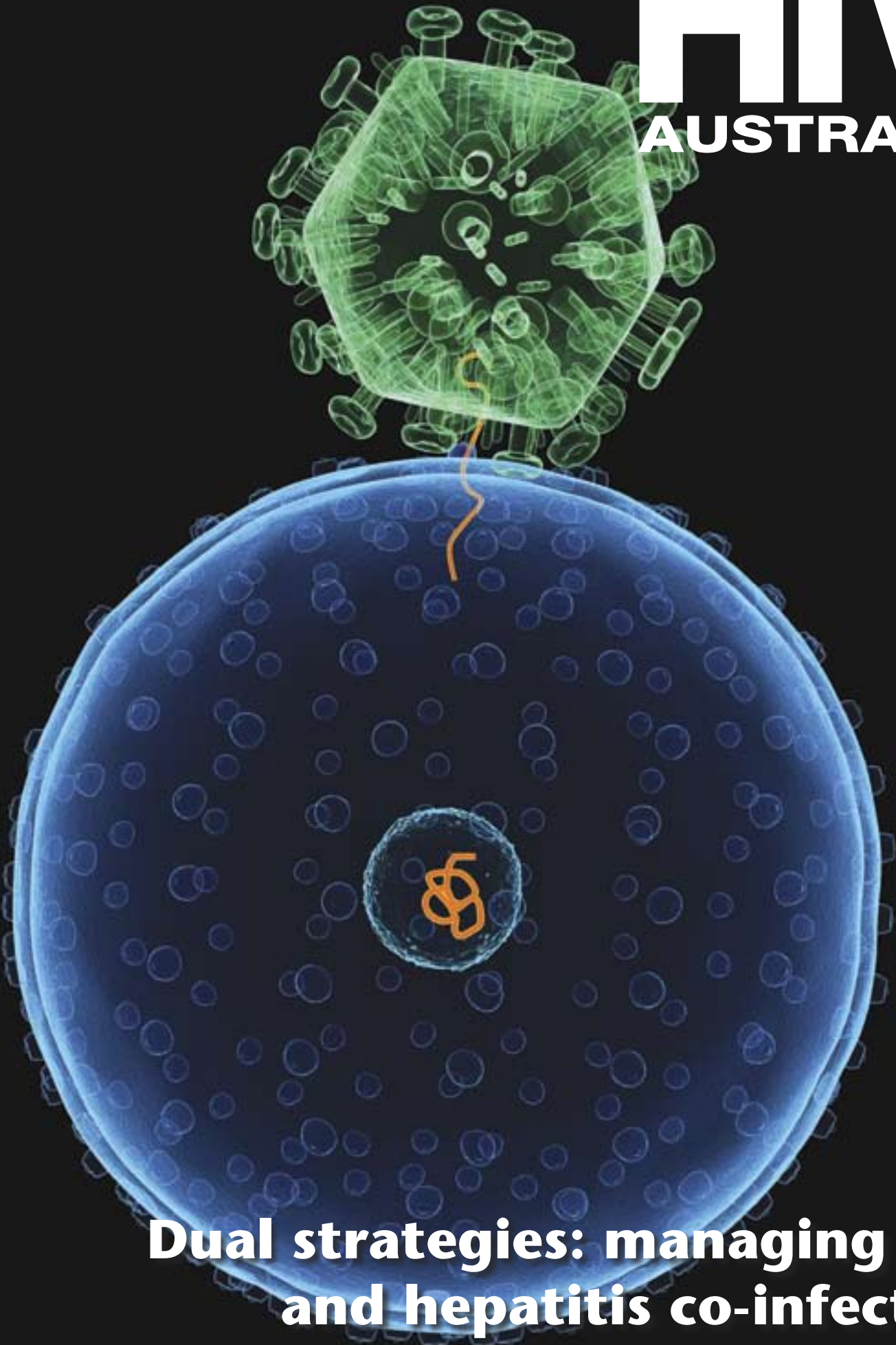


HIV AUSTRALIA



**Dual strategies: managing HIV
and hepatitis co-infection**

Volume 8 • Number 1

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AFAO's aims are to:

- Advocate on behalf of its members at the Federal level, thereby providing the HIV/AIDS community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV/AIDS;
- Develop and formulate policy on HIV/AIDS issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV/AIDS and its effects.

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AFAO is the peak non-government organisation representing Australia's community-based response to the epidemic of HIV/AIDS. AFAO's members are the state and territory AIDS councils, the National Association of People Living with HIV/AIDS, the Australian Injecting and Illicit Drug Users League, Scarlet Alliance and the Anwernekenhe National Alliance.



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AUSTRALIAN NEWS

Major overhaul of Australia's health system

The Australian government's proposed restructure of Australia's health system has met with a variety of strong reactions – especially from state and territory governments.

