

# Psychosocial aspects of living with hepatitis C

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Hepatitis C is a blood-borne virus infecting over 170 million people worldwide. About 200 000 people in Australia are estimated to have chronic infection, with about 10 000 new infections yearly (Ministerial Advisory Committee, 2006). The most common cause of transmission (around 80%) is injecting drug use. Other causes include blood transfusions and other medical and dental procedures, either in Australia or overseas. Since 1990, when screening of blood for hepatitis C was implemented, causes other than drug injecting have become rarer. Hepatitis C infection has an uncertain disease course that varies from person to person. The most common symptom is fatigue, both mental and physical. Other symptoms include nausea, joint pain, depression and irritability.

Hepatitis C infection is not life-threatening for the majority of people who contract it. About 25% clear the infection spontaneously, but many have chronic infection and some go on to develop serious liver disease. Chronic hepatitis C infection is associated with a significantly reduced quality of life, but clinical markers such as indicators of liver function are not good indicators of subjective well-being or the severity of symptoms (Miller et al., 2001). Quality of life can also be affected by stigma, fear around disclosure and transmission, and difficulties in employment and sexual relationships.

While more men than women have hepatitis C, the last few years have seen a rise in its incidence in young women in Australia. Attention to gender issues is important for appropriate care and prevention strategies. Women appear to experience stigma associated with injecting drug use and hepatitis C more keenly than men. Men tend to downplay the physical and social impact of infection and be less active in seeking out health care or advice (see summaries SRB8/003 and SRB8/004 below).

## Diagnosis

A diagnosis of hepatitis C virus infection is often unexpected and can be devastating. People with hepatitis C are not a homogenous group. For some, transmission may have occurred through a past dalliance with drug use, or a pre-1990 blood transfusion, rather than as a result of current injecting. The shock of diagnosis is exacerbated by a documented lack of pre- and post-test counselling (or even informed consent to test for the virus) and often discriminatory treatment from health care professionals. The experience of diagnosis seems not to have improved significantly over the past decade, although hepatitis C has been prioritised by the Australian government in a

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national strategy. While dissemination of information has improved somewhat, current injecting drug users are especially likely to receive inadequate care, counselling, information and referrals to support and specialist services (Hopwood & Treloar, 2003; 2005). Rodger et al.'s findings (SRB8/002 below) suggest that people may feel healthier if they do not know they are infected. As treatment for hepatitis C is often debilitating, with side effects that are sometimes severe and no guarantee of efficacy, health care workers have a significant moral obligation to obtain informed consent for testing and to ensure non-discriminatory care and support.

## Decisions about treatment

Papers concerned with treatment are not summarised in this *Brief*, but were covered in SRB3, 'New treatment for hepatitis C infection' (December 2003). Currently the standard therapy is a course of pegylated interferon and ribavirin, usually lasting six or 12 months depending on the genotype of the virus with which the person is infected. Treatment has a number of problematic side effects and, as efficacy is not guaranteed (success rates are around 50% to 80%), the issue of whether to embark on treatment is fraught for many people. A person's ability to undertake and remain on treatment may be affected by their motivation for treatment, the severity of side effects, the impact of treatment on work and relationships, issues around drug and alcohol use and the availability of medical and social support (McNally et al., 2004; Coughlan et al., 2004; Fraenkel et al., 2006; Hopwood & Treloar, 2005). Some people with hepatitis C never face these issues because they are unaware that any treatment is available or that they may qualify to receive it.

## Stigma

The continuing association of hepatitis C virus infection with injecting drug use raises issues of discrimination and stigmatisation. The rights to health and well-being of people who inject drugs are undermined by their peripheral status in debates on public health. Stigma related to hepatitis C has been found to have negative effects on self-esteem, access to health care, employment and social support (Crockett & Gifford, 2004), and major deleterious effects upon health and well-being (Ward et al., 2000; Loveday et al., 2005). It is one of the principal barriers that prevent people from coming forward for testing, management and treatment (Anti-Discrimination Board of NSW, 2001; SRB8/009; SRB8/010). Unfortunately the health care

sector is where most discrimination is experienced (Crofts et al., 1997; Anti-Discrimination Board of NSW, 2001; Hopwood & Treloar, 2003; SRB8/003). One probable reason for this is that people with hepatitis C are more likely to disclose their status in a medical setting, whether this is unavoidable or done voluntarily through a desire to prevent transmission (Treloar & Hopwood, 2004). Incidents of discrimination in health care settings, where people go to seek care and support, are doubly distressing. The assumption by health care workers that someone with hepatitis C is an injecting drug user appears to lie at the core of such discrimination, but the reasons for people feeling entitled to hold a low opinion of drug injectors are not well understood and little researched.

