthcare. For some, the journey ends with treatment and eradication of viral infection while for many the journey is recursive as treatment fails, is refused, or is denied. 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. This is living with hepatitis C.



## CHAPTER 2

Living with hepatitis C

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## INTRODUCTION

The hepatitis C epidemic represents a major public health challenge both in terms of preventing transmission and dealing with the long term social and economic impact of large numbers of people with chronic hepatitis C infection. To date, hepatitis C research, both in Australia and internationally, has focused on the epidemiology of the virus and medical treatments of infection, with social research literature concentrating on risks for transmission. There has been little systematic exploration of issues relating to the socio-cultural dimensions of living with hepatitis C. This area of the literature is a mix of a nascent scholarly research, information from government reports and personal accounts of living with the infection. While valid, at times rigorous and providing important information, the majority of this literature is not systematic social research that investigates a wide range of the affected population. Rather the information is based on: individual case study accounts of personal experiences (e.g. English and Foster, 1997; Dolan, 1997); clinical observation of small numbers of patients (e.g. Everson and Weinberg, 1999); a handful of exploratory qualitative studies using small samples (e.g. Crofts et al., 1997; Glacken et al., 2001; Hepworth and Krug, 1997 & 1999) and government reports that allude to social issues related to the epidemic but provide little elaboration of these (e.g. Burrows and Bassett, 1996; Wood, 1997). This article draws together this literature in order to review strengths and gaps in current knowledge of living with hepatitis C.

The main strategy used to identify peer-reviewed and other scholarly literature involved systematic searches of the databases Medline, Current Contents, PsycInfo, APAIS Health and Sociological Abstracts, using keywords and phrases associated with, and including, hepatitis C (for example, 'non-A non-B hepatitis' and 'blood-borne virus'). Specialist libraries and resource centres were consulted regarding policy documents and other grey materials such as needs assessments and technical reports. These libraries included the Centre for Education and Information in Drugs and Alcohol (CEIDA), New South Wales Users and AIDS Association (NUAA) Resource Centre, and the National Centre in HIV Social Research Library. In addition, key researchers, educators and health providers were contacted with regard to locating grey material unobtainable from other sources.

The review commences with background information on the hepatitis C epidemic. Several key areas are examined, including the experience of diagnosis, disclosure of hepatitis C status, stigmatisation and discrimination. The literature on hepatitis C treatments and health-related quality of life is explored, as are the psychiatric effects of interferon treatment. A budding sociological literature that critically assesses the medicalisation of people with hepatitis C is also 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 con-

taminated blood products and therapeutic injections (Everson and Weinberg, 1999). Most people infected do not know that they have hepatitis C as symptoms usually do not present until many years, even decades, after infection occurs (Everson and Weinberg, 1999). Currently, an estimated 170 million people (about 3% of the world's population) are infected with hepatitis C (Crofts, Dore and Locarnini, 2001). 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 younger people (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 persons and appears to be the result of unsafe therapeutic injections and use of contaminated medical blood products. This epidemiological profile also occurs in some developed countries, such as France, where nosocomial transmissions are evident. 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 et al., 2001a). 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 et al., 2001a). 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. Globally, prevalence rates of hepatitis C infection are many times those of HIV infection. The World Health Organisation (2001) provides estimates of prevalence rates for HIV infection among people aged 15 to 49 years in the following countries: USA 0.6%; Australia 0.1%; France 0.3%; Italy 0.4%; Russia 0.9%; China 0.1%; and Japan <0.1%.

## Background to the epidemic in Australia

A diagnostic test to detect antibodies was available in Australia from February 1990 (Crofts, Louie and Loff, 1997a). Law's (1999) study of the virus in Australia place the number of people infected at around 196,000 (lower and upper limits of 149,000 and 234,000). Approximately 90,000 of these reside in the most highly populated state of New South Wales (ANCARD, 1998). Currently, hepatitis C is the most frequently reported notifiable infection in Australia (National Centre in HIV Epidemiology and Clinical Research, 1998). 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 et al., 1997b; Carruthers et al., 1997; MacDonald et al., 1996). The Hepatitis C Council of New South Wales (2000) estimates that approximately 10% of all hepatitis C infections in Australia are the result of blood transfusions or the use of blood products prior to 1990 when screening was introduced. Some studies indicate that a number of people report no known vector of transmission to explain their infection (Abraham, Degli-Esposti and Marino, 1999; Sladden et al., 1997).

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). Besides injecting drug use, other routes of transmission include the use of non-sterile skin penetration instruments for tattooing, skin and ear piercing, acupuncture, and needle-stick and 'sharps' injuries (Sladden et al., 1997). The sharing of toothbrushes and razors also provides conditions sufficient for the transmission of hepatitis C. Sexual transmission is thought to be rare, however the risk increases when blood is present, for example, during menstruation or anal sex (Kaldor and Dore, 2000; Leruez-Ville et al., 2000; Rooney and Gilson, 1998). Vertical transmission also appears to be rare with about a 7% chance of transmitting the virus from mother to child during delivery (Kaldor and Dore, 2000).

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 virus have been identified throughout the world, with indications that more strains exist (Trepo, 2000; Sherman, 1997). In Australia, 55% of all infections are genotype 1; a further 38% of infections are genotype 3, and 7% are genotype 2 (McCaw et al., 1997). Specific genotypes are associated with how an infection is acquired. McCaw et al. (1997) found that younger people (those aged between 21 years and 40 years) tended to have genotype 3. Infection with this genotype appears to be associated with injecting drug use (Abraham et al., 1999; McCaw et al., 1997; Crofts et al., 1993). Those people who became infected through blood transfusions are likely to have genotype 1b (Sherman, 1997). Response rates to treatment with interferon also differ according to genotype (Trepo, 2000). Studies suggest that people chronically infected with genotype 1 respond less well to treatment with interferon than those people infected with other genotypes (Barbaro et al., 2000; Di Marco et al., 2000; Lai, 2000; Pianko and McHutchison, 2000). While the condition is acute, all genotypes respond equally well to interferon treatment (Jaeckel et al., 2001; Vogel et al., 1996).

According to research into the impact of infection on health-related quality of life, hepatitis C infection is often discovered incidentally. Approximately half of the people living with the virus have symptoms that cause them to seek medical attention, which then reveals their hepatitis C infection (Ware et al., 1999). Law's (1999) model of the hepatitis C epidemic in Australia estimated that around 8,500 people were living with hepatitis C-related cirrhosis and that there were around 80 incident cases of hepatitis C-related liver cancer. Projected estimates suggest that these rates of hepatitis C-related cirrhosis and liver cancer could more than double in Australia by 2010. 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).

## Living with hepatitis C

While the sociological literature on living with hepatitis C is scant, both popular and scholarly works, as well as government reports, point 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 infection; experiences of discrimination resulting from infection with a stigmatised virus; the impact of interferon 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 leads some people to 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, and 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 may be old issues and regrets that are then 'relived' (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 following a positive diagnosis (Hepworth and Krug, 1999; Burrows and Bassett, 1996; Krug, 1995). These findings are supported by an Irish study (Glacken, Kernohan and Coates, 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 this redefinition of the hepatitis C positive person and this can create friction within these networks.

A study of current injecting drug users conducted in Perth, Western Australia, found that respondents who tested positive for blood-borne viruses, including hepatitis C, on the whole did not change their risk-taking behaviours (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 their behaviour as safe. The authors conclude that the present testing situation in Australia is not a means by which to promote behaviour change.

Sladden et al. (1998) highlight the diverse consequences and 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. Stereotyping, isolation, stress and discrimination at work were reported, as were concerns about commencing personal relationships. Sexual contacts decreased and fatigue, nausea and insomnia were reported to affect work performance. Positive effects of a hepatitis C diagnosis were also reported, for example, some people described improving their diet (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.

Besides this small amount of empirical research, sources of information on the impact of a positive diagnosis include 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 (Hepatitis C Council of NSW, 2000; 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 experiences of diagnosis and living with the virus (Dolan, 1997; English and Foster, 1997).

## Disclosure

There is little scholarly research on the psycho-social effects of disclosing a positive hepatitis C status. Gifford et al. (2001) found that when women with hepatitis C disclosed their status, most of their partners were supportive, whether the partner had hepatitis C or not. However submissions to the Anti-Discrimination Board of New South Wales' recent Enquiry into Hepatitis C-related Discrimination (2001) revealed that disclosure usually precipitated discriminatory behaviour and that some people avoided disclosing their positive status to circumvent discrimination, particularly in health care settings. Recommendations were made by the enquiry to enact hepatitis C-related anti-discrimination legislation to offer an avenue for redress for people who experience discrimination. Other sources of information regarding disclosure include government reports and health promotion material. These have canvassed the issue in relation to disclosure to family members (Hepatitis C Council of NSW, 2000; Lowe and Cotton, 1999; Australian Hepatitis Council and the Australian National Council on AIDS and Related Diseases, 1999; Standing Committee on Social Issues, 1998). Here the issue of disclosure is entwined with people's fear of transmission within families, particularly to partners and children.

Whereas past research has demonstrated the beneficial psychological health effects of disclosure in relation to chronic illness (Pennebaker, 1995) negative social effects may also be produced. The literature concerning disclosure of HIV infection illustrates that revealing a positive diagnosis to others does not always lead to improved health and

well being (Holt et al., 1998; Malcolm et al., 1998; Ariss, 1997). These sources suggest that while there are often beneficial health outcomes 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 to explain to families, loved ones, casual partners, even sometimes their doctor, how hepatitis C infection affects their lives. Disclosing a positive status can be traumatic. People's reactions are unpredictable and confusion about the implications of being close to a sero-positive person, either as a family member or work colleague, often means that people 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 interaction, some become more reckless due to despair at being infected and increase their risk-taking while others make positive changes to their lifestyles and outlooks. 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**

Hepatitis C-related discrimination is barely mentioned in the scholarly literature; however it does appear as an issue within several government reports and among the popular literature. 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 et al., 1997a; Burrows and Bassett, 1996). Early in the Australian epidemic, hepatitis C did not receive the same level of attention 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 not constitutive of 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 in Australia and a lack of concern about the possibility that hepatitis C could cross over into mainstream society are reasons given for why governments were slow to respond to a mounting public health crisis. Power to make and inform public health policy concerning hepatitis C had shifted back to senior health bureaucrats and away from 'affected' communities (Hulse, 1997). This form of bureaucratic discrimination endangered the development of policy sensitive to the needs of a diverse population as represented by the 'hepatitis C community'.

Some sources have cited 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; Anti-Discrimination Board of NSW, 2001). Nevertheless, empirical investigation of the social dynamics of hepatitis C-related discrimination has been minimal. Several small studies have been con-

ducted however they provide limited detail about the extent and nature of discrimination and its effects on people with hepatitis C infection (e.g. Crofts et al., 1997a; Hepworth and Krug, 1997).

A hepatitis C diagnosis is often delivered in an insensitive manner by doctors who assume deviant behaviour led to infection. Some health care workers continue this line of reasoning, resulting in the poor treatment of patients with hepatitis C (National Centre in HIV Social Research, 2001). Community concerns over hepatitis C have led to reports of individuals suffering discrimination fuelled, among other things, by negative media portrayals of people with the infection (Anti-Discrimination Board of NSW, 2001). The manifestations of discrimination toward people with hepatitis C 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 drugs (Anti-Discrimination Board of NSW, 2001; Hepworth and Krug, 1997). Discrimination also occurs when consideration is being given to who can afford treatments and who will be 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).

Crofts et al. (1997a) looked at case studies of people with hepatitis C infection and the discrimination they faced from health care workers, other service providers, partners, family and friends, workmates and employers. According to their findings, people with hepatitis C experienced most instances of discrimination from health care professionals. The Anti-Discrimination Board of NSW reported similar findings from their enquiry (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 health care workers, sometimes under the guise of infection control. The authors call for occurrences of discrimination to be acted upon as a prerequisite for controlling the continued spread of hepatitis C among injecting drug users. Only through the provision of non-judgmental 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 with chronic hepatitis C infection usually involve either interferon alpha-2b monotherapy or interferon and ribavirin (Rebetron) combination therapy (Battaglia and Hagemeyer, 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 undetect-

able 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, however this depends upon a range of variables like a person's age and viral genotype (Hadzijannis, 2000; Barbaro et al., 2000; Di Marco et al., 2000; Lai, 2000; Malnick, Beergabel and Lurie, 2000). 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. It is expected that when used in combination with ribavirin, even better response rates will ensue. (Glue et al., 2000; Sobesky & Buffet, 2001; Gervais et al., 2001). For the time being however only a minority of people show a long-term favourable response to current interferon treatments, while many people experience severe physical and psychiatric side effects.

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 on people (Bonkovsky, Woolley and CISG, 1999; Singh et al., 1999; Ware et al., 1999; Foster, Goldin and Thomas, 1998; Koff, 1998; Owens, 1998; Carithers, Sugano and Bayliss, 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, Dunne and MacDonald, 2001; Miller, Hiller and Shaw, 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.

Popular literature discusses alternative and complementary treatments for hepatitis C infection including Traditional Chinese Medicine, Western herbal medicine, homeopathy, vitamin, mineral and amino acid supplementation (Salmond, 1999; Dolan, 1997). Some authors site changes to lifestyle emphasising exercise, healthy diet and abstaining from alcohol and other drugs as treatment options (Everson and Weinberg, 1999; Dolan, 1997).

### **Psychiatric effects of interferon treatment for chronic hepatitis C**

Interferon treatments often produce severe psychiatric side effects in people. 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, Willenbring and Ho, 2000; Kraus et al., 2000; Clemensen,

Eshelman and Belville-Robertson, 1999; Miyaoka et al., 1999; Maunder, Hunter and Feinman, 1998; Sasaki et al., 1997). Interferon therapy has long been associated with an increased vulnerability to emotion 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 treatment in patients with chronic hepatitis C infection is the 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 treatment compliance and overall quality of life.

As these studies document, people who receive interferon treatment for hepatitis C infection suffer negative impacts on health-related quality of life as measured by several reliable instruments. Psychiatric and physical side effects from interferon treatment affect people's well being and often compromise their ability to fulfill 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 health care 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.

### **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 article 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' (Krug, 1995 p.317) around hepatitis C infection. The dominance of medical discourses and a relative lack of alternative 'voices' around living with hepatitis C have material effects on the way people with the infection experience life. 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 to patients 'facts' and information about hepatitis C that are 'still preliminary and contested findings' (Krug, 1995 p. 306) within medical and scientific literature. Medical diagnoses may become self-fulfilling prophecies for some patients. Such a conse-

quence of medicalisation is illustrated in research by Rodger et al. (1999) who demonstrated the deleterious health effects that knowledge of a hepatitis C diagnosis can have on people previously unaware of their infection.

Hepworth and Krug (1999) argue that medical and scientific discourses deny the experience of hepatitis C infection from 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 trivialised yet these issues remain as central themes in the lives of many people affected by the virus. These authors believe that stories which give back a sense of meaning to life are needed most, more so 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; Radley, 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 and for people to reposition themselves among the power discourses around hepatitis C. 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 hepatitis C diagnosis many doctors play down the health implications, causing 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 doctors' advice concerning 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 probably underestimate the impact of hepatitis C infection on functional health and well being. Similarly, Krug (1995) writes that it is common for people with hepatitis C to express concern that most physicians, scientists and the state underestimate the severity of the virus.

Conversely, Owens (1998) writes that doctors may, under certain circumstances, 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 of hepatitis C infection on quality of life, such as the SF36 Health Survey, focus on patients' physical and mental functioning. While these tests show good reliability and validity, Owens calls for a complementary study to assess how bothered patients are by the symptoms that they experience. This would enable people to express how their symptoms impact on 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 (Hepworth and Krug, 1997). To date, epidemiology and virology dictate political and public health discussions concerning hepatitis C infection. An exclusively scientific understanding of hepatitis C impedes recognition and interpretation of related issues, like discrimination, because the discursive field of science has no language to deal with such issues. The most salient 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) highlight how issues like discrimination are not helped by epidemiological understandings of the virus however such understandings inform all levels of government policy. The dominant hepatitis C discourse 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 rational and social impoverishment (Hepworth and Krug, 1997). However such opinions and practices waste valuable resources that are to be found among people with hepatitis C infection. Strong arguments are posited by these authors for the voice of affected people to be heard in the construction of hepatitis C policy.

## CONCLUSION

### Some future directions in hepatitis C social research

The literature concerning hepatitis C predominantly focuses on medical and scientific aspects of infection. The paucity of research into social issues highlights a significant gap in the literature. For example, scant attention has been paid to hepatitis C-related discrimination. Crofts et al. (1997b), Burrows and Bassett's (1996) and the government enquiry report 'Hepatitis C: The Neglected Epidemic' (1998), all highlight the need for further social research into discrimination. This would enable a fuller understanding of the implications of hepatitis C-related discrimination, particularly in relation to its impact on prevention of transmission and access to healthcare. Other lifestyle considerations worthy of investigation include people's ability to cope with

an infection that has varying and at times debilitating symptoms. This work would explore people's need for, and current use of, home and community care services.

While social research into hepatitis C infection is at an early stage, a number of commentators have identified key areas for investigation. For example, research into the social and psychological implications for people diagnosed with hepatitis C (Hepworth and Krug, 1999; Krug, 1995). The impact of interferon 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 living with hepatitis C infection and the personal and social impact of being associated with injecting drug use (Hepworth and Krug, 1999; Dolan, 1997).

Furthermore, we would argue that any investigation of living with hepatitis C infection should take into account the heterogeneous social groups affected by the virus. For example, the experience of people from culturally and linguistically diverse communities warrants comprehensive 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 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 those who no longer inject and who contracted the virus in the dim past may differ dramatically from those who continue to inject drugs. 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-judgmental health care 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 first Australian National Hepatitis C Strategy 1999-2000 to 2003-2004.

Other fruitful avenues for investigation touched upon in the literature include an analysis of the 'folk knowledges' that surround living with hepatitis C, particularly with relation to understandings of household transmission, disease prognosis and coping with chronic illness. Uncovering non-medicalised constructions of the 'contagious' and 'chronically ill' self may offer useful material for health promotion. This includes a comparison of those people not on treatment with those on alternative therapies and those undergoing mono and 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 is also an area ripe for research, particularly given the potential impact of discrimination. 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 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 and health promotion and therapeutic models are to be devised and implemented.

## CHAPTER 3

Diagnosed with hepatitis C

Adapted from:  
*Hopwood, M., and  
Treloar, C. (2004).  
Receiving a hepatitis C  
positive diagnosis.  
Internal Medicine Journal,  
34, 526-531.*

## INTRODUCTION

The hepatitis C epidemic represents a significant challenge to public health in Australia, both in terms of preventing further transmission and managing future social and economic impacts. Over 16,000 new infections were estimated to have occurred in 2001; a 45% increase on 1997 incidence estimates (Law, 1999; National Centre in HIV Epidemiology and Clinical Research, 2002). In the decade ahead, as awareness of the epidemic increases, many Australians will be diagnosed with hepatitis C infection. Individual experiences of diagnosis may have implications for the long-term management of infection and for the prevention of further transmission (Anti-Discrimination Board of New South Wales, 2001).

A recent enquiry into hepatitis C-related discrimination in NSW found that doctors often gave hepatitis C positive test results to patients without any pre or post-test counselling (Anti-Discrimination Board of New South Wales, 2001). Similarly, a recent study of injecting drug users found that people who presented for hepatitis C testing often received inadequate or no pre and post-test counselling, very few were referred to local support agencies and written information about hepatitis C infection was not offered to a majority of newly diagnosed patients (Loxley, Davidson, Heale & Sullivan, 2000). Similar findings are reported in the international literature, where following a positive diagnosis, receiving an explanation of hepatitis C infection and acquiring information on available treatments and the possibility of a cure was described as 'notably absent' (Glacken, Kernohan & Coates, 2001).

The experience of receiving a hepatitis C positive diagnosis is likely to vary according to gendered expectations and needs. Identifiable differences in men and women's patterns of health seeking behaviour affect the way genders engage with the healthcare sector. For example, men often delay seeking healthcare and may comply less than women with medical advice, whereas women tend to present more often than men for healthcare (Smith, Mischewski & Gifford, 1999). Similarly, gender has been demonstrated to shape individual perceptions of satisfaction with medical services (Oakley, 1993).

The literature aimed at improving clinical interactional skills suggests a complete diagnosis should include information regarding the physical, psychological and social impact of disease (Enelow, Forde & Brummel-Smith, 1996; Gordon & Sterling Edwards, 1995; National Health and Medical Research Council, 1997; Smith & Norton, 1999). Relevant information given at diagnosis can reduce a patient's fear of disease and influence their capacity to take control of their health (Dolan, 1997; Glacken, Kernohan & Coates, 2001). The National Hepatitis C Strategy 1999–2000 to 2003–2004 recognises that education and training of healthcare workers is necessary to improve the quality and experience 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 (Commonwealth Department of Health and Aged Care, 2000). In 1999, the Australasian Society of HIV Medicine,

with similar aims, developed a hepatitis C continuing medical education program for general practitioners (Australasian Society of HIV Medicine, 2003).

Following a hepatitis C diagnosis, a doctor's referral to appropriate information and support services can facilitate better health outcomes for patients. Referral has been aided by 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 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 via resources including telephone information lines, magazines and pamphlets. It was against this background that we sought to explore people's experiences of receiving a hepatitis C positive diagnosis. This paper reports findings on the experience of diagnosis from a study of people with hepatitis C infection. The focus is on patients' perceptions of doctors' provision of information, advice and referral at the time of diagnosis.

## METHOD

### Procedure

The participants were men and women with hepatitis C infection living in New South Wales. Recruitment proceeded between March and November 2001. This was a convenience sample of people with hepatitis C, obtained via two recruitment strategies. The first strategy consisted of inserting a reply-paid questionnaire into the March and June 2001 editions of *The Hep C Review*, a quarterly news and information publication produced by the Hepatitis C Council of New South Wales (HCC of NSW), and posting the questionnaire to callers to the HCC of NSW telephone help-line, a counselling service for people with hepatitis C infection in New South Wales. Subscribers to the magazine include individuals with hepatitis C, general practitioners and other health care workers, government and non-government organisations, needle and syringe programs (NSP) and methadone clinics. Organisations were sent extra copies of the questionnaire for staff to pass onto people who fulfilled the inclusion criteria and were interested in being involved but did not subscribe or have access to *The Hep C Review*.