The government argues that the current health system is no longer viable; that without fundamental restructuring, state/territory governments would be placed under overwhelming and unsustainable financial pressure – particularly given the ageing of the population. The government states its proposed restructure 'will represent the biggest change to Australia's health and hospital system since the introduction of Medicare, and one of the most significant reforms to the federation in its history'.

The restructure includes plans to create a single national network of hospitals, replacing eight separate systems within each state/territory and the establishment of national hospital service standards. Under the new system, the federal government would provide 60% of health funding, while local hospital networks will be established to make decisions on local hospital administration. General practice and primary health care will also be restructured to improve clinical governance, quality of care and efficiency.

The government intends to seek the agreement of the states and

territories at the upcoming Council of Australian Governments meeting in April. If agreement cannot be reached, the proposal will be put to referendum – either before or during this year's election.

Australian author refused visa to visit China

China's refusal to grant a visa to prize-winning Australian novelist Robert Dessaix on the basis of his HIV status has brought the country's entry ban on people with HIV into the spotlight.

Dessaix had been invited to attend the Shanghai International Literary Festival and also had been invited to speak in Beijing and Chengdu. However, he was refused a visa after stating in his application that he has HIV.

China's travel ban dates back to the 1980s, when the HIV epidemic first emerged in the country. A temporary waiver was issued in 2008, to allow people with HIV to attend the Beijing Olympics. It was understood that the country's health ministry aimed to fully repeal the ban in time for a trade exposition that opens in Shanghai on 1 May this year.

Mr Dessaix said he felt humiliated by the refusal. 'I am not a threat. I don't write on political issues. I feel I've been spat on,' he said.

Australian Federation of AIDS Organisations Executive Director Don

Baxter said that the Chinese decision was disappointing. 'China is one of the few remaining countries that discriminates against HIV-positive travellers. The United States has recently lifted its travel ban against people with HIV, and we look forward to the Chinese government doing the same,' he said.

Chlamydia rates hit an all-time high in Australia

The National Notifiable Diseases Surveillance System shows that 61,172 notifications of chlamydia were recorded in 2009. Chlamydia is the most commonly reported notifiable condition in Australia, and diagnoses have tripled in the last decade. In 2000, there were 16,960 reports of the infection.

National Clinical Adviser of Marie Stopes International, Jill Michelson, says the increase is 'frightening'. People with chlamydia often experience no symptoms, but the infection can cause infertility if left untreated. Ms Michelson urged people to have regular sexual health testing, warning that 'those that don't use condoms are at risk.'

'It is vital that sexually active women and men learn how to identify the symptoms of STIs, and be aware that some STIs can be carried without displaying any obvious signs of infection,' she said.



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NEWS FROM THE ASIA PACIFIC

Fiji moves to de-criminalise homosexuality

Gay groups have welcomed Fiji's move to recognise the gay community by introducing a decree to decriminalise homosexuality.

The Pacific Coordinator of UNAIDS, Stuart Watson said that the decree was a helpful step in dealing with HIV/AIDS and other sexually transmitted infections.

'We'd just like to compliment Fiji on taking a really very bold step. The crimes decree removing sodomy and decriminalising homosexuality makes Fiji a first in the Pacific. And it certainly is a huge step forward in achieving a rights respecting legal framework for men who have sex with men and for really the entire community,' Watson said.

Asaeli Sinusetaki, a member of the gay organisation Men Fiji, says it paves the way for people like him to be more open about their sexuality.

'For myself it is such a huge step that this change has come up now. The fact that Fiji has become the first Pacific nation to decriminalise it [homosexuality]. I think it's a huge step and I think it's a great step for homosexual and gay men here in Fiji,' he said.

Philippines HIV cases spike

The Philippines has recorded a 'spike' in HIV infections, with 143 people diagnosed in January – the highest on record since the beginning of the epidemic there. The country's health Health Secretary, Esperanza Cabral, says an average of around 60 Filipinos had been diagnosed as

HIV-positive each month, but that figure rose sharply to 126 cases in December. 'We're alarmed over the sudden big increase of HIV infection cases since December 2009,' Ms Cabral said. 'At the rate we are going, in three years we are going to have more than 30,000 people with HIV/AIDS in the Philippines.'

The Philippines is considered a low prevalence country, with 4,424 reported cases of HIV since 1984. National prevalence is estimated at between 0.1 and 0.2%.

Most of the January cases were males infected through sexual contact with men, the health department said, and a majority of people infected were between ages 25 and 29. Ms Cabral said that she would seek more public funds to distribute condoms among high-risk groups.

Cabral's efforts to promote condom use in the Philippines have been controversial due to opposition from the Roman Catholic Church. 'I will continue to distribute condoms as a tool to create awareness on HIV/AIDS prevention,' Ms Cabral told Reuters, adding she would ask the government to fund the purchase of condoms for disease prevention rather than contraception.

Ms Cabral said the government has stopped allocating funds for condoms due to church pressure.