## Conclusion

Hepatitis C infection has a significant impact on quality of life. Not only do symptoms such as fatigue diminish functioning, but living with a chronic stigmatised illness with an uncertain future creates dilemmas around disclosure, accessing support, and sustaining self-esteem, employment and relationships. Although Australia has responded comparatively quickly to the epidemic, the research so far reveals that people with hepatitis C have unmet health care needs and have experienced unsatisfactory care and barriers to treatment. Stigma needs to be addressed both in research and in programs to counter discrimination in health care. In the short term, health care workers can help by

providing better pre- and post-test counselling, information, non-discriminatory service and referrals to appropriate social and clinical support. These improvements are essential if people with hepatitis C are to access treatment willingly and easily and have the chance to clear the virus and avoid future liver disease, particularly as success rates may rise as new more effective treatments become available.

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## SRB 8/001

Spiegel, B. M. R., Younossi, Z. M., Hays, R. D., Revicki, D., Robbins, S., & Kanwal, F. (2005). Impact of hepatitis C on health related quality of life: A systematic review and quantitative assessment. *Hepatology*, 41, 790–800.

While initially hepatitis C infection was thought to be asymptomatic, it has become clear that infection diminishes health-related quality of life. Having hepatitis C may affect people through effects of the virus on the body (including the brain), or through a synergy between hepatitis C infection and other psychosocial problems. Clinical studies now often measure patient-oriented outcomes as well as biological outcomes such as viral load or the condition of the liver.

Spiegel et al. set out to systematically examine the medical literature (1990 to June 2004) on health-related quality of life in people with hepatitis C infection and to compare them with healthy people. Pooling 15 studies using the SF-36 scale that compared people with and without hepatitis C, the authors found a clinically important difference between the two groups. People with hepatitis C had lower quality of life than healthy people, and the impact was greatest in social and physical function, general health and vitality. This was improved if treatment achieved sustained virological response.

Clinical outcomes related to the disease, such as liver enzyme levels and physical changes in the liver, did not correlate with health-related quality of life, leading the authors to conclude that traditional measures of liver function fail to capture the full range of illness in people with chronic hepatitis C infection.

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## SRB 8/002

Rodger, A. J., Jolley, D., Thompson, S. C., Lanigan, A., & Crofts, N. (1999). The impact of diagnosis of hepatitis C virus on quality of life. *Hepatology*, 30, 1299–1301.

This ingenious study set out to determine whether people with hepatitis C felt worse because of physiological effects of the virus, or whether knowing they were infected had its own effect on their well-being. It was based on a retrospective study looking at people who were diagnosed with acute viral hepatitis, and from whom stored blood serum was available, at one hospital in Melbourne in the 1970s.

The investigators tested the stored serum and found samples from 238 patients that had hepatitis C virus antibodies. They located and recruited into the study 91 individuals (47%). Of the 91, approximately half of those recruited were unaware of their hepatitis C status; they were informed of their diagnosis at the end of the study. Health outcomes were assessed by

clinical examination and serological, virological and liver function tests, as well as a questionnaire and completion of a generic quality-of-life instrument, the SF-36 scale.

In analysing the results, researchers excluded participants who were found to be currently hepatitis-C-negative, had cirrhosis or clinically detectable liver disease, were symptomatic or had medical conditions other than hepatitis C that could affect their quality of life. That left 34 people: 15 of them knew they had hepatitis C before being approached by the researchers and 19 did not know. None of the 15 who already knew had been tested because they had symptoms, but rather for reasons such as having a history of injecting drug use, their partner having hepatitis C, or during routine health screening.

The two groups, those aware of their hepatitis C status and those unaware, had been infected for an average of 26 years. All individuals had a history of injecting, though none had injected within the past two years. None had been treated with standard or naturopathic therapies. The only difference was that those who knew they had hepatitis C were less likely to drink alcohol, probably because they had been advised not to when they were diagnosed.