The second strategy for recruitment was implemented to increase the number of current injecting drug users in our sample. This involved staff from the Resource and Education Program for Injecting Drug Users (a large inner-Sydney needle and syringe program) informing their clients about the study and the criteria for participation. Staff told clients that the study was seeking to understand what it is like to live with hepatitis C infection. Those who were interested completed the questionnaire

in November 2001. A researcher was present to answer questions. No payment was offered to participants from either recruitment strategy.

## Measures

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. Items relating specifically to diagnosis included: year of diagnosis; who gave the diagnosis; impact of diagnosis; and doctors' explanation of hepatitis C, and provision of information, advice and referral.

## Analyses

Data were analysed using SPSS for Windows (version 10.0). The analyses presented below are descriptive. Percentages are given for categorical variables. The Pearson chi-square test was used to explore associations between categorical variables. For the purpose of analyses conducted throughout this paper, only those participants (n=417) who received a hepatitis C positive diagnosis – that is, those diagnosed since 1988 – have been included. It was shortly after this time in Australia that the epidemic was clearly recognised to primarily affect injecting drug users (Crofts, Dore & Locarnini, 2001). The association between injecting drug use and hepatitis C may have implications for the experience of receiving a positive diagnosis. People diagnosed with non A non B hepatitis were excluded from analysis because it was felt that they were subjected to different social processes and contexts to those which determine how the current hepatitis C epidemic is perceived.

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 was compared with those diagnosed from 1997 to 2001.

The study had approval of the University of New South Wales' Human Research Ethics Committee and the Ethics Review Committee of the Central Sydney Area Health Service.

## RESULTS

### Sample characteristics

A total of 6000 questionnaires were distributed via The Hep C Review, the Helpline and the NSP. Over eight months, 504 completed questionnaires were collected: 450 surveys were returned from The Hep C Review and telephone help-line recruitment strategy, and 54 from clients at the NSP. Sample characteristics for those participants diagnosed since 1988 (82.7%, n=417) are presented in Table 1. The sample comprised almost equal numbers of men and women. The age of participants ranged between 18 and 77 years (mean age 42 years) and most were born in Australia (80.3%, n=335). Participants reported a broad range of educational experiences. Most (66.4%, n=277) reported that their annual gross earnings were less than AUD 30,000 dollars per year, and more than a third earned less than AUD 10,000 dollars per year. A majority of participants were on a pension, unemployed, studying or doing a mix of these. Most identified as heterosexual. Approximately a quarter of participants had injected drugs during the month prior to the survey. A majority of participants reported that they had acquired their infection from injecting drug use (Table 2). Most participants (76.3%, n=318) reported that they had been diagnosed with hepatitis C infection between 1992 and 1999 (mode=1995), and a majority estimated that they had contracted the virus between 11 and 20 years ago, or more than 20 years prior to being surveyed (Table 2).

### Doctors' explanation of hepatitis C infection

A majority (78.2%, n=326) of participants diagnosed with hepatitis C first learnt of their infection from a doctor, with the remainder being told by another healthcare worker. Participants were asked if their doctor had explained what it meant to have hepatitis C infection following receipt of their positive diagnosis. In all, 174 (41.7%) participants reported that their doctor had 'partly explained' hepatitis C infection and 116 (27.8%) reported that their doctor 'had explained' what it meant to have hepatitis C infection at the time of diagnosis. Nearly a third of participants (29.5%, n=123) said that they had received no explanation from their doctor after receiving their hepatitis C positive test-result. Women were significantly more likely to report receiving no explanation from their doctor than men (35.4% v 23.7%,  $\chi^2=7.647$ ,  $df=1$ ,  $p<.05$ ). Participants diagnosed from 1997 to 2001 were significantly more likely to report receiving an explanation about hepatitis C from their doctor (37.5% vs 23.0%,  $\chi^2=9.797$ ,  $df=1$ ,  $p<.01$ ) than participants diagnosed from 1989 to 1996.

Table 1 Characteristics of sample (N=417)<sup>a</sup>

<b>Characteristic</b>	<b>n</b>	<b>%</b>
<i>Gender (n=414)</i>		
Male	200	48.0
Female	213	51.1
Transgender	1	0.2
<i>Age (n=396)</i>		
18-30 years	59	14.1
31-50 years	277	66.4
51-77 years	60	14.4
<i>Country of birth (n=414)</i>		
Australia	335	80.3
Other	79	18.9
<i>Education (n=409)</i>		
Up to and including Year 12	215	51.6
Diploma/Trade certificate	83	19.9
Attended university	37	8.9
Undergraduate Degree	39	9.4
Postgraduate Degree	38	9.1
<i>Income per year (n=371)</i>		
<\$10,000	149	35.7
\$10,001–\$20,000	80	19.2
\$20,001–\$30,000	48	11.5
\$30,001–\$40,000	23	5.5
\$40,001–\$50,000	28	6.7
\$50,001–\$60,000	25	6.0
>\$60,000	18	4.3
<i>Employment (n=410)</i>		
Employed full time	77	18.5
Employed part time	40	9.6
Self-employed	30	7.2
Unemployed	74	17.7
Pension	137	32.9
Student	11	2.6
Mix of work/study/pension	41	9.8

Table 1 Characteristics of sample (N=417)<sup>a</sup>

<b>Characteristic</b>	<b>n</b>	<b>%</b>
<i>Sexual identity (n=409)</i>		
Heterosexual	340	81.5
Gay/Homosexual/Queer	35	8.4
Bisexual	28	6.7
Other	6	1.4
<i>Injected in the last month (n=411)</i>		
Yes	108	25.9
No	303	72.7

<sup>a</sup> Proportions do not add to 100% due to missing data

Table 2 Mode of hepatitis C acquisition and time since infection<sup>a</sup>

	<b>n</b>	<b>%</b>
<i>Self-reported source of infection (n=411)</i>		
Injecting drug use	231	55.4
Medical blood products	63	15.1
Tattooing	17	4.1
Sex	14	3.4
Body piercing	3	0.7
Other	39	9.4
Multiple responses	42	10.1
<i>Self-reported time since infection (n=410)</i>		
Between 11 and 20 yrs ago	163	39.1
Over 20 years ago	96	23.0
Between 6 and 10 yrs ago	76	18.2
Between 1 and 5 yrs ago	58	13.9
Within the last year	12	2.9
11-20 yrs ago or >20 yrs ago	5	1.2

<sup>a</sup> Proportions do not add to 100% due to missing data

Table 3 Received from doctor at diagnosis (n=409)<sup>a</sup>

<b>Received from doctor</b>	<b>Yes n (%)</b>	<b>No n (%)</b>
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)

<sup>a</sup> Missing data = 8

### Post diagnosis

Participants were asked if following their positive diagnosis their doctor had given them any information about conventional treatments, advice regarding natural therapies, referral to a specialist, pamphlets with information about hepatitis C infection, counselling, information about how the virus might affect health or information about support groups (Table 3). A total of 137 (32.9%) participants reported that their doctor had given them none of the above at the time of their diagnosis. Participants who reported receiving none of the above were: more likely than not to be currently injecting (42.9% vs 30.2%,  $\chi^2=5.582$ ,  $df=1$ ,  $p<.05$ ); or more likely to be diagnosed from 1989 to 1996 than later (37.6% vs 25.9%,  $\chi^2=5.735$ ,  $df=1$ ,  $p<.05$ ).

Participants diagnosed from 1997 to 2001 reported that they were more likely than those diagnosed from 1989 to 1996 to have received from their doctor at diagnosis: information about hepatitis C treatments (24.5% vs 16.2%,  $\chi^2=4.161$ ,  $df=1$ ,  $p<.05$ ); advice regarding natural therapies (9.1% vs 3.8%,  $\chi^2=4.981$ ,  $df=1$ ,  $p<.05$ ); and pamphlets containing information about hepatitis C infection (39.2% vs 23.7%,  $\chi^2=10.798$ ,  $df=1$ ,  $p<.01$ ). Doctors' provision of counselling, information about support groups, information about how hepatitis C might affect health, and referral to specialists did not vary from 1989 to 2001.

## DISCUSSION

There are a number of methodological limitations to consider when interpreting the results from this study. We used a convenience-sampling frame and the recruitment strategies may have contributed to a number of biases. Specifically, by targeting readers of the Hep C Review and callers to the HCC of NSW help-line, we may have overly surveyed people with a higher expectation and need for information than would be normally represented. Similarly, NSP staff invited attendees to participate in the study and it is possible that this strategy contributed to sampling bias via their selection of particular clients. Therefore, our sample is not representative of all people in NSW with hepatitis C infection. This is evident from a comparison with known attributes of the 'hepatitis C community'. Around 55% of our sample reported contracting their infection from injecting drug use and this compares with estimates that 83% of all hepatitis C infections in Australia are from injecting drug use (Australian National Council on AIDS, Hepatitis C and Related Diseases, 2002). Our sample contained almost equal numbers of men and women, whereas approximately 35% of all hepatitis C diagnoses in Australia are among women (Australian National Council on AIDS, Hepatitis C and Related Diseases, 2002).

While this sample is not representative of all people in NSW with hepatitis C, it is unlikely that we only recruited people who were frustrated at their medical experience and saw the questionnaire as an opportunity to register a complaint. The participant information sheet, the questionnaire form, posters and fliers advertising the study and NSP staff each explained to participants that the aim of the study was to find out what life was like for people with hepatitis C. There was no specific mention of diagnosis during the recruitment process as it was but one part of a broad ranging investigation. There are likely to be many reasons for why people chose to complete and return the questionnaires. It is likely that some people participated because they were afforded a rare opportunity to be part of a social study about living with hepatitis C.

While approximately one-third of NSP participants who were approached agreed to participate, our method of recruitment via the HCC of NSW did not enable an accurate assessment of response rates. A lower response rate (<10%) was obtained via this method. This is because the Council's mailing list includes healthcare workers and large organizations where it is likely that many questionnaire forms did not reach their target because employees of large organizations may have been limited, due to work constraints, in the time that they had to promote the study and distribute the questionnaires to their clients and patients. Finally, we did not enquire into the state or country participants received their diagnosis from, but given that the vast majority of participants were Australian born, it is likely most reported experiences of diagnosis pertain to an Australian context.

Importantly, these data provide evidence of an increase in information provided by doctors to newly diagnosed patients with hepatitis C infection. While a large number of participants reported receiving no explanation about hepatitis C infection

from their doctor at diagnosis, it is encouraging to find that participants diagnosed from 1997 to 2001 were more likely to receive an explanation about hepatitis C than if diagnosed earlier. Throughout the 1990s, awareness of the hepatitis C epidemic among doctors in Australia increased through medical and epidemiological research, and this finding probably reflects doctors' growing engagement and familiarity with this literature. However these findings are based on participants' self-reported recollections of their diagnoses, and as such they are subject to the distortions of memory. Many variables impact on one's memory, including the length of time since the recalled event and the nature of the information received, and these factors might have influenced participants' self-reported satisfaction with their doctor's explanation following diagnosis.

There was evidence of gendered differences in the experience of diagnosis. As mentioned, our sample comprised a higher proportion of women than is evident in the general population of people with hepatitis C, and this may have influenced our finding. None the less, women in the present study were more likely than men to report receiving no explanation about their infection at diagnosis. A reason may also be found in the variation in patterns of men and women's health seeking behaviours. In our study, some men could have been less engaged or concerned with their diagnosis than some women. Men may have been satisfied with receiving a test result without an explanation, assuming that the doctor would have provided further explanation if it was warranted. On the other hand, women may have expected or demanded a detailed explanation from their doctor, for example, concerning household transmission risks to children and impacts of infection on pregnancy. Women may have been more concerned about their condition and the opportunity for treatment from the point of view of being a mother or future parent. However this finding needs further investigation.

Participants diagnosed from 1997 to 2001 were more likely to report receiving pamphlets about hepatitis C, information about treatments and advice regarding natural therapies than those diagnosed earlier in the epidemic. Again, this finding probably reflects the steady growth in resources that occurred throughout the decade. However reports of doctors' provision of information about support groups, information about the health effects of hepatitis C, counselling and referral to specialists appear to be rare and rates do not change significantly from 1989 to 2001. Without access to information, counselling and referral, people are disadvantaged in their attempts to cope with a newly diagnosed infection. Since the mid 1990s, state hepatitis C councils and the Australian Hepatitis Council have provided support and advice for affected people, and produced educational resources about hepatitis C and the prevention of transmission. Doctors would be advised to utilise these resources and refer patients to such organisations, especially if they perceive they are unable to provide information about hepatitis C to their patients' satisfaction (Glacken, Kernohan & Coates, 2001).

Our data show that current injecting drug users were more likely to report receiving 'nothing' from their doctor at diagnosis than participants who were not currently

injecting. These findings resonate with Loxley et al., (2000) study of injecting drug users from Western Australia. People who currently inject need access to pre and post-test counselling to assist in preventing infection, if testing negative, or if positive, to reduce the likelihood of further transmission of hepatitis C to other users. Testing for blood-borne viruses provides an opportunity for injecting drug users to access information and referral. Our data suggest that a continued effort by general practitioners is needed to engage patients who inject drugs in order to test, treat and distribute information to prevent further transmission of hepatitis C.

The literature on clinical interactional skills recommends that doctors provide patients with comprehensive information about their disease at diagnosis (Enelow, Forde & Brummel-Smith, 1996; Gordon & Sterling Edwards, 1995; Smith & Norton, 1999). As evidenced by previous research, some general practitioners are not well informed about hepatitis C infection (Glacken, Kernohan & Coates, 2001) and the number of participants in our sample who reported receiving 'nothing' at diagnosis may be highlighting gaps in doctors' knowledge. With the implementation of continuing medical education programs for general practitioners and a growing output of hepatitis C information from organisations such as the hepatitis C councils, the increase in provision of information at diagnosis that we have seen in our data throughout the latter 1990s should continue. Improvement in referrals to information and support agencies may eventually be an outcome of these changes. 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 these, as inadequate provision of information and a lack of referral to relevant support services at the point of diagnosis will obstruct efforts to prevent the further spread of the virus among the community.



## CHAPTER 4

### Hepatitis C-related discrimination

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## INTRODUCTION

The hepatitis C virus epidemic represents a major global public health challenge with over 170 million people infected world-wide. In Australia, an estimated 16,000 new infections occurred during 2001, which is a 45 per cent increase on 1997 incidence estimates (Australian National Council on AIDS, Hepatitis C and Related Diseases (ANCAHRD) Hepatitis C Sub-Committee, 2002). Around 91 per cent of new infections in Australia are from injecting drug use (National Centre in HIV Epidemiology and Clinical Research, 2002). For most people hepatitis C is not life threatening however it is associated with significant long term morbidity.

In recent years a nascent academic investigation has found that discrimination is a salient issue for people with hepatitis C (Crofts et al., 1997; Habib & Adorjany, 2003; Treloar & Hopwood, 2004; Zickmund et al., 2003). These sources contend that discrimination occurs because of widespread confounding of injecting drug use with hepatitis C and inadequate knowledge about viral transmission risks. Submissions tendered to the Anti-Discrimination Board of New South Wales (ADB of NSW) enquiry into hepatitis C-related discrimination stated that people with hepatitis C and ex and current injecting drug users most commonly experienced discrimination from healthcare workers, regardless of whether they had hepatitis C infection or not (ADB of NSW, 2001). The implication of widespread discrimination within healthcare settings is a primary concern. Discrimination may alienate people with hepatitis C and people who inject from health services and inhibit access to blood-borne virus (BBV) testing, drug-treatment (Day et al., 2003) and general healthcare as well as reduce exposure to BBV transmission prevention information essential for curtailing the epidemic (ADB of NSW, 2001). Such outcomes are clearly not in the interests of public health, yet they are not without precedent. The HIV/AIDS epidemic illustrated how a socially proscriptive attitude to homosexuality underpinned an epidemic of discrimination within healthcare against people with HIV infection, with negative health consequences (Herek, 1999; Kippax et al., 1991). A similar dynamic has been replayed over the past fifteen years in the context of hepatitis C, where the 'villains' are injecting drug users.

Beyond the health care sector, community concerns over hepatitis C infection have led to reports of individuals suffering workplace stress, isolation and stereotyping fuelled by among other things, negative media portrayals of people with hepatitis C infection (ADB of NSW, 2001; Sladden et al., 1998). Hepatitis C-related discrimination can have significant negative impacts on one's physical and psychological health, personal relationships and employment, and add burden to an already compromised quality of life (Miller et al., 2001). Because of the increasing prevalence of the infection among the community and the broad, debilitating range of effects of stigmatisation (Goffman, 1963; Scambler & Hopkins, 1986), hepatitis C-related discrimination is a significant public health and social justice issue. Hepatitis C affects people from a wide variety of geographical, ethnic, cultural and class backgrounds. The diversity of people affected and the illegality of injecting drug use make it difficult for communi-

ties to mobilise resources in order to resist discrimination and advocate for change in policy to improve their lives (Orr & Leeder, 1998; Wodak, 1997).

Given this background, the aim of this article is to present self-report data regarding discrimination from an exploratory study of people with hepatitis C infection in NSW, Australia. Participants' experiences of discrimination within a range of contexts are discussed. The authors compared a variety of reported discrimination experiences and explored predictors of any discrimination and higher levels of discrimination.

## METHOD

### Participants and Procedure

A cross-sectional survey was conducted during 2001 and 2002. The eligibility criteria for participation in the study were people living in NSW, Australia with self-reported chronic hepatitis C infection. Participants were recruited via an advertisement in the March and June 2001 editions of the Hepatitis C Council of NSW quarterly magazine *The Hep C Review*. An advertisement explained that the study was about living with hepatitis C infection. Reply paid survey forms were inserted in these editions and mailed to subscribers of the magazine, which comprised people with hepatitis C and related health and community organisations. Eligible callers to the Council's telephone information and help line were also asked if they would like to participate. In all, 450 completed survey forms were returned from these recruitment strategies. To increase the number of current injecting drug users in the sample, 54 clients of a large needle and syringe programme (NSP) in central Sydney were recruited during November 2001. Posters and fliers advertising the study were placed in the NSP and staff asked clients to participate. Questionnaires were completed by eligible participants during their visit at the NSP. A researcher was present to assist with queries. No financial incentives were extended to participants from either recruitment strategy.

A comparison of demographic variables of the groups obtained via the two recruitment strategies revealed no significant differences. Similarly, a comparison of current injecting drug users recruited via the two strategies revealed minor differences: compared with current injecting drug users recruited via the mail-out, current injecting drug users who attended the NSP were more likely to have injected the methamphetamine 'ecstasy' (63.3 vs 0.0%,  $\chi^2 = 68.6$ ,  $df=1$ ,  $p<.001$ ), were less likely to have ever received treatment for hepatitis C (5.9 vs 22.1%,  $\chi^2 = 6.2$ ,  $df=1$ ,  $p<.05$ ) and were less likely to report feeling tired from their infection (36.0 vs 60.0%,  $\chi^2 = 7.3$ ,  $df=1$ ,  $p<.01$ ). On all other dimensions, including the outcome variable 'any discrimination', these two groups did not differ.

It is evident from a comparison with known attributes of Australians diagnosed with hepatitis C that the study sample was not representative (ANCAHRD Hepatitis C Sub-Committee, 2002). Around 58 per cent of the study sample reported acquiring their infection from injecting compared with 83 per cent nationally, and males comprised about half of the study's sample, whereas approximately 65 per cent of all hepatitis C diagnoses in Australia are among males. The decision to use a convenience sampling frame however enabled the researchers to uncover some of the salient issues for this group of affected people. Although the above differences are acknowledged, this sample was similar on other dimensions to the national profile of people diagnosed with hepatitis C infection.

## Materials

Items investigating discrimination were developed following an extensive review of the literature pertaining to living with hepatitis C (Hopwood & Southgate, 2003). The principle author also attended hearings of the ADB of NSW enquiry into hepatitis C-related discrimination where data obtained from seven public hearings, two private hearings and 62 written submissions from individuals, employers and health service providers indicated that discrimination was a commonly understood term and that the present study's items regarding hepatitis C and injecting-related discrimination were consistent with the lay meaning utilized throughout the enquiry. In accordance with the approach used by the ADB of NSW (2001) and Crofts et al (1997), we did not define discrimination for participants. Interview data from the qualitative arm of this study (Treloar & Hopwood, 2004) confirmed that participants understood and used the lay definition of the word. Being treated differently and unfairly in comparison to others is the meaning of discrimination deployed throughout the ADB enquiry and this study. The proportion of participants who understood discrimination to mean something else is likely to be negligible.

The questionnaire took approximately 15-20 minutes to complete and contained 58 items that enquired into: participants' experience of hepatitis C diagnosis; disclosure of hepatitis C infection; hepatitis C-related discrimination; and several items regarding treatment, information needs and quality of life. Four items asked if participants had ever been refused medical treatment because of either hepatitis C or injecting drug use, or whether they had ever experienced hepatitis C or injecting-related discrimination.

## Analyses

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 that you were an injecting drug user?" The response categories for these two items were: my doctor, other health care worker(s), a landlord, my family, my flatmate(s), my friend(s), my boss, 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 often do not know the precise reason they had been discriminated against (i.e. whether because they were considered an infectious risk or for being perceived as an injecting drug user, or both). A discrimination scale ranging from one to nine was developed where a score of one to four categories of people indicated lower level discrimination, and a score of five to nine categories of people indicated higher level discrimination. The scale had a Cronbach alpha of 0.65. Although this scale does not indicate the absolute number of people that participants reported experiencing discrimination from, it does capture the breadth of hepatitis C and injecting-related discrimination.

Following a series of univariate analyses to examine associations between the discrimination scale and other variables, two logistic regression models were fitted. Data were screened to check for suitability for use in logistic regression. This included checks for the adequacy of expected frequencies, outliers or cases that were poorly predicted by the model, and the ratio of cases to predictor variables (Tabachnick & Fidell, 1996). The data were suitable for regression modelling, having no expected cell frequencies of zero and no more than five outliers in each model. However model two (predicting higher levels of discrimination) used a high number of predictor variables in relation to the sample size. The variables introduced in the model included participants' demographics such as age, gender, income, employment and sexual identity, as well as participants' presumed sources of infection, time since infection, self-reported fatigue/tiredness, the number of people with hepatitis C known to a participant and whether or not participants had been treated for hepatitis C. All variables were entered simultaneously into the equation using the block enter method. In this way significant variables can be thought of as significant over and above the effects of all others. A type 1 error rate of 0.05 was used to determine statistical significance.