Nobel winner criticises Singapore over HIV treatment costs

Singapore's reliance on charging for HIV testing and treatment are counter-productive to prevention

efforts, according to Francoise Barre-Sinoussi, the co-discoverer of HIV. Ms Barre-Sinoussi was awarded the Nobel Prize in 2008 for her work in identifying the human immunodeficiency virus (HIV). 'The stigma, the fact that they have to pay for everything, it's the worst conditions for stimulating people to be tested and treated,' she said during a recent visit to Singapore.

New HIV diagnoses in Singapore rose to 456 in 2008, up from 242 in 2003, according to the Ministry of Health. However, Ms Barre-Sinoussi said, 'The numbers they announce are probably much lower than the numbers they have.'

Most insurers in Singapore do not cover the cost of HIV/AIDS treatments, which can be up to \$1,500 (US \$1,073) a month, said Stuart Koe, CEO of Fridae.com, Asia's largest gay website. Generic regimens are not on the market there, so doctors often advise patients to purchase them in Malaysia or Thailand, he said.

'It's a shame, because Singapore is considered by many to be a developed country,' Koe said. 'The HIV/AIDS community here is way behind most of the neighbouring countries as a result.'

In January, the government announced that it would subsidise treatments for people on low incomes. Even so, an anonymous HIV test costs \$30 (US \$21), according to Action for AIDS, Singapore's largest provider of anonymous screening.

'The situation is even worse than in developing countries not far from here,' Barre-Sinoussi said. 'In Cambodia, everything is free.'



INTERNATIONAL NEWS

HIV/AIDS now leading cause of death among women

A UN program on HIV/AIDS has warned that HIV is fast becoming the leading cause of death and disease among women of reproductive age worldwide.

International AIDS Society Executive Director Robin Gorna said, 'We're nearly three decades into the epidemic and we have the depressing news that AIDS is now the leading cause of death of women of reproductive age across the globe.'

'Three decades ago, very few women were infected with HIV. It was a minority issue. But sadly, as HIV has taken its increasing toll on women, the pace of research and the response really hasn't kept up,' Gorna said.

UNAIDS launched a five-year action plan addressing the gender issues which put women at risk, and says a key factor is that 70% of women worldwide have been forced to have unprotected sex. UNAIDS says that experiencing violence hampers women's ability to negotiate safe sex.

'By robbing them of their dignity, we are losing the opportunity to tap half the potential of mankind to achieve the Millennium Development Goals,' said UNAIDS Executive Director Michel Sidibe.

Circumcision no protection for gay men: study

A study in the US has found, despite the experience in Africa with heterosexual men, that circumcision for men who have sex with men does not alter the risk associated with transmitting HIV.

Studies in Africa have reportedly suggested that heterosexual men had a 60% less chance of acquiring HIV if they were circumcised.

The US Centers for Disease Control and Prevention (CDC) used

a three-year trial of an HIV vaccine involving almost 5,000 men – where 7% acquired HIV-positive – that found there was no difference with HIV transmission risk in circumcised or uncircumcised men.

The CDC is currently examining what recommendations it should make about circumcision for men who have sex with men and heterosexual men at high risk of contracting HIV.

But men who have sex with men in Australia are still being urged to continue with current safe sex practices.

'The available evidence does not indicate that circumcision can reduce the risk of HIV transmission among gay and bisexual men in Australia,' ACON's spokesperson said.

'The most effective way for gay and bisexual men to reduce the risk of HIV transmission is to use condoms and lube when having sex,' he said.

HIV associated with poorer sexual function in women

Sexual function is poorer in HIV-positive women than in women who are HIV-negative, according to a recent study published in the *Journal of Acquired Immune Deficiency Syndromes*. For women with HIV, increasing age and a lower CD4 cell count were associated with lower sexual functioning.

There has been little research into sexual function and satisfaction amongst women with HIV to date. 'Our analysis reveals that the burden of sexual problems is significantly higher among HIV-positive compared with HIV-negative women,' the investigators write. It is also possible that antiretroviral treatment may have a detrimental impact on sexual function.

Investigators from the *Women's Interagency HIV Study (WIHS)* conducted a cross-sectional study of 1,279 HIV-positive and 526 HIV-negative women, inquiring about sexual function and satisfaction. Overall, the

women with HIV had significantly lower sexual satisfaction scores than did the HIV-negative women (mean, 13.8 vs 18, $p < 0.001$). 'Our study shows a clear link between HIV infection and sexual problems among women,' the investigators comment.

They believe that their research has implications for the routine care of women with HIV and suggest that 'there is a role for assessment of sexual problems in overall care of women with HIV infection, particularly those classified as having AIDS'.