Both groups scored significantly lower than the general population on quality-of-life scores. Interestingly, the group who were aware of their

diagnosis scored significantly lower than those who were unaware. These results suggest that hepatitis C infection affects quality of life on two levels: physiologically (for example fatigue and nausea) and psychologically (the burden of living with a stigmatised disease with an uncertain trajectory). The authors suggest that physicians may reduce this negative psychological impact through the 'appropriate and sensitive management' of diagnosis.

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### SRB 8/003

Gifford, S. M., O'Brien, M. L., Bammer, G., Banwell, C., & Stooove, M. (2003). Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional study. *Journal of Gastroenterology and Hepatology*, 18, 841-850.

In Australia approximately a third of people living with hepatitis C are women, though among teenagers the numbers of males and females recently infected are roughly equal. When women are a minority of those with a condition (such as HIV in Australia) their needs are often overlooked or care is inappropriate. This study is the first comprehensive social survey of women's experiences of living with hepatitis C in Australia.

Recruitment took place in 2000. Questionnaires were distributed through Victorian and ACT community health centres and specialist liver centres, injecting drug user organisations and hepatitis C councils. A total of 462 women completed the questionnaire, a return rate of 75%.

The women were aged 15 to 71 years (average age 35) and had been infected for 10 years on average. Over half of the women (60%) had contracted hepatitis C virus from injecting drug use, with blood transfusions (12%) the next most common source. Nearly one in five (19%) did not know how they had contracted hepatitis C virus.

Very few (17%) had received pre-test counselling and only half (49%) post-test counselling, despite guidelines recommending this. Over half the women (56%) were currently seeing a doctor for their hepatitis C infection and, of these, 50% were satisfied with their medical care. Nearly half (48%) said they had experienced less favourable treatment from health professionals because of their status. Interferon-based treatment had been given to 17%.

Standardised questionnaires were used to ascertain symptoms and self-rated general health and mental and physical well-being. More than half (58%) had had symptoms of hepatitis C infection, the most common being tiredness, nausea and psychological or emotional problems. Half (48%) rated their health as 'fair' or 'poor', compared with 17% in the general population.

Overall, the 462 women had poorer mental and physical health than the general population, and current or former injecting drug users scored worse than those who had

not used. This suggests there is considerable room for improvement of health care for women with hepatitis C infection, starting from improving pre-test counselling and information provision.

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### SRB 8/004

Gifford, S. M., O'Brien, M. L., Smith, A., Temple-Smith, M., Stooove, M., Mitchell, D., & Jolley, D. (2005). Australian men's experiences of living with hepatitis C virus: Results from a cross-sectional study. *Journal of Gastroenterology and Hepatology*, 20, 79-86.

Approximately two-thirds of those living with hepatitis C in Australia are men. This study collected information to allow comparison with the study of women conducted in 2000 (see SRB 8/003 above) and to investigate men's health concerns, social life and relationships.

Recruitment took place in 2002 with questionnaires distributed through Victorian community health centres and specialist liver centres, injecting drug user organisations and the Hepatitis C Council. The return rate was 54%.

The 312 men who responded were aged 19 to 90 (average age 38). On average, they had been diagnosed seven years earlier and reported having been infected about 13 years earlier, although 32% did not know when they had been infected. Most of the men (86%) had injected drugs and 57% were current injectors. Their socioeconomic status was generally low: 64% were living on social security and more than half had not finished high school. Nearly half (48%) had spent time in prison or on remand. Nearly three-quarters (73%) had been infected through injecting drug use, 9% were infected through blood transfusions, and 9% did not know how they had caught hepatitis C virus.

Few men had received pre-test counselling (18%) and only a third were satisfied with the way they had been told their diagnosis. Less than half (43%) were currently seeing a doctor for their hepatitis C infection and, of these, 50% were satisfied with their current care. Many of the men (40%) perceived that they had received less favourable treatment by health care professionals and 20% had received interferon-based treatment.

Fifty per cent of the men had experienced symptoms of hepatitis C infection, the most common being tiredness, followed by nausea and liver pain. Men were more likely to have ignored symptoms of illness than women; however, 35% rated their health as 'fair' or 'poor', compared with 18% of men in the general population. Many were worried about being able to work and provide for their families, and more than half were concerned about being unable to have a drink with their mates.