The study had ethics approval from the University of New South Wales' Human Research Ethics Committee and the Ethics Review Committee of the Central Sydney Area Health Service.

## RESULTS

### Sample characteristics

The sample comprised approximately equal numbers of men and women (Table 4). The mean age of participants was 42 years (SD 10.4, range 18 – 77 years). Participants reported a broad range of educational experiences, with almost a half having completed their education by age 16. More than a third earned less than AUD 10,000 dollars per year. A majority of participants were on a pension, unemployed, studying

Table 4 Characteristics of sample (N=504)<sup>a</sup>

<b>Characteristic</b>	<b>n</b>	<b>%</b>
<i>Gender (n=499)</i>		
Male	254	50.4
Female	244	48.4
Transgender	1	0.2
<i>Age (n=472)</i>		
18–30 years	65	12.9
31–50 years	334	66.3
51–77 years	73	14.5
<i>Education (n=495)</i>		
Up to and including Year 10	220	43.7
Year 12	49	9.7
Diploma/degree	183	36.2
Postgraduate	43	8.5
<i>Income per year (n=448)</i>		
< \$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
<i>Employment<sup>b</sup> (n=494)</i>		
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
<i>Injected in the last month (n=496)</i>		
Yes	138	27.4
No	358	71.0

Table 4 Characteristics of sample (N=504)<sup>a</sup>

<b>Characteristic</b>	<b>n</b>	<b>%</b>
<i>Drugs injected in last month<sup>b</sup> (n=132)<sup>c</sup></i>		
Heroin	80	61
Speed	54	41
Cocaine	44	33
Ecstasy	31	23
Methadone	30	23
Other	15	11
<i>Self-reported source of HCV infection<sup>b</sup> (n=494)</i>		
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
<i>Self-reported time since HCV infection (n=490)</i>		
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

<sup>a</sup> Proportions do not add to 100% due to missing data

<sup>b</sup> Categories are not mutually exclusive

<sup>c</sup> Percentages rounded off due to small n

or doing a mix of these. More than a quarter of participants had injected a drug during the month prior to the survey. Heroin was the drug most commonly injected. A majority reported that they had acquired their infection from injecting drug use, with most estimating that they had contracted hepatitis C between 11 and 20 years prior to being surveyed. A comparison of ex and current IDU with participants who had never injected revealed that participants who had ever injected were more likely to be younger (78.0 vs 57.1%,  $\chi^2 = 23.0$ ,  $df=1$ ,  $p<.0001$ ), identify as non-heterosexual (23.4 vs 11.6%,  $\chi^2 = 10.8$ ,  $df=1$ ,  $p<.001$ ) and know many other people with hepatitis C infection (93.8 vs 72.4%,  $\chi^2 = 42.3$ ,  $df=1$ ,  $p<.0001$ ). There were no reported differences in gender, education, employment, income, year of diagnosis or estimated duration of hepatitis C infection between these two groups.

## Descriptive statistics

In all, 326 participants (64.7%) reported experiencing hepatitis C-related discrimination. More participants reported experiencing discrimination within healthcare than in other domains. Over a quarter (27.8%, n=140) reported hepatitis C-related discrimination from a healthcare worker (other than a doctor), and 65 participants (12.9%) from a doctor. A total of 64 (12.7%) reported that they had been refused medical treatment because they have hepatitis C. Precisely the same number of participants that had reported hepatitis C-related discrimination from a healthcare worker (other than a doctor) also reported injecting-related discrimination from this source (27.8%, n=140). Almost a quarter of participants (22.8%, n=115) said a doctor had discriminated against them because they were perceived 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. In total, 98 participants (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. Other sites of hepatitis C-related discrimination reported by participants included insurance companies (12.7%, n=64) and work colleagues (5.6%, n=28).

Participants were asked if hepatitis C-related discrimination had had any bad effects on their lives. Almost a half of participants (45.0%, n=227) reported that discrimination had negatively affected their emotional health, with more than a third (35.7%, n=180) reporting that their physical health had been badly affected by discrimination. Finally, participants reported that discrimination had had a bad effect on their employment (21.4%, n=108) and on their personal relationships (26.6%, n=134).

Results of univariate analyses are presented in Table 5. Participants were more likely to report discrimination if they were younger, non-heterosexual, currently injecting, knew a greater number of other people with hepatitis C, had acquired their infection through injecting, reported feeling pessimistic about hepatitis C treatment and their future health, reported feeling very tired from their infection, and were limited in their time spent with family, friends, neighbours and groups due to their hepatitis C infection.

## Regression models

### *Equation 1: Discrimination versus no discrimination*

The first regression equation predicted whether or not a person reported discrimination. Three variables were significantly associated with reports of discrimination (Table 6, Equation 1). Compared to participants who knew six or more people with hepatitis C, those who knew no one with hepatitis C were less likely to report discrimination, as were participants who knew from 1 to 5 people with hepatitis C. Participants who agreed with the statement “In the past month, having hep C has made me feel very tired” were more likely to report discrimination than those who did

Table 5 Significant background and behavioural variables related to discrimination

	No discrimination		Discrimination		Total <i>N</i>	Significance
	<i>n</i>	%	<i>n</i>	%		
<i>Gender</i>						
Male	95	37.4	159	62.6	254	NS
Female	82	33.5	163	66.5	245	
Not stated	1		4		5	
Total	178		326		504	
<i>Sexual identity</i>						
Heterosexual	154	38.2	249	61.8	403	$\chi^2=8.6, p<0.01$
Non-heterosexual	20	22.0	71	78.0	91	
Not stated	4		6		10	
Total	178		326		504	
<i>Education</i>						
Up to and including HSC	97	36.1	172	63.9	269	NS
Diploma/degree	60	32.8	123	67.2	183	
Postgraduate	19	44.2	24	55.8	43	
Not stated	2		7		9	
Total	178		326		504	
<i>Employment</i>						
Unemployed/pension/student	107	33.9	209	66.1	316	NS
Part time	15	30.0	35	70.0	50	
Full time/ self-employed	51	39.8	77	60.2	128	
Not stated	5		5		10	
Total	178		326		504	
<i>Income</i>						
≤ \$30,000	109	32.6	225	67.4	334	NS
\$30,001 - \$50,000	25	40.3	37	59.7	62	
> \$50,000	20	38.5	32	61.5	52	
Not stated	24		32		56	
Total	178		326		504	
<i>Age</i>						
18-30 years	16	24.6	49	75.4	65	$\chi^2=20.1, p<0.001$
31-50 years	109	32.6	225	67.4	334	
51-77 years	42	57.5	31	42.5	73	
Not stated	11		21		32	
Total	178		326		504	

Table 5 Significant background and behavioural variables related to discrimination

	No discrimination		Discrimination		Total <b>N</b>	Significance
	<b>n</b>	<b>%</b>	<b>n</b>	<b>%</b>		
<i>Injecting drug use in past month</i>						
Yes	36	26.1	102	73.9	138	$\chi^2=7.1, p<0.01$
No	139	38.8	219	61.2	358	
Not stated	3		5		8	
Total	178		326		504	
<i>Number of people participant knew with HCV</i>						
No one	47	61.0	30	39.0	77	$\chi^2=38.2, p<0.001$
1-5 people	61	39.9	92	60.1	153	
6-10 people	20	30.8	45	69.2	65	
>10 people	47	22.9	158	77.1	205	
Not stated	3		1		4	
Total	178		326		504	
<i>Time since HCV infection</i>						
≤ 10 years	56	34.8	105	65.2	161	NS
≥ 11 years	119	35.6	215	64.4	334	
Not stated	3		6		9	
Total	178		326		504	
<i>Source of HCV transmission</i>						
IDU	91	31.4	199	68.6	290	$\chi^2=5.0, p<0.05$
Other	84	41.2	120	58.8	204	
Not stated	3		7		10	
Total	178		326		504	
<i>Ever been or currently on HCV treatment</i>						
Yes	63	35.2	116	64.8	179	NS
No	113	35.0	210	65.0	323	
Not stated	2		0		2	
Total	178		326		504	

Table 5 Significant background and behavioural variables related to discrimination

	No discrimination		Discrimination		Total N	Significance
	n	%	n	%		
<i>Amount of time participants were limited in spending with family, friends, neighbours or groups because of HCV</i>						
A lot of the time	13	18.6	57	81.4	70	$\chi^2=17.9, p<0.001$
Some of the time	43	29.5	103	70.5	146	
None of the time	118	43.1	156	56.9	274	
Not stated	4		10		14	
Total	178		326		504	
<i>Optimism/pessimism around HCV treatment and future health</i>						
Positive	94	39.3	145	60.7	239	$\chi^2=8.5, p<0.05$
Neutral	52	38.5	83	61.5	135	
Negative	23	23.2	76	76.8	99	
Not stated	9		22		31	
Total	178		326		504	
<i>HCV has made participant feel very tired</i>						
Yes	80	29.4	192	70.6	272	$\chi^2=9.1, p<0.01$
No	93	42.5	126	57.5	219	
Not stated	5		8		13	
Total	178		326		504	

not agree with this statement. Finally, compared to participants aged from 51 to 77 years, younger participants were more likely to report discrimination. This model correctly predicted 71.3% of cases, and had an overall fit of  $\chi^2 = 69.0, df=21, p<0.001$ .

#### Equation 2: Higher discrimination versus lower discrimination

In a second equation, those participants who reported any discrimination were examined to see which variables predicted higher and lower levels of discrimination (Table 6, Equation 2). Of 326 participants (64.7%) who reported any discrimination, 282 participants (86.5%) indicated that they had experienced lower levels of discrimination (i.e. from 1 to 4 categories of people on the discrimination scale) and 44 participants (13.5%) reported higher levels of discrimination (i.e. from 5 to 9 categories of people on this scale). Three variables were identified as significant predictors of higher levels of discrimination. Compared to participants who knew six or more people with

Table 6 Regression models: Factors independently associated with discrimination

<i>Equation 1: Factors associated with having ever experienced discrimination</i>		
	<b>Odds ratio</b>	<b>Confidence interval</b>
Knowing no one with HCV (compared to knowing $\geq 6$ people)	0.2	0.1 – 0.5
Knowing 1-5 people with HCV (compared to knowing $\geq 6$ people)	0.5	0.3 – 0.9
Reported feeling tired in the last month due to HCV	1.8	1.0 – 3.1
Aged 18-30 years (compared to 51-77 years)	5.4	1.7 – 16.5
Aged 31-50 years (compared to 51-77 years)	2.9	1.4 – 5.8
<i>Equation 2: For those who reported discrimination, factors associated with having experienced higher levels of discrimination</i>		
	<b>Odds ratio</b>	<b>Confidence interval</b>
Knowing 1-5 people with HCV (compared to knowing $\geq 6$ people)	0.06	0.01 – 0.5
Reporting that HCV limited the time spent with family-friends a lot of the time (compared to none of the time)	7.2	1.3 – 38.0
Reporting that HCV limited the time spent with family-friends some of the time (compared to none of the time)	3.8	1.1 – 13.6
Feeling optimistic about HCV treatment and future health (compared to feeling pessimistic)	0.2	0.05 – 0.6

hepatitis C, those who knew from 1 to 5 people were less likely to report higher levels of discrimination. Compared to participants who reported that hepatitis C had not limited their time spent with family, friends, neighbours and groups those who reported that “a lot of time” with these people had been limited due to their infection were more likely to report higher discrimination. Similarly, compared to participants who reported that hepatitis C had not limited their time spent with family, friends, neighbours and groups those reporting “some time” limited with these people were more likely to report higher discrimination. Finally, compared to participants who were pessimistic about treatment and their future living with hepatitis C, those who reported that they were optimistic about their future were less likely to report higher levels of discrimination. This model correctly predicted 87.4% of cases, and had an overall fit of  $\chi^2 = 64.2$ ,  $df=21$ ,  $p<0.001$ .

## DISCUSSION

Findings from this study corroborate reports that hepatitis C-related discrimination is experienced in a variety of social domains such as family and friendship networks and healthcare. It is notable that discrimination was most commonly reported from the healthcare sector. People with hepatitis C may be more likely to disclose their infection to healthcare workers than in other settings (ADB, 2001), and this may account in part for the frequent reports of hepatitis C-related discrimination in this context. None the less, participants reported that the effects of discrimination adversely impacted on their employment, personal relationships and quality of life. While unexamined variables may have contributed to the difference in reports of discrimination that we found, such as individual variation in recall accuracy and thresholds for the detection of discrimination (Day et al., 2003), the findings of this study provide evidence that participants who reported experiencing discrimination were likely to know many other people with hepatitis C, were likely to report fatigue from their infection, and were younger rather than older.

Knowing many other people with hepatitis C predicted reports of any discrimination, as well as higher levels of discrimination, among participants in this study. Having contact with other people with the virus increases the probability of developing an awareness of the stigma that is accorded to people with hepatitis C. Hearing and sharing experiences within a network of similarly affected others sensitises one to inhabiting a 'spoiled' identity (Goffman, 1963; Fraser & Treloar, 2003), and the multiple contexts and ways in which discrimination is felt and enacted (Scambler & Hopkins, 1986). Hepatitis C support groups and networks of injecting partners for example provide a context for people to learn about the prevalence of hepatitis C-related discrimination in public and private domains such as healthcare and social networks. The transfer of knowledge and information regarding discrimination is facilitated by the growth in Australia over the past decade of hepatitis C councils (Hopwood and Treloar, 2004). These state-based, non-government organisations have successfully contributed to the creation of a hepatitis C community and they have effectively increased awareness of many hepatitis C-related issues, like discrimination. Identification with and access to this community occurs through magazines and web sites, presenting opportunities to learn about and engage with others affected by hepatitis C-related discrimination. Conversely, those people who knew few others with hepatitis C or were completely isolated from the experiences of other affected people were less likely to engage with or encounter issues such as discrimination.

Participants who reported hepatitis C-related fatigue were more likely to report discrimination. Similar observations have been made within the HIV/AIDS literature where several studies have found that AIDS symptom burden significantly predicted HIV discrimination and strong relationships were identified between AIDS-related physical symptoms and psychological distress, ability to cope and HIV discrimination (Heckman, 2003; Schmitz and Crystal, 2000). Reports of hepatitis C-related discrimination may be partly a function of the burden of hepatitis C symptoms. One of

the most common symptoms, fatigue is a condition that is difficult to disguise and affects work performance, social arrangements and personal relationships. According to a theory of disease progression (Serovich, 2001), if a symptom like fatigue is a constant in one's life, it is likely that disclosure of hepatitis C infection becomes necessary to account for its impact, and this may increase the likelihood of discriminatory outcomes. Similarly, experiencing fatigue symptoms suggests that affected people will seek medical assistance, resulting in a higher probability of experiencing negative interactions with healthcare workers.

A final predictor of any discrimination in the present study was age; younger participants were many times more likely to report experiencing discrimination than those who were older. Over the past decade research has focused on discrimination against young people from marginalised social groups based on ethnicity and non-hetero sexualities (Smith, 2005; Ryan & Rivers, 2003). Some of this work argues that as young people have become more open about identifying as non-heterosexual and more 'visible', they become vulnerable to discrimination and violence (D'Augelli & Dark, 1994). In this present study, younger people with hepatitis C were more likely to report discrimination than older people because they may have been more open about their infection, or less likely to deny infection if asked. As well, the widespread association between injecting drug use and hepatitis C may make young people more vulnerable to discrimination. In the context of health care, some young people are assumed to be injecting drug users with hepatitis C infection; a stereotypical assumption often based on the way some youth present (ADB of NSW, 2001). Conversely, due to the implementation in the last decade of school-based education programmes aimed at increasing awareness of racism, sexism and homophobia for example, younger participants with hepatitis C may be attuned to the prejudiced behaviour of others and be better able than older people to recognise situations where they have been discriminated against (ADB of NSW, 2001).

Participants who were limited in the time they spent with family, friends, neighbours and groups because of poor health caused by the symptoms of hepatitis C infection reported higher levels of discrimination. A similar finding is reported from a study predicting relationships between perceived discrimination, stress and symptoms of poor health (Veniegas, 1999). Participants from minority groups who perceived more frequent discrimination also reported more frequent symptoms of poor health, and this relationship was mediated by levels of stress. If because of ill health one becomes isolated and unable to benefit from the support and positive reinforcement that family and friends can provide, a sense of disaffection may ensue. Perhaps not unlike our findings in relation to fatigue and discrimination, the stress of coping with disease symptoms in isolation can have a significant impact on emotional well being and health. Having only limited support from family, friends, neighbours and groups implies that an ill person may have to personally interact with a variety of health-related services to ameliorate their symptoms, thereby increasing the probability of experiencing discriminatory interactions with medical staff.

Psychosocial factors are important in explaining the diverse ways in which people cope with chronic illness. In the present study, participants who reported pessimism regarding their future living with hepatitis C and the likelihood of a cure or better treatment for their infection were more likely to report higher levels of discrimination than those who were not pessimistic about their future living with hepatitis C. Pessimism is generally associated with poorer adjustment to living with a chronic illness (McNeal, 2002). Pessimism regarding one's future prognosis is premised on a variety of concerns. Although the bi directionality of cross-sectional designs prevents us from understanding the dynamics of this result, some study participants may have reported pessimism based upon previous experiences of discrimination from health care services and contemplating one's future need for ongoing interaction with the medical system. As detailed in the ADB of NSW enquiry (2001) and elsewhere (Treloar & Hopwood, 2004), many people with hepatitis C are averse to engaging with the health care sector for fear of experiencing further discrimination. This included a reticence to access a variety of important services such as blood and liver testing and treatment. This present finding may represent participants' fear of the health consequences of avoiding medical care and emotional support because of past negative experiences with health care, or fear of future discrimination from health care workers, employers and family and friends (Goffman, 1963; Scambler & Hopkins, 1986). Statistical limitations should be considered when interpreting this finding. The wide confidence intervals reported in Equation 2 (predicting higher levels of discrimination) suggest a problem may exist with the small sample size for this model.

Our recruitment strategy makes it unlikely that the results of this study merely reflect the experiences of a self-selected group of people who had encountered discrimination and saw the questionnaire as an opportunity to register complaint. The study information sheet, the questionnaire form, posters and fliers advertising the study and NSP staff each explained to participants that the aim of the study was to find out what life was like for people with hepatitis C. There was no specific mention of discrimination during the recruitment process as it was one part of a broad ranging investigation. There are likely to be many reasons for why people decided to participate, not the least being the rareness of an opportunity to partake in a social study about living with hepatitis C infection.

## CONCLUSION

Continued widespread discrimination against people with hepatitis C will obstruct efforts to encourage people into treatment and undermine prevention of the spread of the virus among the community. It is only through the provision of emotional support and non-judgemental health services that people with hepatitis C will access appropriate healthcare and information regarding the prevention of hepatitis C transmis-

sion. Addressing the health workforce's lack of knowledge of the disease via education programmes (see Australasian Society of HIV Medicine, n.d.), may contribute to lessening the prevalence of hepatitis C-related discrimination within healthcare. However broad implementation of educational initiatives that include critical reflection on the effects of individual attitudes and beliefs in the provision of healthcare (Treloar & Hopwood, 2004), with the aim of reducing discrimination and facilitating relationships between healthcare, the community, people with hepatitis C and injecting drug users, are urgently needed and could make a significant contribution to the control of the hepatitis C epidemic.

## CHAPTER 5

The experience of  
hepatitis C treatment

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## INTRODUCTION

Hepatitis C is an infectious, virulent and resilient blood borne virus first identified in 1989. Globally, it is estimated to have infected around 170 million people and the epidemic is rapidly spreading (Crofts, Dore and Locarnini, 2001). New infections in Australia increased by 45 percent between 1997 and 2001 to 16,000 annually, and current estimates suggest that up to 250,000 Australians have the virus; that is more than one per cent of the total population (Law, 2003, May). In industrialised nations, the epidemic is mostly found among people who are ex or current injecting drug users. In Australia, more than 90 percent of new hepatitis C virus (HCV) infections occur among people who inject drugs (National Centre in HIV Epidemiology and Clinical Research [NCHECR], 2002). The sharing of any injecting equipment, including spoons, filters and tourniquets is a risk for hepatitis C transmission (Wodak, 1998). Other risks for infection include tattooing, body-piercing and the sharing of utensils like razors and toothbrushes (Sladden, Hickey, Dunn and Beard, 1997). Also at risk are those people who received medical blood products prior to the introduction of hepatitis C antibody screening in 1990. Sexual transmission is thought to be very rare, particularly within monogamous heterosexual relationships (Terrault, 2002), and vertical transmission is also considered to be rare (Everson and Weinberg, 1999).

More than seventy percent of all people exposed to the hepatitis C virus will develop a chronic infection; the remainder will clear their infection within 12 months (Dore, 2001). Of those chronically infected, between five and ten percent will develop cirrhosis of the liver after two decades, and between three and five percent will develop liver cancer or liver failure up to five decades following infection (Dore, 2001). For most people, hepatitis C is not life threatening however it is associated with significant long term morbidity. 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 (Carithers, Sugano and Bayliss, 1996; Davis et al., 1994). These symptoms show improvement in people who respond to interferon treatment (Bonkovsky, Woolley and the Consensus Interferon Study Group, 1999). The aim of treatment is a cure. A cure is achieved if, following a blood test to detect virus RNA, hepatitis C remains undetectable for a period of six months (Sievert, 2001).

In little over a decade, there has been significant improvement in the treatment of hepatitis C infection. Early in the epidemic, the approach to treatment involved administration of unmodified interferon monotherapy which cured up to 20 percent of patients (Sievert, 2001). By the late 1990s, trials of interferon in combination with ribavirin, an antiviral agent, were found to cure up to 40 per cent of those in treatment (Lai, 2000). A recent innovation in therapy, and now prescribed in Australia as the standard treatment, is the combination of pegylated interferon with ribavirin. This regimen cures up to 80 percent of people with hepatitis C infection, depending on a range of variables including an infected person's viral genotype and age (Manns et al.,

2001; Rasenack et al., 2003). Pegylated interferon and ribavirin therapy is effective for people previously considered difficult to treat – for example, those with genotypes one and four, HIV co-infected, and people with advanced fibrosis or cirrhosis (Keating and Curran, 2003).