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US repeals NSP funding ban

Repeal of a ban on federal funding for needle exchange programs (NSPs) has been welcomed by HIV experts in the US. The repeal is 'a big victory for science and for public health,' said House Speaker Nancy Pelosi, whom advocates credit with helping to push the measure through Congress. The new law will make federal grants available for local NSPs that now exist in nearly every state, funded by state and local governments and private contributions.

The federal ban was enacted by Congress in 1988 and has been renewed annually. Supporters of the prohibition said NSPs would encourage the use of dangerous drugs. Robert Martinez, chief of drug policy under President George W. Bush, said government funding for clean needles 'undercuts the credibility of society's message that drug use is illegal and morally wrong'.

In 2000, however, the US Surgeon-General, David Satcher, said scientists had found that NSPs were effective and did not encourage drug use. A 1997 study said HIV infection rates had dropped by 5.8% in 29 cities around the world with the programs, and increased by 5.9% in 52 cities without them.

'Hundreds of thousands of Americans will not get HIV/AIDS or hepatitis C, thanks to Congress repealing the federal syringe funding ban,' said Bill Piper of the Drug Policy Alliance, one of many groups that lobbied for the change.



Murky waters: inquiry into the migration treatment of disability

By Michael Williams

The contemporary political and media obsession with asylum seekers who travel to Australia by boat has long overshadowed the many other iniquities which plague the nation's migration system. One such example is the treatment of refugees and potential migrants who have a chronic health condition or disability.

Under current Australian migration policy, applicants for residency must satisfy the 'health requirement' – a requirement that is iniquitous in several respects. This is particularly so for people living with HIV, who are generally refused permanent residence.¹

Migration lawyers and those within the HIV sector have regularly made proposals for reform of the present health requirement regime, and hopes for change have been heightened by the interest generated by the current joint Parliamentary Inquiry into the Migration Treatment of Disability. A

large number of submissions have been made to the Inquiry, and nation-wide public hearings are ongoing.

This article will discuss the impetus for the inquiry and, by reference to some of the submissions tendered, will detail the current application of the law to prospective migrants living with HIV. It is argued that the current system of regulations and policies is discriminatory and in desperate need of overhaul.

inquiry into the Migration Treatment of Disability

The Parliamentary Inquiry into the Migration Treatment of Disability was prompted by the case of German medical doctor, Bernard Moeller. Dr Moeller was originally granted a 457 temporary visa for skilled migrants, and he and his family travelled to Australia for Dr Moeller to take up work. The Moellers settled into the local

community where Dr Moeller took up work, and they decided to apply for permanent residence.²

The Moellers' applications for permanent visas were rejected – because Dr Moeller's son, who has mild down syndrome, failed the health requirement. If one member of an applicant's family fails the test, all fail, and the Department of Immigration and Citizenship (the Department) refused the whole family's permanent visa applications. Despite Dr Moeller's skills and work capacity, it was determined that allowing the Moellers to stay would 'likely result in significant costs to the Australian community in health care and community services. What followed was intense media scrutiny of the Department's decision and considerable public disquiet in

continued overleaf

the Horsham (Victoria) area, where Dr Moeller was one of only a few physicians servicing a region starved of doctors.³

While the Minister for Immigration and Citizenship, Chris Evans, exercised his statutory discretion to allow the family to remain⁴, the ensuing coverage of the case served to expose something gravely wrong at the heart of the regime for assessing applicants with an illness or disability. The Moeller case highlighted the fact that the current system which fails to recognise the potential contribution that an applicant such as Mr Moeller will obviously make to the community.⁵ Reacting to the controversy over the Moellers, Minister Evans requested on 26 November 2008 that the Joint Standing Committee investigate the operation of the current law.⁶

In the case of applicants with HIV, further iniquities stem from policies for assessing potential health and other costs relating to the condition which are arcane and inappropriately applied. This focus on cost 'burden' is devoid of any recognition that prospective migrants often contribute substantially more to the Australian community, socially and financially, than they 'cost'.

The health requirement in the migration regulations

Every person seeking entry to Australia, either permanently or for an extended temporary stay must meet the health

requirement specified in the *Migration Act 1958* (Cth) and the *Migration Regulations 1994* (Cth) (Regulations).⁷ The Regulations stipulate that all visa applicants must be free of tuberculosis, or a disease or condition which would endanger public health.⁸ Migrants must also be free of health conditions which, due to their potential use of public services, would represent a 'significant cost' to Australia (irrespective of whether the health care or services would actually be used).⁹

The assessment of whether the applicant meets the health requirement is made by a Medical Officer of the Commonwealth (MOC) 'by reference to a hypothetical person who suffers from that form or level of the condition'.¹⁰ According to the Regulations, the MOC must evaluate whether the applicant will require medical care or be eligible to access a community service.^{11,12} For most visa subclasses, it is immaterial to the question of accessing medical and community services whether the applicant is a person of means, or belongs to a family who offers to pay for such services.¹³ Consequently, unless applicants with HIV are seeking a visa which permits a waiver of the health requirement (such as a business or educational visa, or a visa granted on humanitarian grounds), most will fail and thus be denied entry. The basis for this is that the costs of care and treatment, including the cost of antiretroviral medication, would be

significant and therefore be likely to prevent an Australian resident from accessing that healthcare or treatment.¹⁴ The Department's derivation of the particular figure regarding healthcare costs for HIV-positive people in Australia has always been a matter of uncertainty, but it is commonly accepted that the figure relied upon by officials is approximately \$250,000 throughout an individual's lifetime.¹⁵