The study reveals unmet health care needs, unsatisfactory care and barriers to treatment.

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### SRB 8/005

Coughlan, B., Sheehan, J., Hickey, A., & Crowe, J. (2002). Psychological well-being and quality of life in women with an iatrogenic hepatitis C virus infection. *British Journal of Health Psychology*, 7, 105-116.

This Dublin study documents psychological well-being, mental health and quality of life in 93 women diagnosed with medically acquired hepatitis C infection. Also examined is the relationship between hepatitis-C-virus RNA status and the women's adjustment to their illness.

The participants had contracted hepatitis C from contaminated blood transfusions or from contaminated anti-D immunoglobulin for rhesus incompatibility in 1997 or 1991. All of the participants were hepatitis-C-antibody-positive. Of these, 60 had chronic infection (they were hepatitis-C-virus RNA-positive) and 33 had self-limiting infection (they were RNA-negative). The women took part in the study during their clinic visits between October 1996 and February 1997. Psychological well-being, mental health and quality of life were assessed using instruments such as the SF-36 and the General Health Questionnaire-30. Virological tests and biopsy results were also analysed.

Overall, the women in both groups had significantly lower quality of life than the healthy British female population. No difference was found between women who had a past or current hepatitis C virus infection; both groups reported having low energy, poor health and problems with work and other daily activities.

These findings are consistent with those of Rodger et al. (see SRB 8/002 above) in that they indicate that reduced quality of life may be linked to the diagnostic process rather than hepatitis C infection *per se*. While hepatitis C has been shown to have a significant physiological effect on quality of life, it is important not to underestimate the social and psychological consequences of being diagnosed with a stigmatised chronic illness that has an unknown course and outcome.

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### SRB 8/006

Gill, M. L., Atiq, M., Sattar, S., & Khokhar, N. (2005). Psychological implications of hepatitis C virus diagnosis. *Journal of Gastroenterology and Hepatology*, 20, 1741-1744.

Most research that investigates a correlation between hepatitis C infection and lowered quality of life has taken place in developed countries. Gill et al. aim to rectify this imbalance and establish the impact of hepatitis C diagnosis in a developing country. The study was conducted at the Shifa International Hospital, Islamabad, in 2004. Ninety-eight recently diagnosed patients completed a questionnaire that compared stress due to hepatitis C diagnosis with death of a close family member, divorce, loss of source of income and a move to another city. Anxiety was measured in patients using the

Beck Anxiety Inventory. One hundred healthy controls were also enrolled in the study.

Forty-one (42%) of the hepatitis-C-positive participants were women and 57 (58%) were men. Thirty-one (32%) patients who were diagnosed with hepatitis C presented only with fatigue. Sixty-three (64%) patients stated that diagnosis interfered with their daily life in some way. Forty-eight (49%) patients had moderate to severe anxiety, which was related to the stress of hepatitis C diagnosis and self-perceived severity of disease. This was compared to eight (8%) of the controls who exhibited moderate anxiety; none exhibited severe anxiety.

The authors found that hepatitis C diagnosis was significantly more stressful than divorce, loss of source of income, or a move to another city. In Islamabad, divorce and loss of income were major stressors: divorce was a social taboo and there was no state or community financial support for those without an income. The authors recommended that pre- and post-test counselling and psychosocial support would help to reduce the stress associated with hepatitis C diagnosis.

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#### SRB 8/007

Sladden, T. J., Hickey, A. R., Dunn, T. M., & Beard, J. R. (1998). Hepatitis C virus infection: Impacts on behaviour and lifestyle. *Australian and New Zealand Journal of Public Health*, 22, 509–511.

This study was based on the New South Wales North Coast and involved all individuals notified with hepatitis C infection over 21 months in 1993 and 1994. Participants were asked to complete a questionnaire to examine exposures, therapies and behaviours; 467 people responded.

Awareness of risk factors varied: 69% of respondents were aware of potential exposure that might have led to their infection. Of the 398 people who had ever injected drugs, 60% saw this as an exposure.

A majority of participants (338, 72%) reported having had no treatment for hepatitis C and 12 (3%) had used interferon-based treatment. Naturopathy was used by 48 (10%), with homeopathy, stress management, yoga, reduced drug and alcohol intake and counselling also utilised to improve health.