Concurrent with the implementation of this new therapeutic regimen, a raft of structural changes has made access to treatment easier throughout Australia (Dore, 2003, October). As of November 1 2003, pegylated interferon and ribavirin therapy was included in the Australian Pharmaceutical Benefits Scheme's (PBS) S100 government subsidised prescriptions category, making the drugs affordable for most people. In addition, prescribing by accredited general practitioners is being trialled throughout several Australian states and territories, a previous treatment restriction on current injecting drug users has been lifted, and people who did not respond to treatment with unmodified interferon can gain another chance of a cure by accessing this new treatment (Hopwood, 2003). At present, about 1500 to 2000 people begin treatment for hepatitis C infection each year in Australia. With the easing of criteria, an expansion of treatment is planned to curb a looming epidemic of hepatitis C-related liver disease predicted to occur within twenty years (Dore, 2003, October). Hepatitis C-related disease is already the leading indication for liver transplantation in the United States, Australia and other Western countries (Crofts, 2001).

While it has become easier to access hepatitis C treatment in Australia, the toxicity of the drugs and the duration of treatment – that is, either twenty four or forty eight weeks – present significant challenges for patients. Similar to studies of the impact of infection, past research into the impact of hepatitis C treatment on health has utilised quantitative measures of health-related quality of life (Clemensen, Eshelman and Belville-Robertson, 1999; Dieperink, Ho, Thuras and Willenbring, 2003). These studies show that interferon-based treatments produce severe physical and psychiatric side effects including fatigue, myalgia, major depression and anxiety. Although these instruments measure substantial decrements in individuals' physical and mental functioning during treatment, they do not give information about their significance in relation to treatment impact on overall quality of life. Similarly, how people come to make the decision to seek treatment, the experience of treatment and the strategies that people use to cope with treatment side effects are not elucidated by these quantitative measures. Currently, there are no published findings of studies which investigate the experience of hepatitis C treatment and its impact on, for example, personal relationships, work and domestic life. Patients and healthcare workers might use such information to improve their capacity to manage side effects and adhere to treatment. In response to this gap in the research literature, the authors explored people's experiences of interferon-based treatments. Specifically, the aim of this article is to report findings from a study of participants' experiences of treatment side effects and their impact.

## METHOD

A multi-method study into living with hepatitis C was conducted throughout 2001 and 2002. The aim of the study was to identify and explore some of the key issues faced by people with hepatitis C infection. The eligibility criteria for participation in the study were people living in the state of New South Wales, Australia with chronic hepatitis C infection. Convenience sampling was used to recruit participants to the study's quantitative arm (Hopwood and Treloar, 2003). Participants who completed a questionnaire were asked to volunteer for a confidential interview by telephoning a researcher and making arrangements.

### Participants

Nineteen people self-selected to take part in interviews. The interview sample ranged between 22 and 72 years of age, with a mean age of 45 years. Twelve participants were women. Eleven participants were Australian born, with the remainder born in England, The Netherlands, Canada, Uruguay, Cambodia and New Zealand. At the time of interview, ten participants were employed, six were unemployed and three had retired. Two participants reported that they left school before age sixteen, six had no further education after completing high school and four participants had attended university. The remaining participants could not give a clear indication of educational achievement. Eight participants cited injecting drug use as their source of infection, six reported medically acquired infections and five participants reported multiple risk factors.

It is evident from a comparison with known attributes of Australians with hepatitis C that the study's sample was not representative. Around 42 per cent of the interview sample reported contracting their infection from injecting drug use and this compares with estimates that 83 per cent of all hepatitis C infections in Australia are injecting-related (Australian National Council on AIDS, Hepatitis C and Related Diseases [ANCHARD] Hepatitis C Sub-Committee, 2002). Similarly, males comprised only 37 per cent of the study's interview sample, whereas approximately 65 per cent of all hepatitis C diagnoses in Australia are among males (ANCHARD Hepatitis C Sub-Committee, 2002).

### Procedure

Interviews were mainly held in participants' private residences and interview rooms at the University of New South Wales and the Hepatitis C Council of NSW. At the request of the participants, several interviews were conducted in a quiet café during off-peak periods. To protect privacy, an agreement was made between the interviewer and participants prior to commencement that the interview would stop if customers entered the space. An interviewer (MH) experienced in research with people from

marginalised populations conducted all interviews. Interviews were audio-taped and no form of written data was collected during this phase of the study. Before interviews commenced, participants read an information statement. This statement outlined the nature of the study, assured participants of confidentiality, and directed participants to a revocation of consent form in case they decided to terminate the interview. The interview commenced after written consent was obtained. Each participant took part in one interview that lasted for about one hour. No financial incentives were extended to participants however coffee and cake were provided during the interview.

### **Interview schedule**

The semi-structured interview schedule contained items that enquired into a broad range of issues affecting people with hepatitis C infection, including: participants' experience of hepatitis C diagnosis; disclosure of infection; hepatitis C-related discrimination; experience of treatments and sample characteristics. The treatment questions contained in the interview schedule (Table 7) were informed by a literature review that highlighted difficulties patients were having with therapy (Hopwood and Southgate, 2003). The semi-structured nature of the interview schedule allowed participants to elaborate on the interview topics.

### **Data analysis**

Audio-taped interviews were transcribed verbatim. Any reference made by participants to actual places or people were substituted with pseudonyms or deleted to ensure anonymity. The de-identified interview transcripts were entered into qualitative software (Richards & Richards, 1999). Findings reported in this article are from a qualitative content analysis of interview data (Grbich, 1999). The authors independently constructed a code list of major themes that emerged from the transcripts. The authors compared coding decisions and discussed any differences until consensus was reached.

To answer the research question 'What it is like to be in treatment for hepatitis C infection?' analysis of data for this article focused on the sections of text relating specifically to the theme of treatment and its side effects. Extracts that most clearly illustrated participants' experiences of side effects have been selected and presented. The analysis is descriptive and introduces the issue of interferon-based treatment side effects. The study was approved by the Ethics Review Committees of the University of New South Wales and the Central Sydney Area Health Service.

Table 7 Semi-structured interview schedule – hepatitis C treatments

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Why did you decide to go on treatment?

- Explore lead up to treatment

Tell me about your experience of treatment.

- Explore past and current treatment history
- Explore reactions to disclosure of treatment, any mention of side effects, discuss integration of treatment into lifestyle routine, discuss adherence issues

How do you feel since completing treatment?

- Explore physical and emotional well being

Tell me about your relationship with health care providers while you were on treatment?

- Explore shared care arrangements, relationship with doctors, specialists, nurses
- Explore issues of stigma and hepatitis C-related discrimination

How do you feel about your future?

- Explore outcome of treatment on participants' lives
- 

## RESULTS

Most interview participants had not received treatment. In all, six participants had received interferon-based treatment for hepatitis C infection and four of these were nearing completion of treatment at the time of interview. One participant reported termination of treatment several years earlier due to side effects, and another had completed an interferon and ribavirin trial three years prior to the interview (Table 8).

Participants reported that the decision to begin treatment usually followed a clinical evaluation of their suitability. Before entering treatment, all participants said that they were aware that interferon was associated with significant side effects. This information had been gleaned from a range of sources including doctors, a magazine and support groups. The following sections highlight participants' experiences of side effects from interferon-based treatments mostly administered in 2001 and 2002.

### Treatment side effects reported by participants

All participants reported side effects from their treatment, some of which were serious. The following extracts from two women, aged 40 and 57 respectively, refer to the

Table 8 Participants who have received interferon (IFN) treatment for HCV (n=6)

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Diagnosed HCV+</b>	<b>Treatment (Rx)</b>	<b>Rx year</b>
1	Male	35	2001	IFN + ribavirin	2002
2	Female	57	1995	IFN + ribavirin (discontinued)	1999
3	Male	38	2000	IFN + ribavirin	2002
4	Female	40	1989	IFN monotherapy	1993
				IFN + ribavirin (trial)	1998
5	Male	54	1998	IFN + ribavirin	2001
6	Female	22	2001	IFN + ribavirin	2002

development of interferon-related adverse effects on heart function. Both had received interferon monotherapy, the first woman in 1993 and the second in 1999.

So I went on to the interferon and, by May I fell apart. I ended up in the hospital in April .... with heart fibrillations, so I was quite crook and we didn't know what was going on. I kept going back to the GP and she kept saying 'Well, it's all side effects from the interferon' ... I was beside myself. I ended up at work just a mess on the floor in tears and it's not like me at all. I was so exhausted.

... [the specialists] had to stop [my treatment]. They can't give me the interferon now because of my heart ... ah, I think it was because I wasn't taking it very well ... I was sort of feeling funny, you know.

Interferon treatment is contraindicated for people who have experienced cardiac failure. If cardiac symptoms arise during treatment, as in the two cases above, treatment will be re-evaluated and possibly discontinued (Sievert, 2001). While interferon can potentially damage the heart, less than one per cent of people experience congestive heart failure from interferon-based treatments (Fried, 2002).

Participants reported that where possible, the dosing of drugs was timed to minimise interference with other demands on their lives. Some described the period immediately following their thrice weekly interferon injection as difficult; sleep was disrupted and physical and psychiatric side effects manifested. Participants commented on the subsequent restrictions to their lifestyle. For example, a 22 year-old woman described her health on the day after receiving an injection.

[T]he next morning after the injection, I would be sick and ... I get puffed out really easy and my whole chest starts hurting and it's hard for me to breath. Or my liver, or just my stomach area will start hurting and ... the next day I'd be all painful ... [T]he things that I want to do I find too hard to do at the moment ... at times I can't get out of bed because I'm sick or I have major migraines and ... my whole body just

aches ... At times it stops me from doing a lot of things ... I don't like the headaches ... I'll be sitting there and it just comes on me. Ooh! It's the end for me, stressful things ... [Y]ou get tired of going through the pain, going through the aches and stuff, so at times I get very upset. I have a bit of a cry but then I'll be fine after that.

The woman's side effects included respiratory problems, liver and stomach pain, migraine, headache, myalgia, and fatigue. The medical literature reports that over 50 per cent of patients undergoing interferon-based treatments for hepatitis C will experience myalgia, headache and fatigue (Fried, 2002). The upper respiratory congestion experienced by this woman is considered to be a minor but common side effect of ribavirin (Sievert, 2001), as are her gastrointestinal symptoms (Fried, 2002). Although from a clinical perspective these are not considered unusual, the woman poignantly laments her compromised quality of life from the ongoing stress of the side effects which follow her injections.

Similarly, a 38 year-old man below refers to irritability, fatigue and sleep disturbances from his treatment. He hints at the implications of side effects for his capacity to work.

I've been on this course now for twelve weeks ... you do get a bit shitty and that. Sometimes you don't feel like doing anything, you just feel worn out ... I can't, say, go to work if I feel like I feel today, because I can't get up. Sometimes ... I'm flat out making it to where I want to sit down because I actually can feel myself shutting down ... just all of a sudden, I feel like I need to sit down, yeah ... with this, when you have to stop you have to stop right then. [The treatment] might bugger up your sleep every third night or so ... I wake up tired sometimes, just tossing and turning.

According to recent clinical studies, irritability and insomnia highlighted in this extract are experienced by more than 30 per cent of hepatitis C patients in treatment (Fried, 2002). The lethargy and fatigue reported by this patient are also common. Although clinical studies that use quantitative measures of health-related quality of life report decrements in physical and psychological health among patients in treatment, such studies do not articulate the impact that these measured reductions have on individual lives. For example, scales that measure patients' energy levels demonstrate that fatigue is common among people in treatment, however patients' narratives enable a clearer understanding of the implications of fatigue and other side effects for overall quality of life, including one's capacity for employment.

Moving from the significant physical effects of treatment to the psychiatric, below a 54 year-old man reports on his experience of a 12-month regimen. He cites impacts of treatment, such as obsessive thoughts and anxiety, as sustained and increasingly severe over the duration of treatment.

After about three weeks [the treatment] really started to kick in and ... the first thing was just this runny nose and dry eyes. But the depression was the worst. I'd

never had depression in my life before ... this was really bad. I was at a point when I was cutting up some carrots one night and I thought 'Man, how easy for this blade to go straight through my fingers'. It frightened the shit out of me ... I couldn't get this thought out of my mind and that frightened me more than anything. Why do I feel like this? It ended up at the point where I went to see the psych at the hospital. He said 'Oh, that's part of [the treatment]' ... but the side effects did get worse progressively over the year ... As I was getting more and more used to the side effects, they did seem to diminish a little bit but it was only the fact that I was getting used to them ... I'd think 'Shit, I can't handle this stuff' ... the anxiety levels ... this stuff is heavy-duty anxiety.

The flu-like symptoms to which this patient referred are commonly reported side effects of interferon. Some patients experience these symptoms for the duration of treatment while others report a decline in severity as treatment progresses (Fried, 2002; Sievert, 2001). Similarly, depression is one of the most commonly reported psychiatric side effects of interferon-based treatments (Bonaccorso et al, 2002). While this man characterises his psychiatric symptoms as depression, and he states that he had never been depressed prior to treatment, the description contained in the extract suggests that he experienced a variety of psychiatric problems such as obsessional thoughts and generalised anxiety. These have also been reported in clinical studies of psychiatric side effects of interferon (Kraus et al, 2003). Importantly, the above extract suggests that future qualitative research should address the issue of diagnostic labelling and how psychiatric labels are understood by hepatitis C patients in the context of interferon-based treatments. Patients may lump a number of psychiatric side effects under the heading of depression, thereby contributing to an under-reporting of other treatment-induced mood disorders.

Several participants described psychiatric side effects in terms of 'a sensation' that built to a crescendo and moved beyond individuals' ability to withstand the effects. Below, a participant revealed his increasing sense of frustration at the psychotic symptoms he was experiencing. He regularly sought the assistance of a psychiatrist during treatment.

**Sometimes [the side effects] have been really bad and I had hectic times and I thought 'It's just another sensation. It's going to pass, it's not permanent' ... [I] tried to train my psyche 'It'll pass' .... I'd get to the point of frustration and think 'Oh, I can't be like this all the time. I'd better ring [the psychiatrist] and talk to him'. Get on the phone and ... mad stuff, completely irrational stuff.**

The occurrence of mood disorders during treatment, particularly endogenous depression, are the most common reasons given for discontinuation of interferon-based treatment (Sievert, 2001). Psychiatric symptoms have included suicidal ideation, and suicide has been documented among patients on interferon (Janssen, Brouwer, van der Mast & Schalm, 1994). The above extracts highlight the need for patients to access ongoing professional support to manage psychiatric side effects of interferon. The

routine occurrence of significant psychiatric side effects, underline the importance of counselling and related interventions in order to maximise adherence to treatment, and to improve patients' quality of life while in treatment. In areas where counselling and psychiatric services are easily accessible this may not present a problem. However in other less serviced communities, such as rural and regional areas, having limited or no access to psychiatric services while in treatment may be disadvantageous to treatment adherence, and in some instances life threatening.

Variability in reports of side effects is documented in the medical literature (Fried, 2002) and among the present study's participants. Most spoke of their treatment experience as arduous though in the following extract, a 35 year-old man reported that he had not experienced negative side effects. He believed that aspects of his health improved while he was in treatment. Yet in contradictory statements he reported experiencing treatment-related depression and aching joints.

**With the treatment, it does make some people depressed. It sometimes makes people sick but that never happened to me, but it made me feel more depressed than what I was ... I didn't get any side effects at all. You're supposed to get flu-like symptoms when you first start on it and that didn't happen. Probably a week later, I started getting a bit achy-jointed ... I haven't been sick since I've been on the treatment either. I haven't had the flu since I started. So I don't know if it's given me a better immunity system; I think it has.**

Here, side effects are characterised as physical symptoms of treatment. This suggests that people understand the term 'side effect' in diverse ways. This man does not consider his depression to be a side effect of treatment, even though he draws a causal link between the two. He attests to being 'more depressed' since commencing treatment, however he implies that treatment exacerbated a pre-existing disorder, rather than causing a novel side effect. As in a previous extract, this extract hints at the difficulty in accurately determining what it is that patients understand to be a side effect of treatment. Differences in patients' understandings of diagnostic categories and individual differences in attributions of cause and (side) effect may be uncovered through further qualitative research that explores hepatitis C patients' understandings of labels, such as 'depression' and 'side effect'. Many patients may not recognise the aetiology of bodily and emotional changes as the effect of their treatment.

Finally, a woman, 40, who had received two courses of interferon-based treatment approximately five years apart, summarised her most recent treatment experience. She had anticipated difficulties based on her first experience and devised several strategies, such as giving up work and joining a support group, to assist her in coping and adhering to her second round of treatment. While she was prepared, she alluded to the gruelling experience of others.

**Well, it was pretty intense .... I think it would have been impossible, working and being a mum, full-time. It was hard enough without having stuff like that. So I was**

prepared for it, if you like, and I did expect it to be more intense than it was because, by that time, I'd joined support groups with people who were in a similar situation. All these bloody horror stories were coming out ... some of the people were quite sick at different levels and things.

As this extract reveals, people develop individualised coping strategies that sometimes exist outside the gambit of clinical medicine. For patients with the means, this may be as fundamental as organising childcare and stopping work for the duration of treatment. For others, joining a support group may be an option however more innovative strategies need to be identified. Many participants in this study referred to measures they took to calm the effects of their treatment. Some of these involved changes to lifestyle, the use of prescription medication and counselling, or a combination of several measures. Certainly, the range and severity of side effects described in this article indicate the need for further detailed qualitative investigation of their impacts, including a review of the strategies that some patients use to cope.

## DISCUSSION

There are several methodological limitations to consider when interpreting the results of this study. Firstly, because of the sample size and method of recruitment, the study's findings do not represent all hepatitis C patients' experiences of treatment. There are likely to be many more diverse experiences of side effects than those represented in this study and in the medical literature. Secondly, it is possible that the findings were biased by the method of recruitment and data collection. While there is a chance that we only recruited people who had bad experiences of treatment, this is unlikely as the survey form and participant information sheet explained that the aim of the study was to find out what life was like for people with hepatitis C. There was no mention of treatment during the recruitment process as it was only one part of a broad ranging investigation into living with hepatitis C. People unhappy about their treatment experience or health service providers could not have known that the interview aimed to discuss treatment-related issues. There are possibly many reasons for why people volunteered to be interviewed. For some people the invitation to participate presented a novel opportunity to be part of a social study about living with hepatitis C.

Another limitation of our study's findings was a reliance on self reports of treatment experiences. Participants' recollections of their treatment experiences are subject to the distortions of memory and this factor might have influenced our participants' narratives regarding treatment side effects. However of the six participants who had experienced treatment, four were in treatment at the time of the interview and recounted treatment experiences that had occurred within weeks of the interview, making it unlikely that memory and its frailty significantly biased the study's findings.

While acknowledging the limitations, this study enabled an insight into some people's experiences of side effects from interferon-based treatments. Participants reported a range of significant physical and psychiatric adverse events, including depression, anxiety, impacts on heart function, migraine, myalgia, headache, insomnia and fatigue. At times these were severe enough to affect patients' physical health, emotional stability and capacity to function normally. Future research using diverse samples should aim to document in greater detail the range of side effects of treatment and their impacts. The reductions in physical and psychological health as measured by quantitative instruments and reported in the nascent medical literature about side effects, are given broader meaning through research that utilises patients' narratives.

Clinicians and patients would benefit from the emergence of a critical and reflexive literature regarding quality of life for hepatitis C patients in treatment. In recent years a burgeoning qualitative literature about HIV treatments, including the impact of side effects on adherence has emerged (Race and Wakeford, 2000). While reports of side effects from highly active antiretroviral therapy (HAART) for HIV vary between patients and the range of drugs prescribed (Montessori, Press, Harris, Akagi and Montaner, 2004), many HIV patients report similar unwanted effects from treatment as those discussed by hepatitis C patients in this article. Side effects can negatively affect HIV patients' quality of life (Baer and Roberts, 2002). Some side effects persist throughout treatment while others are transient. Similarly, participants in the present study reported both persistent and transient side effects from interferon. However unlike HIV infection, treatments for hepatitis C are administered for a finite period, and once the treatment stops the side effects eventually subside. Whereas, a HIV-positive patient with an undetectable viral load may be advised to remain on HAART indefinitely (Persson, 2004).

People in treatment often experience difficulty adhering to therapy because of side effects. Non-adherence compromises the efficacy of drugs to suppress or eradicate viral replication and this is a significant factor in the failure of treatment for both hepatitis C (Fried, 2002) and HIV infection (Montessori et al, 2004). Interestingly, in the present study there was some evidence of participants deploying individually devised and tailored coping strategies in order to continue with treatment. The contribution these make to treatment adherence and quality of life require further detailed investigation.

The issue of side effects will remain salient over the foreseeable future. In writing about the latest treatment, hepatologist Michael Fried states that: 'All patients treated with peginterferon and ribavirin will experience some adverse events during therapy' (Fried, 2002, S243). When compared with unmodified interferon, some studies suggest similar tolerability of pegylated interferon (Fried, 2002; Rasenack et al., 2003) however one study has reported a higher frequency of some side effects from this new treatment (Manns et al., 2001). Yet this latest regimen may be the means by which health systems can prevent large numbers of people from living and dying with chronic liver diseases. The improved cure rate of the new treatment and the recent

changes to inclusion criteria has paved the way for more people in Australia to access hepatitis C treatment. Given these developments, more people will be exposed to side effects, which if not managed properly will result in dose reductions and treatment discontinuations. There is now, more than ever, an imperative to understand and ameliorate patients' experience of treatment.

Qualitative research can uncover how people cope with treatment-related side effects and what impacts these have on quality of life and treatment adherence. We know from previous research that narratives of chronic illness have assisted many people, including clinicians, in coming to terms with disease, its treatment and associated life upheaval (Kleinman, 1988). A focus on hepatitis C patients' narratives now could significantly improve our understanding of the impact of side effects for those undergoing future interferon-based treatments.



## CHAPTER 6

Health professionals' perspectives  
on hepatitis C treatment

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## INTRODUCTION

Globally 170 million people are estimated to be infected with the hepatitis C virus and between 3 and 4 million persons are newly infected each year (St. John & Sandt, 2005). Treatment for hepatitis C virus infection usually combines anti-viral agents interferon and ribavirin. The regimen is self-administered for 24 or 48 weeks depending upon factors such as viral genotype. The clinical literature reports a raft of physical and psychiatric impacts of interferon and ribavirin, including fatigue and major depression which can significantly reduce patients' social, physical and mental functioning and necessitate dose reduction and treatment discontinuation (e.g. Dieperink et al., 2003). In an effort to ameliorate adverse events and to maximise therapeutic efficacy, treatment is managed by a multi-disciplinary team of specialist physicians, nurses, psychiatrists, psychologists and social workers (Leone, 2002; Strinko et al., 2004; Potgieter et al., 2005). According to the limited amount of literature available, a deficits-based approach to therapy is deployed whereby minor treatment-related impacts are anticipated and preventative measures are taken while serious adverse events are addressed as they occur (Leone, 2002; Australian National Council on AIDS, Hepatitis C and Related Diseases, 2003; Strinko et al., 2004). Leone (2002), and Strinko and colleagues (2004), report that the key to successful completion of hepatitis C treatment resides in patient education and frequent patient and nurse interaction during therapy. Pre-treatment interviews are reportedly an opportunity to inform patients about the side effects of treatment and frequent scheduled meetings during treatment facilitate management of adverse events and contribute to adherence and completion. Nonetheless, high rates of dose reduction and treatment discontinuation due to adverse events are evident in large scale randomised clinical trials around the world (e.g. Bernstein et al., 2001; Potgieter et al., 2005).