A number of submissions to the inquiry argued forcefully that the operation of the present system particularly disadvantages visa applicants living with HIV. As the HIV/AIDS Legal Centre (HALC) pointed out, the current regime 'is blind to some identifiable potential significant health costs, and sensitive to others'¹⁶, in that readily detectable diseases such as HIV or down syndrome are singled out, while applicants with obesity or an addiction to smoking (representing potentially immense future public cost burdens) are more likely to go unnoticed¹⁷. Submissions also pointed out that the current law encourages decision-makers to 'apply a generic notion' of a condition without proper consideration of an applicant's actual state of health¹⁸, and that the system currently screens out applicants with HIV (or any condition) requiring potential future treatment on the basis of an expense that may be never arise for that particular applicant¹⁹.

The submission by Professors McCallum and Crock noted that figures relied upon by the Department to measure the future public 'cost' of migrants with a health condition have historically been based more on ideology (and I would add prejudice regarding particular conditions) than on rigorous empiricism.²⁰ This and other submissions further argued that the health requirement is inconsistent with Australia's obligations under international treaties to remove

This focus on cost 'burden' is devoid of any recognition that prospective migrants often contribute substantially more to the Australian community, socially and financially, than they 'cost'.

discrimination against, and promote a positive vision of, individuals with disabilities and other health conditions.²¹ The health requirement constructs a harmful view of HIV-positive people, namely that they are a drain on public resources and incapable of making a contribution to Australian society.²²

Prospects for reform

The most obvious reform would be to unequivocally state that the *Disability Discrimination Act 1992* (DDA), which makes it illegal to discriminate against individuals on the basis of a health condition, should apply to decisions relating to migration (migration law is currently exempt from the DDA).²³ Further, applicants should not be assessed against a hypothetical person with the same condition because this leads to arbitrary generalisations about the condition and its economic impact.²⁴ Decision-makers should undertake a more personalised assessment, examining the particular health status and prognosis of the applicant in question.²⁵ Reliance on empirical studies relating to the actual costs of treating a condition is also an imperative reform.

Significantly, the government recently announced the tightening of the eligibility criteria for skilled migrants²⁶, suggesting that the ‘ideal’ migrant in these difficult economic times is one whose sole purpose is to improve the economy. Given this statement, and the fact that in election years public debates on immigration are rarely well-informed, I can only be cautiously optimistic that the Inquiry into the Migration Treatment of Disability will promote a more sophisticated view of the economic contribution made by migrants, and that far-reaching reforms to migration policies affecting people with disability or chronic disease will be introduced.

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- 21 In particular, the *United Nations Convention on the Rights of Persons with Disabilities*: *ibid*, p16.
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The health requirement constructs a harmful view of HIV-positive people, namely that they are a drain on public resources and incapable of making a contribution to Australian society.



Hepatitis C for people living with HIV

By Niki Parry

Hepatitis C

Around 200,000 Australians are currently living with the hepatitis C virus (HCV). The virus lives in blood and in liver cells where it can cause damage. Hepatitis C can cause liver inflammation and scarring (known as fibrosis, or when more serious, cirrhosis). Over time this can reduce the liver's ability to perform essential functions. Liver damage from hepatitis C usually takes many years.

Unlike HIV, hepatitis C can be cured, either naturally or by using treatments. Because hepatitis C generally develops very slowly, there is usually plenty of time to make decisions around treatment.

HIV and hepatitis C

In Australia, 13% of people living with HIV are also living with hepatitis C – that means about 2,000 people. Any diagnosis can be difficult, but having two infections may be particularly stressful. If you are diagnosed with hepatitis C, it's important to remember that, just as with HIV, knowledge is constantly evolving and treatments are improving all the time. However, when living with both viruses, there are some issues which may need special consideration, as co-infection can affect both health and treatment options.

Generally speaking, HIV and hepatitis C complicate each other. HIV can cause hepatitis C to progress more rapidly and even though it is unknown at this stage whether hepatitis C has an impact on HIV, it may make HIV treatment

more complicated. This is mainly because most HIV drugs are processed through the liver.