The most commonly reported symptom was fatigue (45%); other symptoms were nausea and emotional disturbances such as depression. For some people hepatitis C had minimal impact, but others reported negative effects including isolation and discrimination. Fatigue and other symptoms affected the ability to work and thus financial circumstances. The effect of hepatitis C infection on new or current relationships was also a concern. The authors noted that many respondents reported deterioration in circumstance and well-being, but for some hepatitis C had motivated changes in lifestyle to reduce liver damage or generally improve health.

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#### SRB 8/008

Krug, G. J. (1995). Hepatitis C: Discursive domains and epistemic chasms. *Journal of Contemporary Ethnography*, 24, 299–322.

This article, while a decade old, is a seminal exploration into the meaning-making processes around hepatitis C. Krug reports that people with hepatitis C infection 'have been told that something important about them and their lives has changed, but no one can say exactly what is different'. Using a framework that draws on postmodern theories of social life and the construction of meaning, the author asks what happens to the individual who is diagnosed. Krug draws on an array of data, including interviews with hepatitis-C-positive people and with physicians, observation at hepatitis C support group meetings and cultural texts such as newspapers and television.

A common response to diagnosis is a medicalising of the self, sometimes with an 'almost fetishized following of medical procedures and test results'. Test results may become an 'objective' measure of damage or illness even for people who do not feel ill. People may monitor, collect and share information about hepatitis C, sometimes believing that officialdom is not acting or taking the disease seriously enough.

In the public domain, community-based organisations and support groups translate medical and scientific information into readable English and often provide referral lists of specialist or sympathetic health care providers. However, 'people do not want abstractions about the statistical probabilities of developing liver cancer; they want to know whether they will develop it.' Much of the worry and distress felt by people with hepatitis C is due to this uncertainty. People with hepatitis C have the task of explaining to others what it means. The only discourse available to them is medical, yet it is inadequate.

The chasm in Krug's title is between the doctors' ways of knowing about hepatitis C (as expressed in many of the other article summaries in this *Brief*) and the person's experience.

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#### SRB 8/009

Hopwood, M., Treloar, C., & Bryant, J. (2006). Hepatitis C and injecting-related discrimination in New South Wales, Australia. *Drugs: Education, Prevention & Policy*, 13, 61–75.

This New South Wales study was based on questionnaires completed by 504 people with hepatitis C in 2001 and 2002. Recruitment was through the Hepatitis C Council of NSW and a needle and syringe program. Over half of the respondents (58%) reported that they had acquired their infection from injecting drug use.

Discrimination, either because they had hepatitis C or were thought to be an injecting

drug user, was reported by 65% of respondents, usually in health care settings. People who had experienced discrimination were more likely to know other people with hepatitis C, have symptoms of fatigue, and to be aged 50 or younger. People who knew many others with hepatitis C, who felt isolated from family, friends, neighbours and groups because of their hepatitis C and who felt pessimistic about treatment and the future because of hepatitis-C-related ill health were more likely to have experienced higher levels of discrimination.

Discrimination may alienate people with hepatitis C and make them reluctant to be tested or to attend drug treatment or other health care, thus reducing their access to information about transmission and prevention. Training for health care workers that includes critical reflection on prejudices and beliefs is needed.

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#### SRB 8/010

Zickmund, S., Ho, E. Y., Masuda, M., Ippolito, L., & LaBrecque, D. R. (2003). 'They treated me like a leper': Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine*, 18, 835–844.

This study was based in a United States specialist liver clinic and combined standard questionnaires and semi-structured qualitative interviews. Of 257 patients who gave full data, 55% had contracted hepatitis C through injecting drug use. A quarter (25%) did not know the source of their infection. More than half of the patients had experienced stigmatisation as a result of having hepatitis C. Women were more likely to report stigmatisation than men, but the experience was unrelated to how people caught the virus. Therefore, the conclusion cannot be drawn that it was characteristics of the patients, such as pre-existing psychological problems in drug users, that brought about discriminatory treatment.

The three most common perceived reasons for stigma were society's association of hepatitis C virus with HIV/AIDS, the attribution of promiscuity, and the assumption that the person with hepatitis C was an injecting drug user. Patients were stigmatised in the health care setting and also in the workplace as a result of misplaced fears of contagion. This also, painfully, occurred within families, with hepatitis-C-positive people being banned from the house or not allowed to touch children.

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