Historically there has been an emphasis on deficit-based models in the field of mental health where attention has focused on maladjustment and treating problems after they have manifested (Tedeschi & Kilmer, 2005). However in recent years there has been a growing interest in the factors which contribute to the development of adaptive outcomes among people who are exposed to a range of adverse circumstances (e.g. Masten, 2001; Tedeschi & Kilmer, 2005). Research into the development of competence, wellness enhancement, human strengths and growth is burgeoning. This work refers to a psychosocial construct known as 'resilience': a common phenomenon which describes a process that is inferred from the coexisting conditions of risk and positive outcomes (Masten, 2001). According to this literature, resilience is facilitated by utilising protective factors and processes, which include having competent and caring adults in the family, having access to supportive community networks, being able to successfully negotiate social services, and feeling self-confident and optimistic (Bonanno, 2004; Luthar, 2003; Masten, 2001). Emerging from this past research is a framework for evaluating and fostering resilience called strengths-based assessment. Strengths-based assessment appraises an individual's capacity for actively seeking help, while identifying and lessening systemic social impediments to positive adjustment. Epstein and Sharma (1998, p.3) define strengths-based assessment as 'the

measurement of emotional and behavioral skills, competencies and characteristics that create a sense of personal accomplishment; contribute to satisfying relationships with family members, peers and adults; enhance one's ability to deal with adversity and stress; and promote one's personal, social and academic development'. Helpful and protective influences (i.e. strengths) are drawn from multiple levels of an individual's context (Bonanno, 2004; Newman, 2005; Tedeschi & Kilmer, 2005). This approach to assessment aims to produce a detailed picture of the quantity and quality of people's resources and supports (Epstein et al., 1998) and identifies and measures the protective factors and processes which are available to individuals from within their personal networks and communities, including people's own emotional and behavioral skills (Tedeschi & Kilmer, 2005). When drawn together these factors and processes can augment an individual's ability to cope under extremely difficult conditions (Bonanno, 2004).

The focus of this article is on health professionals' preparation and management of patients receiving hepatitis C treatment. A method to reduce treatment discontinuation may be suggested by understanding the current approach to patient preparation and management, and situating this within the literature on stress and resilient coping.

## METHOD

### Aims

(i) To report findings from a study of hepatitis C treatment experiences that address the research question 'How do health professionals prepare patients for hepatitis C treatment?'; (ii) To identify and describe the management strategy used by health professionals in this study during hepatitis C treatment.

Semi-structured in-depth interviews were conducted in Sydney, Australia during 2004 and 2005 to explore preparation and management of hepatitis C treatment. As the standard of knowledge in the area of the research question is poor, an exploratory qualitative research design is appropriate.

### Participants

Three treatment facilities situated in major metropolitan hospitals across inner-Sydney were identified as sites where large clinical trials of viral hepatitis treatment occurred. Although spatially close together, anecdotal evidence indicated that these sites serviced several distinct ethnic and sub-cultural communities. A diverse range of health professionals was sought for participation in this study. A theoretical sampling frame

Table 9 Participant profiles

<b>Participants<sup>1</sup></b>	<b>Professional Background</b>	<b>Professional Interests</b>
HP-1	14 years' experience in gastroenterology and viral hepatitis	Health of marginalised populations
HP-2	9 years' experience in HCV treatments <sup>2</sup>	Discrimination in healthcare
HP-3	5 years' experience in HCV treatments	Health promotion education
HP-4	6.5 years' experience in HCV treatments	Health of marginalised populations
HP-5	8.5 years' experience in HCV treatments	HCV-related discrimination
HP-6	20 years' experience in HIV and HCV-related counseling	Health of marginalised populations

<sup>1</sup> Health Professionals (HP)

<sup>2</sup> HCV (Hepatitis C Virus)

was used to guide recruitment and initial participants were chosen on the basis of their expertise in the administration of hepatitis C treatment. Nurses (i.e. clinical nurse consultants) from two of the treatment facilities were contacted via telephone. Three nurses agreed to participate and facilitated recruitment of one more nurse by seeking volunteers through their professional networks. Simultaneously, two participants responded to a study advertisement placed on an email list for health professionals in viral hepatitis which sought participation from workers employed at the remaining site. Overall, two health professionals from each of the three sites were recruited.

All six participants had extensive experience in hepatitis C health service delivery (see Table 9). One participant, a social worker was recruited to discuss the impact of social variables like hepatitis C-related discrimination on the treatment experience. While specialist physicians such as gastroenterologists and hepatologists were approached, all declined to participate in the study.

### Data collection

A semi-structured interview schedule was used to explore: pre-hepatitis C treatment assessment procedures and interviews; management of the therapeutic regimen; and hepatitis C-related stigma and discrimination (Table 10). The question areas contained within the interview schedule were developed from (i) a review of the clinical litera-

Table 10 Extract from health professionals' interview schedule

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### **1. Treatment preparation and management**

- Please describe pre-Rx counselling for patients going into hepatitis C Rx?
- Are there strategies that health professionals use to prepare patients for Rx? If so, what are they?
- With regards to Rx side-effects, can you anticipate or predict which patients are going to experience problems while on Rx and which are not?
  - If so, explore the ways health professionals feel they can tell.
- What are the most commonly reported side-effects of pegylated interferon Rx that you see?
  - Explore side-effects in detail.
- How do health professionals assist patients in coping with side-effects from Rx?
  - Explore in detail the use of drug therapies and psychological therapies.
- To what degree do health professionals rely on clinical markers to assess a patient's report of side-effects from Rx?
- What effect has dose-reduction on side-effects?
  - Discuss implications of early versus late dose reduction for adherence, reducing side-effects and attaining a SVR.
- What are the implications for patients who discontinue Rx due to side-effects?
- What are the implications for patients deemed 'non-responders'?
- What process occurs following completion of Rx?

### **2. HCV Stigma and discrimination**

- What advice do you give to patients going into Rx about issues of disclosure and hepatitis C-related stigma and discrimination?
- Why do you think these patients experience stigma or discrimination?
- What impact on Rx outcomes does stigma and discrimination have?
- What can be done to ameliorate hepatitis C-related stigma and discrimination within the healthcare sector?

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SVR = Sustained Virological Response. A SVR is attained when a polymerase chain reaction test (a process which amplifies pieces of the genetic make-up of a cell or virus in order to detect its presence) at six months post completion of treatment reveals an undetectable viral load for HCV. In such instances, one is deemed to be cured of HCV infection.

ture pertaining to hepatitis C treatment, and (ii) a series of interviews conducted during 2001 and 2002 with people who were receiving treatment (Hopwood and Treloar, 2005). Interviews lasted for between 30 and 60 minutes. The semi-structured format of the interview schedule enabled participants to elaborate on the question areas.

## Ethical considerations

Researchers were mindful of participants' workloads and the need to collect data at a time suitable to participants. The interviews commenced after participants read a study information statement and written informed consent was obtained. Confidentiality and anonymity were assured and have been maintained through de-identifying transcripts and assigning coded identifiers to each participant. Ethics approval for this study was granted from the Human Research Ethics Committee of the University of New South Wales, three area health service ethics committees and one hospital ethics committee.

## Data analysis

The data were analysed using thematic content analysis (Grbich, 1999; Minichiello, et al., 2000). Data analysis followed the transcription of audio-taped interviews. After repeated and close reading of the interview transcripts the authors independently constructed a code list of major themes that emerged. The authors compared coding decisions and revisited transcripts when a difference between authors' coding was identified, and any divergence was discussed until a consensus was reached. The de-identified interview transcripts were then entered into qualitative software and codes were applied to the text. This article focuses on the sections of the interview schedule (and coding list) relating to two question areas: 'information pre-treatment' and 'side effects/adverse events' in order to answer the main research question. 'Information pre-treatment' refers to information and advice given to patients about issues pertaining to treatment preparation. The questions about side effects aimed to document adverse events and explore how they were managed. The semi-structured nature of interviews enabled associated phenomena to surface. It was in this way that resilience was identified throughout participants' narratives regarding their patients' past experiences of hardship. Finally, although this study generated a small number of transcripts for analysis, theoretical sampling by nature does not encourage large samples (Minichiello, et al., 2000). During data collection it became evident that a saturation of themes was quickly obtained and we decided against further recruitment.

## RESULTS

### Pre-treatment assessment interviews

Participants reported that pre-treatment assessment interviews enabled clinicians to establish an empathic, reassuring relationship with new patients. These meetings provided an opportunity to inform patients about treatment-related adverse events and the medical interventions that could assist to ameliorate their impact.

[I] just talk to [patients] about what their expectation of treatment might be, what are the possible side effects that may affect them. I suppose you don't want to scare people completely with this but to be honest it is really important ... (HP-3)

Certainly allowing preparation time for treatment can have a huge benefit ... [L]istening, validating, being organised, being professional, making it aware that there's an excellent communication amongst the team here. Teamwork is imperative ... Communication is vital. Empathy is useful. (HP-5)

Participants reported that pre-treatment assessment interviews aimed to assure patients that they would be supported by a team of clinicians throughout their treatment.

I think [patients] need to know that they can contact you at any stage, that these side effects are very real, they're very predictable, that they are the norm and it's just a matter of letting us know and working out a plan of action so that they are able to cope with it. (HP-1)

And it's a big help for [patients] too to know that we've got a dietitian, counselors, we've got a psychologist, psychiatrist, the nurses are here, you know, to give reassurance; to be realistic but to reassure as well and making them fully aware of what they're entering into ... (HP-4)

These interviews also aimed to assess a patient's vulnerability to adverse events. For example, participants worked with patients identified as having a history of drug dependence:

[I]t brings up a lot of issues being on treatment, a lot of stuff around needles ... I mean, you're injecting yourself every week and often, for a lot of people ... there are lots and lots of work that needs to be done on that before people are presented with their dose and we say "Go stick this in your stomach or the top of your thigh" ... (HP-6)

The preparation stage provided clinicians with an opportunity to identify people in a patient's network who might provide support during treatment, and to plan for situations where patients' had not disclosed hepatitis C treatment, such as the workplace. Participants' concern was that patients have some support from outside the clinic if and when crises occurred during treatment:

Also, telling [patients] to perhaps inform their next-of-kin or their significant others and close people around them [about their treatment] so that they can gather as much support as they possibly can so, if they do run into problems on treatment, there's some back-up there for them. (HP-2)

In addition to building rapport, providing treatment-related information, and enquiring into support the following extracts highlighted two health professionals'

approaches to assessing patients in order to implement effective coping strategies if the side effects of treatment necessitated interventions beyond the common medical and personal strategies. The first quote is appealing to patients to consider making contingency plans in case of emergencies, and to prepare for future problems by focusing on adaptive strategies learned from their past.

We try and talk about those things in depth before they go on treatment. “What are you going to do?” or “If this happens to you when you’re on treatment ...” and this is why I try to talk to patients a whole lot about, things about what makes them tick, what keeps them going, what do they enjoy doing, what are the fun things in their life? So that I know, when they’re having those patches that “These are the things we talked about in the past that you said make you feel better, so why don’t we try doing those things?” So really trying to get them thinking about what keeps them going now so that we’ve got a point of reference to refer back to ... (HP-1)

Finally, when a context such as the workplace was identified as a potential source of isolation and stress during treatment, one health professional’s approach was to focus on identifying other areas in a patient’s life where support could be increased in an attempt to offset the total weight of burden.

So what we will try to do if people really thought they couldn’t disclose at work and that it was really unsafe, we’d say “OK, well what else can you lighten up in your life? What can you do with your weekends? How can you make your nights more relaxed? Are there other people that will support you in the community - friends, family - who will perhaps cook a meal for you once or twice a week if you’re feeling run down?” You know, get your help happening, mobilise your forces. (HP-6)

In summary, pre-treatment assessment interviews centred on treatment-related information provision. This is consistent with reports by Leone (2002) and Strinko and colleagues (2004). Efforts were made to assess patients’ vulnerabilities and supports, and to address patients’ concerns regarding disclosing being in treatment. However health professionals’ assumptions that appropriate support will flow from disclosure of being in treatment has been described as problematic (Hopwood et al., 2006). Reportedly, the quality of support from family members following disclosure is at times poor and can exacerbate patients’ efforts to cope during treatment.

These data highlight a predominantly deficits-based approach to managing treatment; that is, while trying to anticipate and prevent minor or pre-existing problems, in the main clinicians planned to respond to crises once they had manifest. Nonetheless, these narratives reveal an intuition on the part of some health professionals to identify patients’ strengths during pre-treatment interviews in order to address treatment-related emergencies and to prevent further crises from developing.

## Patient resilience and treatment management

Participants commented on some patients' adeptness at drawing on strengths garnered from past experiences of adversity in order to cope with treatment-related adverse events. In the following extracts, nurses referred to their patients' past circumstances as contexts that galvanised individual strengths and facilitated the development of adaptive coping strategies:

... [S]ome [patients] are more resilient because they say "I've been through everything in life" or "Life's thrown everything at me. Well, I'll be fine" but some are really resilient like that and will tend to draw on services a lot more to help them through [treatment] ... (HP-4)

Oh, I think a lot of coping strategies that patients use do work for a great proportion of them ... [Y]eah, they tell me different things about how they manage ... so we talk about what they did in the past when they had some bad times ... (HP-2)

Participants noted variation in patients' resilient coping. They reported that some patients like those who had emigrated from developing countries, coped well with hepatitis C treatment and were able to successfully incorporate past responses to hardship to lessen the impacts of treatment:

[M]y experience with patients [who have come from developing countries] ... they're just more accepting that ... "Well, this is the treatment, this is a side effect, this is what I've got to do to get rid of it" ... Maybe it's their life experiences so that this [treatment] for them, is a piece of cake ... (HP-1)

[Coping with treatment] can be hard but it really just depends on the person, the coping strategies they've always had in life and what their lot is now and how much they have to juggle and what physical and mental resources they have ... (HP-5)

Similarly, it was reported that people who had prior experience with complex treatment regimens for other chronic illness coped better with the hepatitis C treatment regimen:

... [Also] patients who've had a history of depression and may have had antidepressants ... seem to cope a lot better with the mood fluctuations [associated with interferon-based treatments]. And I think that's just because they've already got those coping mechanisms there ... They know what to do, they're not frightened to put their hand up and they will seek assistance ... (HP-1)

... [T]he co-infected guys with HIV and hep C - the gay population - they're totally different because a lot of them have already been exposed to having to be in a routine to take the antiretrovirals and they have already had to take notice of their

**lifestyle and their blood counts and all of that ... And they're very, very organised. They plan everything ... so they cope with side effects a lot better because they are more organised. (HP-4)**

Participants acknowledged a relationship between their patients' prior experiences of adversity, including coping with chronic illness, and present resilient coping strategies. Given that many people with hepatitis C infection in Australia and other developed nations come from socially and economically disadvantaged backgrounds, this association might have significant implications for improving adherence and the likelihood of treatment completion.

## DISCUSSION

The above findings are from a qualitative study that was exploratory, descriptive and limited in generalisability, and there are several limitations to this study. First, there is a risk that because the research explored clinical practice, participants may have given socially desirable and selective responses during interviews to establish their exactitude and professionalism. Second, there is some minor variation in the shared-care models available for treatment provision in Australia, and health professionals in other hepatitis C treatment facilities might apply a slightly different approach to management than was evident in this study. Finally, and related to the above point the study's sample was small and geographically focused. The three hospitals and the six health professionals comprised a homogeneous group therefore a saturation of themes was obtained quickly from this sample. Without greater diversity in the sample, it was not possible to explore a range of treatment-related issues. Nonetheless, our participants were experienced clinicians who collectively had spent many years managing hepatitis C treatments. There was broad agreement among them of the approach taken to treatment preparation and management. Similarly, there was agreement regarding participants' impressions of their patients in relation to coping styles and support needs. Further research will overcome some of the limitations evident in this study.

These findings show that a deficits-based approach to treatment preparation and management is applied at these facilities, and that pre-treatment interviews are primarily opportunities for giving new and prospective patients (i) information regarding the side effects of treatment, (ii) information about the medical and personal strategies to ameliorate the impact of side effects (iii) reassurance that patients would be supported if and when problems occur, (iv) advice on to whom patients should disclose that they are receiving treatment, and (v) an assessment of a patient's risks during treatment. These findings accord with Leone (2002) and Strinko et al. (2004), who emphasised the importance of comprehensive nursing support.

Viewing these data through the psychosocial framework of resilience (Masten, 2001), hepatitis C treatment dose reductions and discontinuations might be minimised by incorporating a strengths-based approach to treatment preparation and management. Health professionals' acknowledged in this study that patients' past experiences of social and economic marginalisation and earlier experiences of chronic illness could assist them to cope with treatment side effects. Some patients reportedly drew upon resources from their community and successfully applied previously utilised adaptive coping strategies during their hepatitis C treatment regimen. These findings accord with previous work from developmental psychology into resilience where coping was enhanced among some people routinely exposed to hardship. However our health professionals did not systematically evaluate or exploit these contributions to coping with treatment. While they attempted to 'mobilise [patient] forces' by identifying patients' opportunities for support, salient risk factors, and problems with disclosure, their approaches were not embedded within a theoretical framework of resilience and strengths-based assessment. Health professionals' practices of making contingency plans, finding out what made 'a patient tick' and trying to strategise around disclosing reflected an informal and intuitive approach to reducing the impact of treatment-related problems. On the other hand, a systematic strengths-based assessment procedure could uncover individuals' prior coping strategies and accessible human and material resources. Such an approach could be evaluated in a randomised control trial (Luthar & Cicchetti, 2000) for its contribution to preventing the occurrence of problems, improving treatment adherence and facilitating completion. Validated assessment instruments (e.g. Moos et al., 1994), or qualitative checklists and interviews (Tedeschi et al., 2005) might help clinicians to assess patient dynamics, like family environment, which are associated with positive adjustment to adverse circumstances. Through a detailed assessment of patients' strengths health professionals might assist individuals to identify and utilise elements which facilitate enhanced adaptation to hepatitis C treatment.

## CONCLUSION

Data from this study are relevant to many professionals working in hepatitis C treatment facilities around the world. Our findings concur with literature which describes the human capacity to cope and thrive during extreme hardship. Linking our participants' observations with this literature, strengths-based assessment should be investigated for its utility in complementing current methods of pre-treatment assessment. Patients can be assisted by acknowledging their agency as effective social beings with resources and abilities that can help them complete this arduous treatment regimen. Further research is recommended to understand the contribution strengths-based assessment might make to minimising dose reduction and treatment discontinuation.



## CHAPTER 7

Illicit drug use during  
hepatitis C treatment

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Injecting and other illicit drug use  
during treatment for hepatitis C infection.  
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## INTRODUCTION

The hepatitis C virus epidemic thrives within a global legislative context of drug prohibition, and the laws governing which substances citizens can imbibe have a pernicious influence on the experience of healthcare for many affected people. Health systems today increasingly come into contact with illicit drug users seeking testing and treatment for blood-borne viral infections. However there is scant discussion of illicit drug use whilst undergoing anti-viral therapies in the medical literature. Often, the stigma of illicit drug use, the pleasurable qualities of drugs, and the rules and conventions of medical practice intersect in the bodies of those receiving treatment for hepatitis C infection. This article reports on the awkward negotiation that ensues from this overlap within the clinic, from the perspective of one group of health professionals.

Within HIV/AIDS research, clinicians commonly see current illicit drug use as a barrier to commencing treatment for HIV infection (Clarke and Mulcahy, 2000; Malow, et al., 1998; Bangsberg, Tulskey, and Hecht, 1997; Vlahov and Celentano, 2006) and people who inject are often not encouraged to access treatment for HIV if they are not enrolled in alcohol or other drug treatment programmes (Strathdee, et al., 2003). There is a clear message in this literature that substance 'abusers' are problematic: they present an increased risk for elevated rates of HIV disease progression, they have a greater need for medical services, they can not be relied on to adhere to therapy and they are more likely to develop viral resistance to therapeutic drugs than people who do not inject (Malone and Osborne, 2000; Wood, et al., 2003). Reportedly, the effects of illicit drugs lead to sedation, euphoria and agitation; which contribute to unreliable, non-adherent behaviour, unsafe sex, disinhibition and poor judgement (Malone and Osborne, 2000; Avants, Margolin, Warburton, Hawkins, & Shi, 2001). According to this perspective, people who use illicit drugs inevitably become addicted and their focus becomes the procurement of drugs at the expense of all other concerns. The goal of clinicians is to stop people using illicit drugs before they can proceed to HIV treatment, or otherwise devise interventions such as daily dosing supervision to improve adherence (Altice, et al., 2004; Wood, et al., 2003).

In the context of treatment for hepatitis C infection, similar fears are expressed: reportedly, most US physicians withhold hepatitis C treatment from current users because it is considered that a person's illicit drug use poses a greater short-term threat to their health than hepatitis C infection (Dalgard, 2005; Davis and Rodrigue, 2001; Sylvestre, 2006). Injecting drug users are seen as problematic because they experience mood and anxiety disorders, cognitive deficits, temperament disorders, and personality vulnerabilities (Scheft and Fontenette, 2005). Studies report that current users are at an increased risk of negative side effects from hepatitis C treatment, they have poorer adherence to treatment than non-users, current users are more likely to discontinue treatment or have their doses reduced leading to poorer therapeutic outcomes, they often drink alcohol at higher rates which reduces the efficacy of interferon, they are believed to be at increased risk of re-infection after treatment, and there is little evidence regarding the efficacy of therapy among current users (Dalgard,

2005; Davis and Rodrigue, 2001; Jowett, et al., 2001; Robaey, et al., 2006). However findings are mixed regarding current injecting and adherence to hepatitis C regimens. According to some research the biggest barrier for physicians in prescribing hepatitis C treatment to current users is a perception that users will not adhere to treatment (Edlin, et al., 2001; Sylvestre, 2006). A growing number of studies indicate that current injecting drug use during treatment for hepatitis C infection may not be as problematic as some commentators have reported, especially when social support is available (Scheft and Fontenette, 2005; Robaey, et al., 2006). It is difficult to generalise about injecting drug users with regards to suitability for hepatitis C treatment as they are a varied group in relation to the type of drugs used, how much is used and how often, and there are differences in levels of dependency and the stability of their lives, as well as other variable factors which impact on treatment, like access to support (Edlin, et al., 2001).