As people with HIV are living longer, healthier lives, the effective management of hepatitis C is critical for people who are co-infected. The hepatitis C virus tends to be more virulent in people who have HIV as well, particularly as CD4 cells decrease. It is thought that this reduced immunity enables hepatitis C to progress more easily and, therefore, damage to the liver may occur more rapidly. Some research has found a direct correlation between CD4 levels and hepatitis C activity.¹

Other factors can also accelerate the progression of hepatitis C, such as alcohol intake, ageing, duration of infection, if a person is aged over 40 at time of infection, and the presence of hepatitis B co-infection. Hepatitis C may also progress faster in men. As hepatitis C can be more serious and progress faster in people with HIV, regular testing and monitoring are even more important.

Self-management

Probably the most important aspect of dealing with any medical condition is having the time and support to become better informed about the choices that affect your health. It is also important to look at other aspects of your life in order to reduce stress and improve your quality of life and general health.

Some of these lifestyle factors can also reduce the risk of hepatitis C progression – especially things like

cutting down on alcohol. Other general things like stopping smoking, eating a healthy balanced diet and resting properly, cutting out stress and ensuring you get some exercise are important for everyone. Herbal remedies may also help you to manage symptoms and increase energy levels, as one of the most common symptoms of living with hepatitis C is fatigue.

When living with co-infection it can be difficult to find correct and reliable information. It is important to have someone you can trust, so try to find a GP who is HIV and hepatitis C friendly and determine a health plan that is right for you together. For example, it is important to have regular liver function testing – at least every six months. It is also a good idea to consult a specialist on a regular basis. Having one illness that impacts on your liver is enough, so it is recommended that people with hepatitis C get vaccinated for hepatitis A and hepatitis B. Lots of people also find it helpful to get support by asking questions and sharing experiences from other people who are co-infected.

People living with HIV experience a wide range of symptoms related to hepatitis C: from none at all, to symptoms that are severe. Alongside fatigue and sleep disturbances, many people experience muscle and joint pain (including discomfort around the liver), headaches, nausea, skin problems, fever and night sweats and general malaise. Cognitive and psychological symptoms can include brain fog, changes to thought processes, memory and

concentration problems. Some people also experience low mood, depression and anxiety.

Treatment Issues

As started earlier, hepatitis C treatments are always being researched and improved. The current treatment for hepatitis C includes a course of two medications: pegylated interferon and ribavirin. This treatment is often referred to as 'combination therapy'. Treatment will not be recommended for everyone who has hepatitis C as soon as they are diagnosed, whether they have co-infection or not. Some people may not require treatment and others may be reluctant to embark on the treatment process for many reasons, one of which is that hepatitis C treatment is not always successful in clearing the virus and it can cause unpleasant side effects for some people.

With hepatitis C, people have different genotypes (or strains). Genotypes 1 and 4 have a 50% chance of cure and require treatment for a year. Genotypes 2 and 3 have an 80% cure rate and are treated for six months. However, people who have both HIV and hepatitis C are usually treated for a year, regardless of their hepatitis C genotype. This is because higher relapse rates have been reported in people with HIV.

However certain factors *may* indicate that co-infected people with HCV genotype 2 or 3 can be successfully treated for only six months. Individual characteristics need to be taken into consideration, and this is something to talk over with your GP. Although responses rates vary- generally most people living with co-infection can be treated for both HIV and hepatitis C. HIV can still be treated even if you have hepatitis C. In fact it is really important to be aware of your HIV viral load and CD4 cell count and to treat HIV to keep it under control.

Hepatitis C can affect treatment choices, because of the potentially toxic side effects some HIV drugs have on the liver. There are no suggested or specific HIV treatments for people with both HIV and hepatitis C. Many

Some advantages for people with co-infection using hepatitis C treatment are:

- You can clear the virus!
- Treating HIV before starting hepatitis C treatment will reduce the risk of liver-related side effects.
- Treatment may reduce the risk of long term complications, including liver cancer. This may be true even in people who do not clear their hepatitis C.
- Hepatitis C treatment can improve liver health by reducing inflammation. It may even reverse fibrosis. (This can still happen in people who do not clear the virus, although less often.)
- It will stop the risk of passing hepatitis C on to sexual and drug using partners. It also will remove the risk of vertical (mother to baby) transmission.
- The treatment period is only likely to be for 12 months – it will not last forever!
- It may be important not to delay treatment, as it can be less effective for people with more severe liver scarring.

Some tips on managing treatment:

- Identify people in your life who will be a good source of support for you.
- Be prepared before seeing your doctor – make a list of questions.
- Take someone to appointments with you – particularly if there are things concerning you
- Consider other avenues of support – for example; join a support group, contact HIV or hepatitis helplines, utilise internet forums, etc.

HIV medications can affect your liver in both the short and long term, but you will need to consider both viruses and carefully plan your treatment journey with your GP. Your GP can regularly check up on how your liver is coping to make sure HIV drugs aren't causing any problems.

Generally speaking, the infection which poses the greatest concern to your health should be treated first. There is some evidence to suggest that starting treatment early is especially important for people with both HIV and hepatitis C. HIV treatment can boost the immune system and this may mean that the rate of liver scarring is significantly slowed.

Early treatment is often recommended because of higher clearance rates, but this needs to be balanced against the side effects of treatment. Some people do not treat early because of the hope that improved drugs which are easier to tolerate will appear in the next few years. Getting the balance right between delaying treatment and not waiting too long is challenging and can cause stress and anxiety for many people. It is important to remember that both conditions can be managed and treated

and the benefits of treatment will usually outweigh the risks.

There can be a lot of information for people with co-infection to take in, particularly if you have just been diagnosed. It can be overwhelming, but remember that it is not an all or nothing situation. Anything you can do to become healthier is a success! Remember to take small or simple steps when dealing with any major change and congratulate yourself along the way.

When it comes down to it, YOU are the person who is control of your health and only you can make the right choice for yourself. An individual approach to your own health care will be the best one. Having said that, you do not have to do it alone – get as much support as possible from family, friends, GPs and other health care workers.

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Double agents: living with HIV and hepatitis C co-infection

By James May

James May interviewed three people living with hepatitis and HIV co-infection about their personal experience with service providers and treatment.

Two men and a woman with very different circumstances took part in the research. One person had attempted treatment without success, while another had cleared the hepatitis C virus after a year on the ribavirin/interferon combination. The third participant will commence treatment in a few months. They also spoke about their HIV diagnosis and the impact this has had on sex, relationships and quality of life.

Patrick has been living with HIV/hepatitis C co-infection for over ten years. Most of his treatment has focused on HIV, as the hepatitis symptoms have never been an issue for him. He sees his HIV diagnosis as a positive thing. It made him a stronger person and changed his life for the better, and he's also not too affected physically, unlike many of his peers who have struggled with HIV combination therapy. He chooses who he confides in carefully and

has never told family overseas. He finds it hard to talk about his co-infected status, due to the stigma associated with both diseases. 'It's still hard to talk about due to the judgments around it and the assumption that you're either gay or a drug user,' he says.

Patrick signed up for a co-infection drug trial with the infectious disease unit at The Alfred and tried the combination of ribavirin and interferon. He quit after two weeks because he became physically ill and extremely depressed – to the point where he couldn't function and had to use antidepressants. He now maintains his health with HIV medication, a balanced lifestyle, healthy food and exercise. He monitors his hepatitis C regularly, and has found great support with complementary therapies such as multi-vitamins and selenium. He says he would try a new hepatitis C regimen

if it was easier to manage, but he's not really concerned as it doesn't impact his HIV viral load or make him tired. 'If it wasn't for regular visits to the doctor, I'd forget I even have it.'

As a heterosexual man with co-infection, he was concerned about finding a partner, negotiating safe sex and issues around having children. He has now been partnered for eight years and they made a conscious decision not to have kids, although it has nothing to do with the illness – it's just too big a responsibility at this stage in life.

He finds health service support networks quite adequate, although they can be hard to access as a full-time worker. 'You need to be selective with doctors, make sure they hear you out and [ensure that you] question their actions. Some doctors don't know how to communicate sensitively and ask questions like "where did you get it?", which is very inappropriate.'

'Treatment services have come a long way and there's a great mix of people at World AIDS Day celebrations now. People come together regardless of their situation or sexuality.' He recently joined the PLWHA Public Speaker's Bureau to encourage young people to be more cautious. Patrick says he's gone on a journey with HIV from early denial, to dealing with the disease, to taking an active role in raising awareness.

Michelle was diagnosed with co-infection in Europe in 1989 and given four years to live. She was initially told she had hepatitis 'non A /non B'. Around 1990, she was diagnosed with hepatitis C, which is believed to be the cause of most cases of 'non-A non-B' hepatitis.¹ This diagnosis was never clearly explained to her, so she focused on managing her HIV which began to cause serious problems a few years later. She suffered from disseminated shingles and was diagnosed with wasting syndrome. Her health improved after returning to Australia and making contact with peer support

groups and family. 'Meeting other positive women was a big help,' she recalls. Combination therapy for HIV in '95 was a huge turning point for her as well.

Despite health gains, Michelle always felt physically worse than her peers. That's when she started investigating hepatitis C treatment. She saw a co-infection specialist at The Alfred, had a liver biopsy and signed up for the ribavirin/interferon combination in 2004. She was diagnosed as genotype 4, which only had a 50% chance of clearance. With stage 2 inflammation (on a scale of 1 to 4) she was encouraged to proceed to avert cirrhosis of the liver. Michelle put support networks in place to deal with the isolation and depression caused by treatment and adhered to antidepressant medication. She used acupuncture and massage, and sought help with cleaning and shopping through her local council. She went to support groups at the hepatitis C Council to get first-hand information from people who had been through the procedure.