Much remains unknown about people's use of illicit drugs during hepatitis C treatment. The silence on this issue in the clinical literature is palpable. The aim of this article is to report findings from a recent exploratory qualitative study that investigated a group of health professionals' perspectives on patients' use of illicit drugs during hepatitis C treatment. These workers' narratives indicate that further research is needed to understand the phenomenon of illicit drug use during hepatitis C treatment, including the risks and benefits for patients.

## METHOD

### Participants and procedure

Semi structured, in-depth interviews were conducted in Sydney, Australia during 2004 and 2005 to explore management of hepatitis C treatment. Three treatment facilities situated in major metropolitan hospitals across inner-Sydney were identified as sites where large clinical trials of viral hepatitis treatment occurred. Three clinical nurse consultants were contacted via telephone and agreed to participate in the study. These participants facilitated recruitment of one more nurse by contacting others in their professional networks. Simultaneously, a fifth nurse and a social worker responded to a study advertisement placed on an email list for health professionals in viral hepatitis which sought participation from workers employed at the remaining site. Overall, two health professionals from each of the three sites were recruited and these interviews constitute the data reported in this article. All health professionals had extensive experience in hepatitis C health service delivery. A social worker was recruited to discuss the impact of social-contextual variables on the treatment experience. Participants had a mix of post-graduate qualifications, undergraduate degrees and hospital training. The nurses had managed hepatitis C treatment regimens for between 5 and 14

years. The social worker had 20 years experience in HIV and hepatitis C counselling. All participants expressed a strong professional commitment to the health of marginalised populations and to combating discrimination within healthcare. We attempted to recruit specialist physicians involved in the administration of hepatitis C treatment however due to work commitments they were unable to participate.

In addition, a total of twenty participants who were receiving treatment for hepatitis C infection were recruited from across the three treatment facilities. Most participants receiving treatment in our sample reported medically acquired hepatitis C infection and reported no history of illicit drug use. None of these participants volunteered information about current injecting or other illicit drug use during interviews and we did not enquire into current drug use. Health professionals were interviewed toward the conclusion of data collection and it was then that the issue of patients' use of illicit drugs was raised.

### Data collection and analysis

The interviews commenced after participants read a study information statement and written informed consent was obtained. Confidentiality and anonymity were assured and have been maintained by de-identifying transcripts and assigning coded identifiers to each participant. A semi-structured interview schedule was used to explore management of the therapeutic regimen, and clinician and patient strategies to reduce the occurrence of adverse events during treatment. Interviews lasted for between 30 and 60 minutes. Data analysis followed the transcription of audio-taped interviews. After repeated and close reading of the interview transcripts the authors independently constructed a code list of major themes that emerged. The authors compared coding decisions and revisited transcripts when a difference between authors' coding was identified, and any divergence was discussed until a consensus was reached. The de-identified interview transcripts were then entered into qualitative software and codes were applied to the text. Salient allusions to the factors and processes which participants reported to assist coping during hepatitis C treatment were examined and collated.

One of the strengths of qualitative methods is they enable phenomenon not directly under investigation to surface in the course of a study, which facilitates the generation of new hypotheses for testing in future studies. One such factor which all health professionals commented on was patients' use of illicit drugs during treatment. The themes to emerge from health professionals' discussion of this issue included (i) illicit drug use and healthcare settings; (ii) omitting selected clinical information; (iii) injecting drug use and hepatitis C treatment; and (iv) the medicinal use of cannabis. These issues constitute the focus of this article.

Ethics approval for this study was granted from the Human Research Ethics Committee of the University of New South Wales, three Area Health Service ethics committees and one hospital ethics committee.

## RESULTS

### Illicit drug use and healthcare settings

In Australia, the medical profession is regarded as having conservative views about illicit drug use (Anti-Discrimination Board of NSW, 2001). According to some commentators, conservatives are less willing to accept change and are more likely to react negatively to people who represent difference (Kerlinger, 1984; Wilson, 1973), like illicit drug users. Indeed, during the twentieth century science and medicine redefined drug addiction as a disease (Acker, 1993), and today medical practitioners remain largely resistant to the notion of harmless, recreational, non-dependent injecting and other illicit drug use (Anti-Discrimination Board of NSW, 2001). This view is reinforced by decades of anti drug messages and the explicit demonisation of drug users; elements integral to the prohibition message (Gilmore, 1996; Levine, 2003). Prohibition positions drug users as self-indulgent, addicted, lacking social worth, weak willed, criminal, and a danger to the community because they are likely to spread their negative characteristics to others. This seems especially true if the drug user comes from a poor socio-economic background and injects heroin (Acker, 1993; Jones, 1984). Participants in our study discussed health professionals' conservative mainstream values regarding illicit drug users and the impact that these attitudes had on their management of hepatitis C treatment. This sample of health professionals juxtaposed the life experiences and the conservative attitudes of their work colleagues in liver clinics against street-savvy, tolerant workers employed by inner-urban health services for injecting drug users. Below, a social worker discussed her experience of employment in a medical setting where illicit drug use in patients is not accommodated instead it is seen as transgressing accepted health values.

... [T]his [hospital] is a very conservative environment ... [T]his clinic, yes, is very, very, very conservative. The doctors here are really nice doctors but they're conservative about drug use ... [I]t's a really conservative environment ... So [working in this clinic] is a lot about working through that stuff. (HP-6)

Nurses and social workers shared the care of patients on hepatitis C treatment with specialist physicians, psychiatrists and psychologists. In this context, 'working through that stuff' meant that social workers and nurses would have to routinely advocate for people seeking treatment in order that they be considered ready by specialist physicians. Only after careful negotiation with specialist physicians about the nurses' and social workers' capacity to manage patients with a recent history of injecting and other illicit drug use would some people be allowed to commence treatment:

Well, patient advocacy is enormous. You may well have to lobby strongly for some people ... (HP-5)

A government enquiry reported that illicit drug using patients were considered less deserving of medical treatment because medical practitioners believed they were

responsible for their own ill health (Anti-Discrimination Board of New South Wales, 2001). According to the health professionals that we interviewed, doctors and nurses working in mainstream health settings held similar views. They were characterised as intolerant of illicit drug use, ill-informed about drug-related issues and resistant to changing their views about illicit drug users. They reported that any illicit drug use was understood as ‘excessive’ and problematic by most health professionals.

### Omitting selected clinical information: Secret nurses’ business

Nurses and social workers reportedly developed close relationships with patients throughout their treatment regimen, seeing them on at least a weekly basis over many months. This proximity helped create a rapport where frank and honest disclosure around injecting and other illicit drug use was expected. As one health professional stated:

**People aren’t going to be thrown off treatment if they inject drugs, but we need to know, we need to see that what their bloods are telling us, their mouths are telling us. (HP-6)**

However it was reported that patient information regarding illicit drug use was best kept from the attention of some health professionals under the shared-care model. For example, specialist physicians were characterised by both patients and nurses as primarily interested in clinical markers; they were reported to lack empathy with patients’ drug use, and were concerned about treating viral infections rather than engaging with patients’ quality of life issues. In our sample, health professionals reported that they omitted information about patients’ illicit drug use during treatment if they considered that it was tangential to clinical care. This information was not made available to the specialist physician, and patients were advised against disclosing their illicit drug use to specialist physicians. As one health professional stated:

**There are certainly people who have got through this treatment and have used heroin through it, and that’s okay. But what I would say to them is “Down-play that stuff when you talk to the doctor. Talk about it openly when you talk to us”. And that’s because, I don’t think that that needs to be written in their hospital notes, unless it’s impacting on their treatment. (HP-6)**

Information about injecting and other illicit drug use during hepatitis C treatment was reportedly carefully managed and information management was a process conducted by some nurses and social workers in order to construct a patient that conformed to the norms of mainstream clinical medicine, and palatable to specialist physicians. Omitting information about a patient’s illicit drug use removed the chance that a specialist might react negatively, making treatment more difficult for a patient.

## Injecting drug use and HCV treatment

Since May 2001 current injecting drug users have had the same entitlement to access subsidised hepatitis C treatment through the Australian Government's Pharmaceutical Benefits Scheme S100 prescriptions category as people who do not inject drugs. Since then, enough time has passed for some current injectors to access treatment and anecdotal evidence to emerge in relation to injecting and adherence, drug interactions and treatment efficacy. All health professionals interviewed for this study reported from their experience that given the right management and care, current injecting drug users were suitable candidates for hepatitis C treatment. But they cautioned that careful pre-treatment assessments are needed to ensure that current users are appropriately prepared for treatment:

... [B]efore you put patients who are injecting onto treatment, there is a decision about whether they're ready. I think you'd be silly to try and put somebody who was totally chaotic on to treatment because you'd be setting them up for failure and that's not what this is about ... Obviously [some current injecting drug users] are not ready for treatment ... it's just that, at their time point, they have other priorities and that may be accommodation, food or whatever ... (HP-1)

That's really useful to see [current users] a month or two at the least before they're going to start [treatment] because, depending on their existing personal circumstances; whether they are working, their family, their various social commitments, there are some very useful tactics they can take. (HP 5)

According to our sample of health professionals, the key to successfully treating current users is to have them contain their frequency of injecting:

[T]here are a couple of people we have that have used via injecting equipment all the way through their treatment, socially or irregularly, which means less than once every two weeks, okay. So once every two weeks they might go out and use but that's it; so that's their level of dependency, while being on methadone or something like that as well. That tends to be manageable enough. (HP-6)

... [W]e've got one guy, he injects probably once a week and he comes for his appointments. You know, he's a long-term user and probably will be, you know, he's not trying to work towards not using, that's just part of his life. I think it is important that people like him manage to access treatment, that it's not an exclusion criteria, you know. (HP-3)

A reason often cited for why injecting drug users were excluded from accessing hepatitis C treatment in Australia prior to May 2001, involved concerns about re-infection either during treatment or following treatment and viral clearance. This unease is still evident in some health professionals' narratives, however most reported that re-infec-

tion was more likely to occur among people using heavily, and as previously stated heavily dependent users were not considered ready for hepatitis C treatment:

... I think for those patients that are still injecting and that want to go on to treatment, they are usually committed to go on to treatment and they do seem to go OK. I don't see them being too problematic. I guess, from my point of view, the key elements there would be to educate them about the risk of re-infection ... (HP-4)

From the preceding extracts it is evident that while specialist physicians in these treatment facilities may remain unaware, patients reportedly adhered to and completed hepatitis C treatment successfully while injecting. However the contribution that illicit drugs can make to quality of life, adherence and successful completion of treatment was silenced by the information management practices of the health professionals that we interviewed. The accumulation of clinical evidence to support or refute the benefits of for example injecting opiates or smoking cannabis during hepatitis C treatment under these conditions is denied because this information falls between the cracks.

### Medicinal cannabis and hepatitis C treatment

In this study, a nurse and a social worker spontaneously offered personal perspectives on patients' use of cannabis to ameliorate hepatitis C treatment-related side effects. They reported that cannabis use is common among people in treatment and that people use cannabis to relieve a range of troublesome side effects. While they could not recommend to their patients the use of an illicit substance, there was more than just a tacit acknowledgement and acceptance of the practice. Like with injecting, health concerns were focused mainly on the frequency of cannabis use during treatment where the nurses and a social worker cautioned against 'excess' or escalating use which might prompt changes in patterns of side effects. For example, feelings of depression and anxiety were believed to be affected by increasing cannabis use, although with regard to depression there was uncertainty about the direction of causality and the contribution of interferon in the equation. It was generally accepted however that cannabis had assisted people during hepatitis C treatment:

But certainly there are a few of the strategies that patients use that help us with [managing side effects]. Quite a few patients smoke cannabis and cannabis-smoking is very common (laughs). You know, I don't recommend patients smoke cannabis but they often do for relief of nausea, to help them sleep, to help with aches and pains, to help them relax. So, if they continue to do that, that's fine. I just ask them to tell me how much they're doing it and, if they increase it a lot, because it can impact on mood ... I guess those sorts of things are what patients come back and tell me about. (HP-2)

We have got lots of clients who say "Look, I smoke a joint at night. Is that cool? And I go: "That's fine"; Smoke to get to sleep? "Fine". But, we say "Just remember, that when you stop sleeping, when changes happen, you've got to tell us because you may

not go to sleep as well as you used to and that's because of the interferon and we might have to look at other means for that." (HP-6)

All health professionals reported that they encouraged open and honest disclosure from patients about illicit drug use. Their aim was to facilitate the development of a harm reduction sensibility to hepatitis C treatment, that is, there was an acknowledgement and acceptance that illicit drug use including injecting was a practice that some of their patients continued throughout their treatment. These health professionals believed that by monitoring their illicit drug using patients they could keep alert to the development of problems.

## CONCLUSION

There are several limitations evident in this study. Firstly, we used a small, non-randomly selected sample of health professionals therefore our findings can not be generalised across all treatment facilities in Australia. It is possible that health professionals in other facilities contend with different issues to those uncovered in this study, and they might manage patients differently to the group that we recruited. Secondly, we were unable to interview a broad range of health professionals like specialist physicians to hear their perspectives of managing patients in relation to hepatitis C treatment and concurrent illicit drug use. Because the three hospitals and the six health professionals comprised a homogeneous group, a saturation of themes was obtained quickly from this sample. Without greater diversity in the sample, it was not possible to explore a range of treatment-related issues. Finally, the participants receiving treatment that we interviewed did not disclose illicit drug use. This may have been because our participants were not current drug users, but it could also have been because of a social desirability bias which is common in studies where illicit drug use is a factor (Latkin & Vlahov, 1998). These participants may have feared the consequences of disclosing information pertaining to their illicit practice during interviews. Similarly, it is not possible to assess whether patients disclosed the full extent of their illicit drug use to the health professionals that we interviewed and whether the health professionals might have under-reported patients' illicit drug use in our study. Given these limitations, this study can not describe the prevalence of injecting and other illicit drug use during hepatitis C treatment, nor how common the practices of our sample of health professionals are in relation to other treatment facilities in Australia. There may be many more elements pertaining to the issue of illicit drug use during hepatitis C treatment than is evident from this study. Nonetheless, these findings are useful for initiating further investigation.

Clinical literature has often portrayed illicit drug users, particularly current injectors as a homogeneous group who are unsuitable candidates for hepatitis C treat-

ment. However from the perspective of the health professionals that we interviewed, patients who were injecting during hepatitis C treatment adhered to therapy and had no greater need for medical services than non-injectors. Current injecting drug users were reported to be no less reliable or more difficult to manage than other non-injecting patients. Similarly, these health professionals reported no evidence that current injectors experienced more side effects, dose reductions or treatment discontinuations, or were less likely to eradicate their infection than people who were not injecting throughout treatment. According to the health professionals, the key to successful treatment outcomes was in the preparation of current injecting drug users for treatment and ensuring that they had access to good quality support.

Given that hepatitis C treatment is administered throughout Australia almost exclusively from treatment facilities situated in large, urban hospitals which are staffed by teams of clinical nurse consultants, social workers, and specialist physicians using a shared care model, the observations of this study's small group of health professionals may in part resonate with the experiences of other professionals working in hepatitis C treatment. However further studies are needed to understand the implications for patients who use illicit drugs during hepatitis C treatment, and to uncover other health professionals' approaches to managing patients. Future investigation might include testing hypotheses, such as: (i) illicit drugs are used widely by people receiving treatment for hepatitis C infection; (ii) some patients are at increased risk during hepatitis C treatment because they fear the consequences from disclosing illicit drug use to health professionals; and, (iii) some health professionals routinely omit information in medical records about hepatitis C patients' illicit drug use.

In an early study of functional injecting drug use, the authors stated that “[society's punitive approach to illicit drug use] ... prohibits the transmission of honest, scientifically accurate, explicit information about drugs and safe drug use ...” (Sharp, et al., 1991, p.104). Indeed, perhaps prohibition's greatest 'achievement' has been to thwart the emergence of research and the transference of knowledge that can inform a sophisticated debate regarding the place of specific classes of drugs in society. The practice of sanitising people in order that they become acceptable patients for specialist physicians sustains a culture of ignorance among specialists and the clinical research literature regarding the extent of illicit drug use and its relation to hepatitis C treatment adherence, side effect management and treatment suitability. These practices also place an unfair responsibility on nurses and social workers for their patients' wellbeing. While some people may question the professionalism of our participants, their actions were altruistic, brave and pragmatic efforts designed to circumvent personal and institutionalised prejudice for the benefit of their patients. However their practices point to a need for investigation of a more worrying issue pertaining to professional ethics in medicine under a prohibitionist regime (Brushwood, 2003); that is, the perpetuation of a duplicitous health system where senior health professionals disavow patients' use of the un-mentionable drugs. Perhaps, as Thomas Gray the eighteenth century poet wrote, it is a case of: 'Where ignorance is bliss, 'tis folly to be wise'.

## CHAPTER 8

Social marginalisation, resilience  
and hepatitis C treatment

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## INTRODUCTION

Social marginalisation is understood to increase vulnerability to risk (Wilkinson & Marmot, 2003). The scholarly literature contains a myriad of studies that attest to the negative impact of marginalisation on for example, education and employment opportunities (O'Brien, 2003; Welsh, Lawes, Parsons, & Papatheodorou, 2002), physical and emotional health and well-being (Trivedi, 2002; Williams & Collins, 2004) and access to mainstream institutions (Milbourne, 2002). The exigent conditions inherent to living in complex post-industrial societies and the health impacts incurred on marginalised populations are key areas of interest to social scientific enquiry. Over recent decades, research has revealed unexpected dynamics in relation to adaptation and coping among people who are routinely exposed to adversity and it is this phenomenon that is explored here. Specifically, the aim of this article is to present data from a study of hepatitis C treatment that highlights participants' recognition that experiences of social and economic marginalisation can equip people with adaptive coping strategies that may subsequently be deployed to withstand the often-severe side effects of this treatment.

### Stress and coping

Stress and coping research has been dominated by theoretical models that describe personality dispositions and the characteristics of stressors as primary determinants of coping outcomes (David & Suls, 1999; Folkman & Moskowitz, 2000; Lazarus & Folkman, 1984). Lazarus, an architect of the transactional theory of stress and coping, defines coping as a process that changes over time according to situational contexts in which stress occurs. Individual appraisals of stress situations are the key influences on coping efforts (Lazarus, 1993; Lazarus & Folkman, 1984). Recent studies indicate that people tend to use both problem-focused and emotion-focused coping strategies during real-life stress (e.g. Cheng, 2003; Bagdi & Pfister, 2006; Tate, Van Den Berg, Hansen, Kochman, & Sikkema, 2006), and a variety of coping styles is identified in this literature (e.g. Bonanno, 2004; Gore-Felton et al., 2006). The effectiveness of coping strategies may depend on the abstract properties of the stressor (e.g. whether a stressor is chronic or acute, and controllable or uncontrollable), the specific subtype of stressor (e.g. illness, interpersonal problem, or loss) or some combination of both aspects (Thoits, 1995). One of the most studied coping strategies, having access to social support, is often found to be associated with, and predictive of, positive mental health outcomes. Social support has been found to protect against or buffer stress in for example, elderly nursing home patients (Jongenelis et al., 2004), US public hospital workers (Park, Wilson, & Lee, 2004), and young students (Abela, Vanderbilt, & Rochon, 2004). Social support is integral to maintaining a good quality of life across a variety of contexts.

## The construct of resilience

Concomitant with the developments in stress and coping research is the considerable interest that has arisen in factors that contribute to adaptive outcomes in individuals who experience extremely adverse life events. Studies of childhood development during extreme hardship, living with chronic illness and disability, and adult responses to loss and trauma have focused on the psychosocial construct of 'resilience' (Cook, Woolard, & McCollum, 2004; Trickett, Kurtz, & Pizzigati, 2004). Contrary to early conceptualisations, resilience is not a rare personality disposition; rather, it is a common phenomenon and describes a process that is inferred from the coexisting conditions of risk and positive outcomes (Masten, 2001; Luthar & Zelazo, 2003; Bonanno, 2004). Masten defines resilience as 'a class of phenomena characterised by good outcomes in spite of serious threats to adaptation or development' (2001, p. 228). This definition alludes to adaptive and supportive factors and processes found within individuals, families and communities such as having competent and caring adults in the family, having access to supportive community networks, spirituality, self-confidence and optimism (Bonanno, 2004; Tedeschi & Kilmer, 2005; Walsh, 1998). Protective factors and processes are coalesced to enhance an individual's ability to cope with adversity (King et al., 2003). Similarly, 'resilient coping' is defined as the ability of people to maintain relatively stable and healthy levels of psychological and physical functioning when confronted with a highly disruptive situation (Bonanno, 2004). Resilient coping is distinguished from other forms of coping by an emphasis on (i) the chronic and uncontrollable properties of stressors (i.e. the stressor implies extreme, ongoing adversity), and (ii) the social-contextual factors that facilitate adaptation. On the other hand, resilient coping is similar to other ways of managing stress in that it describes coping as a process and emphasises the transactional nature of, for example, childhood development and living with chronic illness.

## Resilience and treatment for hepatitis C infection

Because of the two component constructs of risk and positive adaptation, the authors use the term 'resilience' as conceptualised by recent commentators (Bonanno, 2004; Masten, 2001; Luthar & Zelazo, 2003) to explain adaptive outcomes in a therapeutic context. There are several indications for the construct of resilience being relevant to the experience of receiving hepatitis C treatment. To begin with, this regimen is long, either 24 or 48 weeks depending on factors like viral genotype. Secondly, the treatment drugs interferon and ribavirin are associated with severe and sustained physical and psychiatric side effects (Clemensen, Eshelman, & Belville-Robertson, 1999; Hopwood & Treloar, 2005). Finally, a majority of people with hepatitis C in the Australian population are living in socially and economically marginalised circumstances and include former and current injecting drug users and people who are incarcerated or those who have been in custodial settings (Dore, MacDonald, Law, & Kaldor, 2003). For many people who exist on the margins of the mainstream, hepatitis C treatment is simply another hurdle to negotiate in lives routinely confronted by formidable challenges.

Drawing on past research and a recent study of the experience of hepatitis C treatment the authors sought to answer the research question, 'How do people cope with the side effects from the therapeutic drugs used in the treatment of hepatitis C virus infection?' This article explores the factors and processes reported by participants as having facilitated coping during hepatitis C treatment. The article concludes with a brief rationale for applying strengths-based assessment in pre-treatment interviews to enhance resilient coping during treatment.

## METHOD

An exploratory qualitative study of people receiving treatment for hepatitis C infection was conducted during 2004 and 2005. The study aimed to uncover some of the strategies that people deployed to cope with the side effects associated with therapy. A purposive sampling frame was used to recruit participants from liver clinics situated in three large metropolitan hospitals across inner Sydney, Australia. To be included in the study, people had to have been either currently receiving hepatitis C treatment for a minimum of four weeks, or had to have completed treatment within the previous six months in order to comment on the impact of side effects on their quality of life.

### Participants and procedure

Twenty people ( $n = 20$ ) who were currently receiving or had recently completed hepatitis C treatment self-selected to take part in interviews (Table 11). Most participants had been in treatment for between eight and 48 weeks. Currently little is known about who accesses hepatitis C treatment in Australia (McNally, Temple-Smith, & Pitts, 2004) therefore it is not possible to compare this study's sample with a national profile of people receiving hepatitis C treatment.

The interview commenced after written consent had been obtained and each interview was audiotaped. All interviews lasted between 30 and 60 minutes and were conducted in private consultation rooms in hospital liver clinics. No financial incentives were extended to participants.

### Interview schedule and data analysis

A semi-structured interview schedule included items about disclosure of treatment, sources of support, side effects and participants' coping strategies (Table 12). Audiotaped interviews were transcribed and, following repeated and close reading of the twenty interview transcripts, the authors independently constructed a code list

Table 11 Sample characteristics (n = 20)

<b>Mean age (years)</b>	<b>49 (range 35–73 years)</b>
<b>Year of HCV+ diagnosis (mode)</b>	<b>1995 (range 1975–2004)</b>
Gender	n
Male	13
Female	7
Total	20
HCV genotype	n
1	5
2	2
3	6
4	0
5	0
6	0
Unsure	7
Total	20
Mode of HCV acquisition	n
Injecting drug use (IDU)	8
Medical	6
Unsure	6
Total	20
HCV treatment length	n
24 weeks	11
48 weeks	9
Total	20

of major themes that emerged. The authors revisited transcripts when a divergence in authors' coding was identified and differences were discussed until a consensus was reached. The de-identified interview transcripts were then entered into qualitative software (Richards & Richards, 1999) and codes were applied to the text.

The findings and extracts reported in this article are from a thematic content analysis of interview data (Grbich, 1999). This article focuses on the sections of the interview schedule (and coding list) relating to four question areas: 'disclosure of treatment', 'support', 'side effects', and 'coping strategies', in order to answer the main research question. Disclosure of being in treatment was explored to determine a participant's opportunities for obtaining support. Information regarding participants' sources of

Table 12 Interview schedule extract: Coping with side effects, support and disclosure.

- 
- Who do you tell that you are on treatment?
  - Why do you disclose this information to these people?
  - Please tell me who supported you during treatment.
    - Explore support from partner, family and friends, support groups and other key support mechanisms.
  - Please describe any treatment-related side effects you may be experiencing.
    - Obtain detailed description of side effects and/or changes in the participant's symptoms e.g. what they are, when do they occur, how do they affect QoL.
  - How have you been managing your side effects in order to cope with treatment?
    - Obtain detailed description of what participant does when side effects appear (look for personal coping strategies and clinically pre-determined strategies).
    - Ask participant to discuss one instance in detail relating the onset of side effects and how they responded.
  - How does treatment and its side-effects affect:
    - (i) your close personal relationships (i.e. support networks)?
    - (ii) your work performance?
    - (iii) socialising?
    - (iv) your physical and emotional health and well being?
    - (v) your sense-of-self?
    - (vi) your future outlook?
    - Explore patterns of coping in each area.
- 

support and their involvement with support groups was collected to assess the role of support during treatment. The questions about side effects aimed to document adverse events and provide an understanding of their reported impact on quality of life. Finally, the question regarding coping strategies aimed to (i) elicit a participant's coping style (i.e. their habitual preferences for approaching problems), (ii) uncover the processes that facilitated coping, and (iii) review participants' use of medically and personally derived strategies. The semi-structured nature of interviews enabled associated phenomena to surface. It was in this way that resilient coping was identified throughout participants' narratives regarding past experiences of hardship. Salient allusions to the factors and processes that participants reported to assist coping were examined and collated. These 'resilience' narratives were represented by the following major themes: (i) past experiences of drug dependence, (ii) living with chronic illness, and (iii) social disadvantage, which contained two sub-themes: utilising community resources, and lessons from the past. Extracts that most clearly illustrated participants' experiences of resilient coping are presented.

The study had ethics approval from the Human Research Ethics Committee of the University of New South Wales, three area health service human research ethics committees and one hospital research ethics committee.

## RESULTS AND DISCUSSION

The strategies that participants reported using to cope with side effects included medical interventions for physical and psychiatric impacts and personal coping strategies such as reduced work hours and relaxation. Notable in our data were seven participants who deployed resilient coping styles throughout treatment. When asked about management of side effects, these seven participants reported drawing on prior experiences of drug dependence, chronic illness and social disadvantage to assist with coping. In contrast to the other 13 participants in our sample, most of these participants were not in a relationship, most had injecting-acquired infections (as opposed to medically acquired infection), all reported both physical and psychiatric side effects and most reported low socioeconomic backgrounds. Their approaches to coping were distinguished from those of other participants by the utilisation of community resources such as welfare organisations. The following extracts illustrate the factors and processes that were reported to facilitate coping. Participants have been assigned a pseudonym to protect anonymity.

### Drawing on past experience of drug dependence

Kate, a 38-year-old woman who was interviewed in her last week of a 48-week treatment regimen, reported that her past experience of withdrawing from heroin and methadone had taught her to cope with the physical pain of treatment side effects. The most significant side effect to impact on her quality of life during treatment was depression. Her prior experience of drug treatment counselling, combined with an ability to access and utilise the services of mental health practitioners, assisted Kate in managing depression during hepatitis C treatment. In this extract she acknowledged that her years of drug dependence had assisted her in coping with side effects:

Yeah, I just think that [hepatitis C treatment] is a reality that you have to deal with. That's learned only through having been through heroin addiction and stuff like that ... and even my friends would say that to me, before I started treatment, 'You'll breeze through it! You've been through heroin addiction; it'll be a walk in the park' ... And in a way I kind of agree ... I do feel sorry for people who've never experienced ... that level of discomfort in their lives. Yes, [hepatitis C treatment] would be tough for them. But I've kind of been through it before ... just the rough knocks during my life too ... because I'd been through withdrawals and all of that, so of course I could handle, you know, itchy skin or that physical side of things ... because heroin addiction ... and actually getting off methadone was worse.

The protective factors that helped Kate create a stable environment from which significant adaptive change could occur included re-establishment in a geographic area where she had lived as a child, with her friends and familiar places close by. As she explained:

So when I got back to [city] I thought ... 'What a perfect time to start treatment' ... I've got a nice little flat in [a suburb] near the beach. ... I felt as fit and as healthy as I'd probably ever be, because I was off drugs and I was near the beach and I love swimming. So I thought, 'Now is probably the perfect time to do it ... I'm going to take advantage of the hospital; I'm going to see the counsellors'... That was another project to do, to get myself sorted out ... And that's what I did. I would take advantage of the counsellors here and have very long talks.

With help from the psychological services at her liver clinic, Kate implemented processes to assist coping during difficult periods throughout treatment. She also utilised a key community resource – The Hepatitis C Council of New South Wales – which she had first learned about while using heroin. This non-government organisation acted as a directory for hepatitis C support services. In summary, the processes that acted to ameliorate the impacts of Kate's treatment included returning to familiar territory, increasing cardiovascular fitness, accessing and learning new information, and attending regular counselling sessions.

Other former injecting drug users also reported that they had accessed mental health services during hepatitis C treatment because counselling had helped them in their efforts to cease dependent drug use. For example, Sally experienced interferon-induced depression during 24 weeks of treatment. However she reported that years of counselling had helped her to manage and limit negative thinking, which facilitated her completion of treatment:

But I've learned a lot of how to manage my own thinking around depression. ... Umm, there are some type of subjects for me personally that I can't go and dwell on too long. I've had the same counsellor for twenty years (on and off over twenty years) ... so he has often advised me not to go too deeply into my family's history while I'm on this stuff [interferon]. So I try very hard not to ...

Kate and Sally acknowledged similarities in emotional and physical states between drug dependence and receiving hepatitis C treatment, and both participants drew upon their earlier life experiences to manage treatment. Similar to the debilitating impacts of drug dependence is living with incapacitating symptoms of disease. The following section explores how, for some people, prior personal experience of chronic illness management facilitated coping during hepatitis C treatment.

### Living with chronic illness

Gerry, a 48-year-old man who was interviewed in the final week of a 24-week regimen, reported having lived with symptoms of hepatitis C infection, like insomnia and lethargy, for most of his life. He reported that chronic fatigue had contributed to an ongoing sense of despair that was eventually diagnosed as depression. Nonetheless,

Gerry believed that his long experience of coping with adverse health had enhanced his capacity for dealing with treatment side effects:

... [H]aving lived with chronic pain for the whole of my adult life basically, I already had coping mechanisms to handle those things ... I'm used to just not being able to get out of bed for two or three days in a row. That happens occasionally; I just live with it ... [I] may be in a better position than some other people to cope with the [hepatitis C] treatment because I'm used to being in a debilitated state ...that's not a good thing, but it's a fact. I guess the coping mechanisms were always there, from over a long period of time.

To optimise his chances of successfully completing treatment, Gerry utilised a resource he had identified years earlier among his social network and sought the financial assistance of a friend. Extra funds enabled Gerry to move into an apartment, which facilitated the establishment of basic healthy living patterns:

... [I]t's been very good for me that I got some extra assistance during this treatment from one of my friends, without which there is no way I would have made it through, financially. So I'm living in a much more comfortable environment than I was living in before the treatment. That helped enormously ... [A]t the beginning of the treatment, I started cooking for myself and I saved so much money on eating out which, you know, I had to do before because I didn't have any cooking facilities: no fridge, no stove that worked, no hot water in the sink. So that lifestyle improvement made a big difference.

Thoits (1995) argues that money is usually an overlooked coping resource, even though money can act as a buffer to stress and people often draw on their finances to cope with problems. Indeed, financial assistance reduced the stress of poverty and improved Gerry's health outcomes during treatment.

Sean, aged 35, and interviewed eight weeks into a 24-week regimen, acknowledged that for most of his life he had dealt with challenges arising from haemophilia and that he was coping with hepatitis C treatment by utilising similar processes. This meant managing symptoms with an array of pharmaceutical drugs, adhering to therapy and keeping a positive attitude. Complying with strict dosing regimens was a normal daily activity for Sean:

I self-treat and have done since I was about ten. I just self-manage, self-regulate it ... I think, with haemophilia too, you tend to be a bit onwards and upwards in your approach to things. It's like okay, right, you started Day One with haemophilia and it throws a whole lot of challenges and you sort of deal with those however you wish ... But again, I'm very much the type who won't let it hinder me; I'll keep forging ahead ... I'm normally a very optimistic person, very up-beat ... very much a Type A personality.

A helpful factor for Sean was a well-developed support network, which included his wife, friends and a haemophilia society, elements which were coalesced to protect him against the adverse impacts of treatment. His determination and optimism enhanced his capacity to cope with the side effects of treatment. While current theorising of resilience has moved away from ascribing the foundations of positive adaptation solely to identifiable personality traits (Luthar & Cicchetti, 2000), the literature does acknowledge that traits like optimism and determination are protective factors that facilitate the development of resilient coping.

No other participants in our sample commented on the influence of past experiences of chronic illness on coping with hepatitis C treatment. However it is possible that other participants' approaches to coping during treatment were mediated by past experience of managing symptoms, but were not acknowledged or articulated during interviews.

### **Social disadvantage: Utilising community resources**

In addition to coping with drug dependence and living with chronic illness, three participants described long-term membership of twelve-step fellowship groups as contexts where adaptive practices and processes were acquired. In past research, spiritual belief, which is a cornerstone of twelve-step groups, is reported to be a protective factor that builds resilience in relationship to coping with ageing, disease and loss (Bower, 1996; King et al., 2003). The sharing of spiritual belief is described as a protective process that helps to foster and sustain supportive relationships and lead to new understandings of the self. Several of our participants reported acquiring skills and supportive relationships from these groups. To illustrate, Chloe, 49, a former dependent injecting drug user and alcoholic, reported a 16-year membership of two twelve-step groups. Chloe reported that group members were assisting her to cope with major treatment-induced depression:

Even though I'm struggling in the water quite a lot ... I know when I go [to the fellowship groups] ... it's a good thing for me to go. Even if I'm raging and angry, I just go there and I'm in a safe, good place and I recognise that. I'm not going there to be good; I'm going there because I feel terrible. And I don't know how to heal myself. ... I try and go there a couple or three times a week. I go there and I know that I'm actively participating in something that is beneficial and loving, I suppose, and forgiving ...

The main processes that acted to support Chloe during treatment were counselling sessions, a familiarity with the dynamics of support groups, and walking several times a week with other members. Chloe deployed a coping strategy commonly used in her fellowship, which involved contacting members when side effects became particularly bothersome:

I just think the support is really, really important. We probably should try to organise more hep C support groups because [my fellowship support group] was the most important thing for me [during treatment]. To actually identify with people to whom I could say, 'Look, I feel so insane! I can't stand this one more minute!' Just being able to talk to people ... What works for me is just to be able to go, 'Yes, I'm mad and it feels mad,' and to be able to ring someone up and cry, 'I'm really sad. This is really lonely. This is horrible.'

Apart from private counselling sessions, Sally also utilised a fellowship group throughout treatment. For people without common modes of support, like a partner and family, fellowship groups performed a primary support role:

No, no [family] support. No, I don't have family; they're all deceased. I don't have a partner through choice. I have a couple of good friends and I have support through my NA fellowship ...

Similarly, Gavin, 48, said that his experience of ceasing drug use and adhering to the stringent requirements of a twelve-step programme had provided him with support and the means to cope with treatment side effects:

I went to Narcotics Anonymous for about five, six years, pretty religiously because I just didn't want to go back to where I'd been and they gave me lots of great tools and ... I think I've adopted a lot of the principles that are suggested and I try to keep them as part of my life.

Participants who had utilised community-based support services in the past and had developed successful approaches to coping were likely to draw on these resources and skills to help meet the challenges presented by hepatitis C treatment side effects.

### **Social disadvantage: Lessons from the past**

Knowledge and use of community resources are described in the resilience literature as key factors in enhancing adaptation to adversity (Tedeschi & Kilmer, 2005). Marsden, aged 50, who was interviewed a month before completing 24 weeks of treatment, reported that he coped with treatment by utilising community services that he had accessed in previous periods of financial difficulty, such as sponsored food vans that provided free meals to homeless and disadvantaged people. He also crocheted hats and blankets which he bartered for goods at community markets, although sometimes he gave his work away free in order to shore up good will among other users of services. Additionally, he situated his adaptation to interferon-induced depression in protective processes he had acquired as a response to childhood sexual abuse:

I'm like a hermit at the moment, to keep ... safe, you know. So that I don't hurt anybody and I don't hurt myself. And I don't have a problem with that because, as a child being sexually abused, I put myself in an isolated world anyway to protect myself ... and that's how I cope with the hep C [treatment] ... isolating myself works ... [M]aybe the sexual abuse as a child was a lesson to be able to cope with this now.

For Marsden isolation reduced the likelihood of damaging relationships. Certain responses to loss and trauma, like self-imposed isolation, appear maladaptive and are typically understood as leading to further problems over time. Nonetheless, some emotion-focused strategies, such as drinking alcohol and using denial, have been shown to be adaptive in the short term (Thoits, 1995). Bonanno (2004) discusses the multiple and sometimes unexpected pathways to resilience that have appeared in past research, and one adaptive phenomena observed among one group of people with histories of sexual abuse was 'repressive coping', a strategy whereby unpleasant thoughts, emotions and memories are avoided. While it is not possible from Marsden's extract to assume similar mechanisms at work, this participant reported applying a strategy that would commonly be understood as maladaptive, but which had an adaptive outcome in the context of hepatitis C treatment. In summary, survival skills acquired from past experiences of social and economic marginalisation, in concert with self-imposed isolation, minimised the potential for interpersonal conflict and facilitated Marsden's successful completion of hepatitis C treatment.

### Resilient versus other coping strategies

Although our study participants were not a representative sample there were notable differences between those who deployed resilient coping strategies and those who did not (Table 13). Our sample contained a high proportion of people who reported medically acquired hepatitis C infection. Unlike the usual profile of people with hepatitis C, these participants had no personal experience of significant social or economic marginalisation and their reported approaches to coping reflected less need for social services and a greater reliance on personal and family resources. They reported no prior experience with community-based support groups or services, counselling, or alcohol and other drug treatment, nor did they report disabling long-term symptoms of chronic illness. The inclusion in this sample of people with medically acquired infection from higher socio-economic backgrounds might partly account for the reported variation in support and approaches to coping and the salient deployment of resilient coping styles among those on lower incomes with injecting-related infections. Another important difference was that most of the participants with medically acquired infection, and those who were not sure how they acquired hepatitis C, reported having a supportive partner. Conversely, of eight participants who reported injecting-related hepatitis C infection only two of these people had a regular partner. McNally and colleagues (2004) found that one of the key concerns for participants when deciding to commence treatment was having a supportive partner. An absence

Table 13 Participants' main supports, side effects and coping strategies (n = 20)

<b>Participants</b>	<b>Moa<sup>2</sup></b>	<b>Partner</b>	<b>Main support</b>	<b>Main side effect(s)</b>	<b>Main coping strategies</b>
<i>Resilient coping<sup>1</sup></i>					
Chloe	IDU	No	Fellowship group <sup>3</sup>	Physical + psychiatric	Counselling, attending fellowship, medical <sup>4</sup>
Gavin	IDU	Yes	Partner	Physical + psychiatric	Attending fellowship, work reduction
Gerry	IDU	No	Friends	Physical + psychiatric	Chronic illness management, loan
Kate	IDU	No	Support group	Physical + psychiatric	Counselling, accessing community-based services
Marsden	Unsure	No	Treating clinic	Physical + psychiatric	Accessing community-based services, isolation
Sally	IDU	No	Fellowship group	Physical + psychiatric	Attending fellowship, counselling
Sean	Med.	Yes	Partner	Physical + psychiatric	Chronic illness management, medical
<i>Other coping strategies<sup>5</sup></i>					
Alfonso	Unsure	Yes	Partner	Physical + psychiatric	Work reduction
Barbara	Med.	Yes	Partner	Physical + psychiatric	Medical, attending clinic-based support group
David	IDU	Yes	Partner	Psychiatric	Medical, exercise, anger management
Helena	IDU	Yes	Partner	Psychiatric	Medical, relaxation
Leonardo	Med.	Yes	Partner	Physical	Work reduction, relaxation
Loren	Med.	Yes	Partner	Physical + psychiatric	Medical, cognitive restructuring
Monica	Med.	Yes	Partner	Physical + psychiatric	Medical, attending clinic-based support group
Nigel	Unsure	Yes	Partner	Physical + psychiatric	Relaxation
Philipe	Unsure	Yes	Partner	Psychiatric	Work reduction
Raymond	Med.	Yes	Partner	Physical + psychiatric	Medical, exercise
Richard	Unsure	Yes	Partner	Physical + psychiatric	Relaxation, exercise
Rob	Unsure	No	Friends	Psychiatric	Medical, attending clinic-based support group
Terry	IDU	No	Parents	Physical + psychiatric	Relaxation

<sup>1</sup> A coping style deployed to manage extremely adverse situations.

<sup>2</sup> Mode of acquisition of hepatitis C virus infection (i.e. IDU = injecting drug use, Med.= medically acquired infection, Unsure = multiple risk factors).

<sup>3</sup> Religion-based support groups like Narcotics Anonymous.

<sup>4</sup> Pharmaceutical coping strategies recommended by the treating clinic (e.g. antidepressants, sedatives, paracetamol, skin creams etc.).

<sup>5</sup> Non-medical approaches to coping recommended by the treating clinic (e.g. reducing work hours, relaxation, cognitive restructuring and anger management techniques).

of a partner implies that support needs must be met away from home. Finally, these 13 participants did not report as many side effects as people who deployed resilient coping and their coping strategies tended to centre on medical interventions, reduced work hours, and relaxation techniques suggested by the clinic, rather than on accessing community services, counselling and support groups.

## CONCLUSION

Paradoxically for some people the experience of marginalisation may enhance resilience. However further research is needed to provide a clearer understanding of the role of marginalisation and resilient coping in a clinical treatment context. Further investigation would overcome some of the limitations evident in the present study, including the use of a small, non-randomly selected sample, where the methods did not enable a quantifiable comparison of treatment experiences and outcomes between people with varying access to support and material resources. Although this study's sample may not be representative of the experience of all people receiving hepatitis C treatment in Australia, and we may have recruited an especially resilient group of individuals, our findings are evidence that adaptive strategies learned from past experiences of adversity can be applied during hepatitis C treatment as a pathway for enhancing resilience. This context represents a novel application of resilience theory.

Promoting clinical interventions that foster resilience among populations of people receiving treatment for hepatitis C infection might produce beneficial outcomes. Strategies that foster resilience are derived from strengths-based assessment, an approach that evaluates an individual's capacity for actively seeking help, while identifying and lessening systemic social impediments to positive adjustment. Epstein and Sharma (1998, p.3) define strengths-based assessment as 'the measurement of emotional and behavioural skills, competencies and characteristics that create a sense of personal accomplishment; contribute to satisfying relationships with family members, peers and adults; enhance one's ability to deal with adversity and stress; and promote one's personal, social and academic development.' Strengths or potential helpful and protective influences are drawn from multiple levels of an individual's context (Bonanno, 2004; Newman, 2005; Tedeschi & Kilmer, 2005). Such an approach is needed to build capacity for positive change within families, to develop individual competencies, to facilitate collaboration between health care services and to capitalise on the social systems that can assist in supporting people throughout treatment (Epps & Jackson, 2000; Gerhardt, Walders, Rosenthal, & Drotar, 2004; Olsson, Boyce, Toumbouro, & Sawyer, 2005).

Clinicians managing hepatitis C treatment could deploy a range of protective elements from an individual's family, social and community context to assist them to cope. The

resilience literature can assist in guiding a strategy of assessment and treatment and contains leads in the form of checklists, open-ended questions and validated quantitative instruments that identify and measure individuals' risks and resources (Luthar & Cicchetti, 2000; Tedeschi & Kilmer, 2005). For example, in light of consistent research findings regarding the importance of positive family relationships in fostering resilience (e.g. Gerhardt et al., 2004; Trickett et al., 2004) instruments such as the Family Environment Scale (Moos & Moos, 1994) and the Family Assessment Device (Epstein, Baldwin, & Bishop, 1983) can be used during evaluation interviews to help clinicians assess family support. Critically the literature also flags limitations and potential pitfalls in the conceptualisation of resilience and its application to clinical practice (Luthar & Cicchetti, 2000).

A focus on an individual's strengths as well as risks in pre-treatment interviews can affirm and motivate people by acknowledging their agency as effective social beings with competencies and resources that will assist their progress throughout treatment (Tedeschi & Kilmer, 2005). The 'art' in this science is for clinicians to listen closely to patients to uncover strengths and potentially reinforcing domains in their lives that are relevant to adaptive coping throughout hepatitis C treatment.

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## SUMMARY

**Chapter 1** presents an overview of the work contained within this thesis. This chapter contextualises the thesis within Green and Kreuter's (1999) educational and ecological approach to health promotion planning. It provides a summary of the latest epidemiological estimates and projections of the hepatitis C epidemic in Australia and contains background information on living with hepatitis C. The chapter then outlines the theoretical frameworks and methods used throughout the thesis including a discussion of the thesis aims and research questions. Finally, an overview of the main findings of the thesis is provided and recent hepatitis C-related psychosocial literature is integrated and added to that which appeared in the author's sociological review of literature published in 2003.

**Chapter 2** reviews international and Australian literature related to living with hepatitis C infection. At present, scholarly research into this worldwide epidemic focuses on medical and scientific understandings of the virus and its effects on people's health-related quality of life. Exploration of the socio-cultural impact of hepatitis C infection is for the most part absent from this literature. However a nascent academic inquiry into living with hepatitis C infection points to a complex range of concerns regarding diagnosis, disclosure, stigmatisation and discrimination against people with hepatitis C. The increasing association of hepatitis C infection with injecting drug use and the medicalisation of those affected by the virus is discussed. This chapter argues for an expanded socio-cultural understanding of hepatitis C to account for the material effects of medicalisation, stigmatisation and discrimination, and the socio-cultural impact of treatment on the lives of people with hepatitis C infection. It concludes with suggestions for future directions in social research to address the silence surrounding living with hepatitis C infection.

**Chapter 3** reports on a study of people's experiences of receiving a positive hepatitis C diagnosis. To address a paucity of academic literature that described people's experiences of receiving a positive diagnosis, including doctors' explanation of the infection and referral to support services, a cross-sectional study was conducted of people with hepatitis C infection living in New South Wales (n=504) during 2001 and 2002. People diagnosed with non-A non-B hepatitis prior to 1989 when the hepatitis C virus was identified were excluded from analysis as it was assumed that these people were subjected to different social dynamics to those diagnosed after 1989, by which time epidemiology had established that hepatitis C infection was commonly associated with injecting drug use. Among participants diagnosed with hepatitis C infection after 1989 (n=417), just under a third (29.5%, n=123) reported that they had received 'no explanation' about their infection from their doctor at diagnosis. Women and those diagnosed from 1989 to 1996 – the year before the Australian Hepatitis Council was established and commenced publishing informational pamphlets – were significantly more likely to report receiving no explanation than men and those diagnosed after 1996 (35.4% vs 23.7% and 37.5% vs 23.0% respectively). Similarly, current injecting drug users and those diagnosed from 1989 to 1996 were

significantly more likely to report receiving no post-test counselling than those who were not currently injecting and those diagnosed later (42.9% vs 30.2% and 37.6% vs 25.9% respectively). Participants diagnosed from 1997 to 2001 were significantly more likely to report receiving pamphlets about hepatitis C infection (39.2% vs 23.7%), information about treatments (24.5% vs 16.2%) and advice regarding natural therapies (9.1% vs 3.8%) than those diagnosed earlier. These data provide evidence of an increase in the dissemination of hepatitis C information by doctors at diagnosis, during the latter stages of the 1990s. However continued effort is needed to improve doctors' provision of information and referral to specialists and support agencies for people newly diagnosed with hepatitis C.

**Chapter 4** presents data regarding hepatitis C-related discrimination. The chapter reports findings from a cross-sectional study of people with self-reported hepatitis C virus infection (n=504) conducted in New South Wales (NSW), Australia throughout 2001 and 2002. Participants completed a self-administered questionnaire enquiring into their experience of living with hepatitis C infection. Over a half of all participants (57.5%, n=290) reported that they had acquired their infection from injecting drug use. Discrimination was reported by 64.7% (n=326) of participants and healthcare was the most commonly reported site where discrimination occurred. A logistic regression identified the predictors of any discrimination as: knowing many other people with hepatitis C infection (i.e., six or more people); feeling 'very tired' due to hepatitis C symptoms; and being younger (i.e., less than 51 years). Predictors of higher levels of discrimination were: knowing many other people with hepatitis C infection (i.e., six or more people); being limited (i.e., either 'some of the time' or 'a lot of the time') in the time spent with family, friends, neighbours and groups due to hepatitis C; and feeling pessimistic about hepatitis C treatment and the future because of hepatitis C-related ill health. Although discrimination occurred in a range of social domains, effort is needed to improve healthcare workers' service delivery to people with hepatitis C infection. Continued discrimination may inhibit people from seeking a range of health services and impede efforts to contain the epidemic.

**Chapter 5** presents one of the first published qualitative studies of the experience of receiving treatment for hepatitis C infection. Clinical trials of interferon-based treatments for hepatitis C infection show decrements in patients' health-related quality of life due to side effects of therapy. The impact of side effects on patients' overall quality of life remains unclear. To explore this issue, people living in New South Wales, Australia who had undergone treatment for hepatitis C were interviewed. This chapter reports participants' experiences of treatment side effects and the impact of the therapeutic regimen. This information is important because a new interferon-based regimen has been adopted as the mainstay of hepatitis C treatment and it is predicted that many more people will seek treatment in Australia. The author argues for further qualitative research to enhance knowledge of the impact of this therapy on quality of life.

**Chapter 6** reports on the experience of preparing and managing people throughout six or twelve month courses of interferon-based treatment for hepatitis C infection. From the clinical literature a high proportion of patients receiving hepatitis C treatment has dose reductions or discontinues treatment because of adverse events arising from the therapeutic drugs. Currently there is no published literature which explores how health professionals prepare patients for hepatitis C treatment and there is a paucity of literature regarding how treatment-related adverse events are managed. Data is presented from the author's exploratory qualitative study which used semi-structured in-depth interviews with a sample of health professionals with experience in managing hepatitis C treatment regimens. The study was conducted in Sydney Australia throughout 2004 and 2005. The study aimed to report health professionals' perspectives regarding hepatitis C treatment preparation, and to identify and describe the hepatitis C treatment management strategy used by health professionals in this study. Participants reported that pre-treatment preparation focused on information provision regarding adverse events and the medical strategies that could ameliorate their impact. Patients' vulnerabilities and supports were assessed prior to treatment and health professionals sought to address patients' problems as they arose during treatment. Participants discussed patients' resilient coping style and the beneficial impact this had on treatment management. These findings indicate that among this sample of health professionals a deficits-based approach was taken to hepatitis C treatment management. While some attempts were made to assess patients' strengths, this was limited to identifying those in family, work and social networks who could lend support to patients when problems occurred. Exploring patients' past experiences of adversity and making a detailed evaluation of a range of patients' strengths (i.e. strengths-based assessment) might assist clinicians in managing hepatitis C treatment regimens.

**Chapter 7** explores the phenomena of people using illicit drugs while receiving hepatitis C treatment from the perspective of one group of health professionals. Exploration of patients' illicit drug use during treatment for hepatitis C virus infection is largely absent from the clinical literature. Data are presented from a qualitative study of health professionals responsible for managing hepatitis C treatment regimens at three major metropolitan hospitals across Sydney, Australia. During semi-structured in-depth interviews participants discussed patients' use of injected and non-injected illicit drugs while coping with a demanding therapeutic regimen. Health professionals highlighted the socially conservative environment of healthcare and its negative perceptions of illicit drug users. Also discussed are the management of people who inject during treatment and the efficacy of cannabis to reduce side effects. The findings of this study indicate that while the health professionals adopted a harm reduction approach to patients' illicit drug use during HCV treatment, information regarding the risks and benefits of illicit drug use is silenced in this context. While ever prohibition remains Australia's illicit drug policy this situation appears unlikely to change. Research which investigates the extent of illicit drug use during hepatitis C treatment, the risks and benefits associated with their use in this context and the harms of perpetuating a duplicitous healthcare system is required.

**Chapter 8** explores a paradoxical association between social marginalisation and positive health outcomes among people receiving treatment for hepatitis C infection. In this chapter, participants who were living in socially disadvantaged circumstances reported applying adaptive approaches which they had learned from past experiences of drug dependence, living with symptoms of chronic illness, coping with depression and childhood sexual abuse to enable them to cope with severe treatment-related side effects. This finding has implications for the clinical management of hepatitis C treatment; the factors and processes that facilitate adaptive coping to adversity associated with social marginalisation can be assessed for their clinical contribution to coping with an arduous regimen.

## SAMENVATTING

**Hoofdstuk 1** geeft een overzicht van het werk dat dit proefschrift bevat. Dit hoofdstuk plaatst het proefschrift in de context van het educationele en ecologische model voor gezondheidsvoorlichting van Green en Kreuter (1999). Het geeft een samenvatting van de meest recente epidemiologische schattingen met betrekking tot de hepatitis C epidemie in Australië. Verder geeft dit hoofdstuk achtergrondinformatie over het leven met hepatitis C. Vervolgens worden in dit hoofdstuk de theoretische kaders en de methoden geschetst die in dit proefschrift worden gebruikt, waaronder de doeleinden en de onderzoeksvragen. Tenslotte wordt een overzicht van de hoofdbevindingen van dit proefschrift gegeven alsmede een update van hepatitis C gerelateerde psychosociale publicaties die verschenen zijn na de review van de auteur uit 2003.

**Hoofdstuk 2** beschrijft de internationale en Australische literatuur die het leven met hepatitis C infectie tot onderwerp heeft. Momenteel legt onderzoek naar deze wereldwijde epidemie de nadruk op medische en wetenschappelijke aspecten van het virus en de invloed ervan op de gezondheidsgerelateerde kwaliteit van leven. Onderzoek naar de socio-culturele gevolgen van hepatitis C ontbreekt grotendeels in deze literatuur. Echter, steeds meer onderzoek naar het leven met hepatitis C wijst op een complexe verscheidenheid aan problemen betreffende de diagnose, openbaring, stigmatisering en discriminatie van personen met hepatitis C. De steeds sterker wordende associatie tussen hepatitis C en druggebruik wordt besproken evenals de medicalisering van degenen die geïnfecteerd zijn met het virus. Dit hoofdstuk pleit voor een uitgebreid socio-cultureel perspectief op hepatitis C om zo rekening te houden met de materiële effecten van medicalisering, stigmatisering en discriminatie, en de socio-culturele invloed van behandeling op de levens van mensen met een hepatitis C infectie. Het hoofdstuk eindigt met suggesties voor toekomstig sociaal onderzoek om de stilte rondom het leven met hepatitis C te doorbreken.

**Hoofdstuk 3** beschrijft een studie naar de ervaringen van personen die een hepatitis C diagnose krijgen. Vanwege de schaarste aan academische literatuur die de ervaringen van personen bij het krijgen van een positieve diagnose beschrijft (inclusief uitleg over de infectie door artsen en verwijzing naar supportorganisaties), is in 2001 en 2002 een cross-sectionele studie uitgevoerd bij personen met een hepatitis C infectie in New South Wales (n=504). Personen die met non-A non-B zijn gediagnosticeerd voor 1989, toen hepatitis C voor het eerst werd geïdentificeerd, zijn niet meegenomen in de studie. Er wordt vanuit gegaan dat deze personen aan een andere sociale dynamiek blootgesteld waren dan ná 1989, toen epidemiologisch was vastgesteld dat hepatitis C met name gerelateerd is aan intraveneus druggebruik. Van de deelnemers gediagnosticeerd met hepatitis C na 1989 (n=417) rapporteerde een kleine dertig procent (29.5%, n=123) 'geen uitleg' van hun dokter te hebben gekregen over hun infectie. Vrouwen en personen gediagnosticeerd tussen 1989 en 1996 (het tijdperk voorafgaand aan de oprichting van de 'Australian Hepatitis Council', die informatieve brochures publiceerde), rapporteerden significant vaker dat ze geen uitleg hadden ontvangen dan mannen en personen gediagnosticeerd na 1996 (respectievelijk

35.4% vs. 23.7% en 37.5% vs. 23.0%). Evenzo, injecterende druggebruikers en personen gediagnosticeerd tussen 1989 en 1996 rapporteerden significant vaker geen counseling na de diagnose te hebben ontvangen dan non-injecterende druggebruikers en personen gediagnosticeerd na 1996 (respectievelijk 42.9% vs. 30.2% en 37.6% vs. 25.9%). Deelnemers gediagnosticeerd tussen 1997 en 2001 rapporteerden significant vaker brochures te hebben ontvangen over hepatitis C (39.2% vs. 23.7%), informatie over behandelingen te hebben gekregen (24.5% vs. 16.2%), en advies over natuurlijke therapieën te hebben gekregen (9.1% vs. 3.8%) dan personen die eerder gediagnosticeerd werden. Deze resultaten wijzen op een groei in de verspreiding van informatie over hepatitis C door artsen bij de diagnostiek aan het einde van de jaren 90. Echter, het blijft nodig om het informatieaanbod van artsen aan nieuw-gediagnosticeerden te bevorderen. Hetzelfde geldt voor het doorverwijzen van deze personen naar specialisten en steunpunten.

**Hoofdstuk 4** handelt over discriminatie gerelateerd aan hepatitis C. Dit hoofdstuk rapporteert resultaten van een cross-sectionele studie bij personen met hepatitis C (n=504) uitgevoerd in New South Wales, Australië in 2001 en 2002. De deelnemers vulden een vragenlijst in over hun ervaringen met het leven met hepatitis C. Meer dan de helft van de deelnemers (57,7%, n=290) rapporteerde dat ze de infectie hadden verkregen door het injecteren van drugs. Discriminatie werd door 64,7% (n=326) gerapporteerd en de gezondheidszorg was de meest vermelde setting waar de discriminatie plaatsvond. Met een logistische regressie werden potentiële voorspelers van blootstelling aan een of meerdere vormen van discriminatie onderzocht. De volgende factoren droegen daar aan bij: veel andere mensen kennen met hepatitis C (i.e., zes personen of meer); "erg moe" voelen door de hepatitis C symptomen; en jonger zijn (i.e., jonger dan 51 jaar). Predictoren voor een sterkere mate van discriminatie waren: veel andere mensen kennen met hepatitis C (i.e., zes of meer); soms of meestal beperkt zijn in sociale contacten met familie, vrienden, burens en andere groepen door de symptomen van hepatitis C; en pessimistisch zijn over de behandeling en de toekomst vanwege een slechte gezondheid veroorzaakt door hepatitis C. Hoewel discriminatie in verschillende sociale domeinen voorkomt, is het belangrijk dat de gezondheidszorg voor patiënten met hepatitis C verbetert. Aanhoudende discriminatie kan mensen weerhouden om gebruik te maken van gezondheidsfaciliteiten en pogingen verhinderen om deze epidemie te bedwingen.

**Hoofdstuk 5** presenteert een van de eerst gepubliceerde kwalitatieve studies naar de ervaringen van patiënten met het krijgen van een hepatitis C behandeling. Klinische studies naar interferonbehandelingen voor hepatitis C laten dalingen zien in de gezondheidsgerelateerde kwaliteit van leven van deze patiënten door de bijwerkingen van de behandelingen. De invloed van de bijwerkingen op de overall kwaliteit van leven van patiënten is onduidelijk. Om dit te onderzoeken werden personen uit New South Wales geïnterviewd die een behandeling voor hepatitis C hadden ondergaan. Dit hoofdstuk rapporteert de ervaringen van patiënten met de bijwerkingen en de effecten van de behandeling. Deze informatie is van belang omdat interferon-behandeling inmiddels de voornaamste behandeling voor hepatitis C is en er naar verwachting

nog veel meer mensen in Australië voor deze behandeling zullen kiezen. De auteur concludeert dat meer kwalitatief onderzoek moet worden uitgevoerd om kennis over de invloed van deze behandeling op kwaliteit van leven te vergroten.

**Hoofdstuk 6** beschrijft ervaringen met het voorbereiden en begeleiden van mensen tijdens een zes of twaalf maanden durende behandeling met interferon voor hepatitis C. De klinische literatuur geeft aan dat een groot deel van de patiënten vanwege bijwerkingen lagere doseringen neemt of helemaal stopt met de behandeling. Thans is er geen gepubliceerde literatuur die beschrijft hoe gezondheidszorgprofessionals patiënten voorbereiden op een hepatitis C behandeling en er is een schaarste aan literatuur over hoe er wordt omgegaan met bijwerkingen. De resultaten van een kwalitatieve studie worden in dit hoofdstuk gepresenteerd. In deze studie werd semi-gestructureerde diepte-interviews gehouden met gezondheidszorgprofessionals die ervaring hebben met het managen van hepatitis C behandeling. Het onderzoek werd uitgevoerd in Sydney (Australië) in 2004 en 2005. Het doel van de studie was om de ervaringen van gezondheidszorgprofessionals met de voorbereiding van een behandeling te rapporteren en daarnaast de behandelingsstrategie van deze professionals bij hepatitis C te identificeren en te beschrijven. Deelnemers rapporteerden dat de voorbereiding, voorafgaande aan de behandeling, met name bestond uit het geven van informatie over de bijwerkingen en over de medische strategieën om de impact hiervan te verminderen. De kwetsbaarheden en sociale steun van de patiënten werden voor de start van de behandeling bepaald en professionals probeerden zo veel mogelijk problemen van de patiënten die zich tijdens de behandeling voordeden aan te pakken. Deelnemers van het onderzoek noemden de resiliënt coping stijl van de patiënten en het profijt dat dit heeft bij de behandeling. De resultaten laten zien dat bij deze steekproef van gezondheidszorgprofessionals een aanpak gebaseerd op beperkingen ('deficits-based approach'), werd gehanteerd bij de behandeling van hepatitis C. Hoewel er pogingen zijn gedaan om de bevorderende factoren in kaart te brengen zijn deze beperkt tot het identificeren van familieleden, collega's en anderen in de sociale netwerken van de patiënt die steun kunnen bieden aan de patiënten wanneer er problemen zijn. Het onderzoeken van eerdere negatieve ervaringen en een gedetailleerde evaluatie van bevorderende factoren ('strengths-based assessment') kunnen klinici helpen bij het managen van een behandeltraject van hepatitis C.

**Hoofdstuk 7** onderzoekt het fenomeen van personen die drugs gebruiken tijdens een behandeling voor hepatitis C, gezien vanuit het perspectief van een groep gezondheidszorgprofessionals. Onderzoek naar druggebruik tijdens een hepatitis C behandeling ontbreekt in de klinische literatuur. Data van een kwalitatieve studie bij professionals die hepatitis C behandelingen verzorgen in drie grote ziekenhuizen in Sydney (Australië) worden gepresenteerd. Tijdens semi-gestructureerde diepte-interviews bespraken de deelnemers het gebruik van zowel geïnjecteerde drugs als niet-geïnjecteerde drugs tijdens een veeleisend therapeutisch traject. De professionals benadrukten de sociaal-conservatieve omgeving van de gezondheidszorg en de negatieve kijk op druggebruikers. Verder werd ook het omgaan met personen die drugs injecteren tijdens de behandeling besproken en de doeltreffendheid van cannabis om bijwerkin-

gen te verminderen. De bevindingen van deze studie geven aan dat hoewel de professionals een harm reduction aanpak hanteren bij patiënten die drugs gebruiken tijdens de HVC behandeling, informatie over de risico's en baten van druggebruik in deze context wordt verzwegen. Aangezien het beleid van Australië druggebruik verbiedt, is het onwaarschijnlijk dat deze situatie zal veranderen. Verder onderzoek dient zich te richten op de mate van druggebruik tijdens hepatitis C behandelingen, de risico's en baten geassocieerd met het gebruik van drugs tijdens een behandeling en de valkuilen van het instandhouden van een deels misleidend gezondheidszorgsysteem.

**Hoofdstuk 8** analyseert de paradoxale associatie tussen sociale marginalisatie en positieve gezondheidsuitkomsten bij personen die een hepatitis C behandeling ondergaan. In dit hoofdstuk rapporteerden deelnemers die in sociaal nadelige omstandigheden leven dat ze adaptieve strategieën gebruikten die ze bij eerdere ervaringen van druggebruik, symptomen van chronische ziekte, depressie en seksueel misbruik in de jeugd hadden geleerd, om zo om te gaan met de zware bijwerkingen van de hepatitis C behandeling. Deze bevinding heeft implicaties voor de klinische behandeling van hepatitis C. Het in kaart brengen van factoren en processen die het omgaan met tegenslagen, geassocieerd aan sociale marginalisatie, vergemakkelijken, kunnen ook een bijdrage leveren aan het omgaan met een zware behandeling.

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I dedicate this thesis to my mother Marge Hopwood for a lifetime of love and support, and for her fabulous sense of humour.

## CURRICULUM VITAE

Max Hopwood graduated from Charles Sturt University in 1997 with a Bachelor of Arts (Honours) majoring in psychology. He then commenced working with the National Centre in HIV Social Research (NCHSR) where for the past decade he has conducted studies into the health and quality of life of socially marginalised populations. Max's main research interests include the psychosocial dimensions of blood borne virus transmission, illicit drug use, quality of life issues for people living with hepatitis C infection, and the impact of stigmatisation and discrimination on health.