The treatment ran for 48 weeks with three-monthly blood tests to monitor progress. This involved two tablets of ribavirin twice a day and one injection of interferon once a week, or what is commonly known as 'combination

therapy'. Michelle experienced headaches, fatigue, nausea, diarrhoea, aches and pains and vomiting. These symptoms lasted for the duration of the treatment. 'I felt fine for a month but then I got a headache which lasted the entire year.'

Michelle maintained combination therapy for the full 48 weeks, achieving an undetectable viral load within three months. It is important that treatment be adhered to for the full course, as the virus can reappear. 'It was a great motivation to see the virus cleared so quickly. The last few months were the worst. I was so exhausted, fatigued and generally over being sick. But it was worth it in the end to avoid cirrhosis.'

Michelle has done public speaking for 17 years around co-infection – visiting schools, medical settings, anywhere she's called upon. Without co-infection she has far more energy and has done a Certificate IV in Disability work and a Certificate IV in Training and Assessing. She also went back to TAFE to do a diploma in welfare. She is currently employed as the peer support co-ordinator of Positive Women Victoria where she provides support through drop-in services, phone contact, outings, dinners and fundraisers.

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[Michelle's] health improved after returning to Australia and making contact with peer support groups and family. 'Meeting other positive women was a big help,' she recalls. Combination therapy for HIV in '95 was a huge turning point as well.

Roger was diagnosed with HIV three years ago and subsequently diagnosed hepatitis C-positive in 2009. His health is good; he has professional employment and a healthy lifestyle. 'I was getting back on track after the HIV diagnosis when hepatitis C came along.' A year ago, he suffered headaches, nausea and flu-like symptoms which resolved on their own. He was then diagnosed with hepatitis C and still has no idea how he contracted the virus, as no unsafe sex or IV drugs were involved. He suspects possibly casual contact through razors or head clippers. 'I look back at my 20s and think how lucky I was to dodge so many bullets. I'm in my 50s now and this has happened.'

He recently saw co-infection specialists at The Alfred and will begin therapy with ribavirin/interferon in a few months to get on top of the virus early, as this may reduce the amount of time he has to be on treatment. He will also be taking a third drug which is unknown to him at this point, as part of a new clinical trial. He's been informed of possible side effects and will be tested every month to monitor effects. The dose will be modified, or treatment stopped, if side effects are too severe. Roger says he was in two

minds about having treatment because the effects of hepatitis C don't appear for long and he's in good shape right now. He asked a friend to move in for support while he copes with the treatment to assist with financial constraints and practical matters. 'It's hard for me to reach out for help but if someone's there, it'll be easier.'

He feels there's an extra burden in terms of disclosure with co-infection and what the future may hold for his health. 'At the moment I just shelve any fears about the future and get on with it – one thing at a time.' He recently ended a new sero-discordant relationship due to the complications of being co-infected as well as upcoming treatment issues.

Roger doesn't have much contact with service providers, but would like to meet others with co-infection. He attended a peer support group through the VAC, which he found helpful to a certain extent, although there were some difficult personalities in the group. He says that services can be hard to access for full-time workers and seem geared for people who are in crisis. 'I'm frustrated by the system. You have to be sick to get any help. What's the point of all this if you can't access it?'

Conclusion

The interviews conducted for this article illustrate a perception that the current treatment for HIV/hepatitis C co-infection is tough to handle. There's a belief that hepatitis C is rather benign in the short term, and therefore, unnecessary to treat in many cases. There's also a view that the side effects of treatment are not worth it, particularly as many people don't feel too physically impaired by the virus.

However, if hepatitis infection is left untreated it can progress to chronic hepatitis, which can cause severe health complications such as cirrhosis of the liver and liver cancer.² There is clear evidence that people do prosper as a result of clearing hepatitis C – although support measures need to be in place before commencing treatment. Some people are unaware that new treatments are available and may be inclined to review their feelings if they knew that treatments were being refined.

In terms of co-infection, it appears as though HIV is the point of focus as far as treatment and seeking support services is concerned. The people interviewed for this article found the support services they accessed to be adequate in terms of medical, dental and emotional support. Accessing services as a full-time worker was a point of frustration. Issues around sex and relationships are as complicated for those with co-infection as they are for those living with a single virus. Disclosure is still a major concern.

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[Michelle's] health improved after returning to Australia and making contact with peer support groups and family. 'Meeting other positive women was a big help,' she recalls. Combination therapy for HIV in '95 was a huge turning point as well.



A healthy exchange: why Australian needle and syringe programs are more than just a ‘good return on investment’

By Luke Williams

Needle and Syringe Programs (NSPs) are credited with keeping Australia’s co-infection rates relatively low. However, the challenges in containing hepatitis amongst drug users remain. Luke Williams visited a 24 hour needle exchange in St Kilda, Melbourne to find the challenges and barriers to reducing rates of co-infection in injecting drug users.

‘The day has been pretty busy so far,’ says Needle and Syringe (NSP) program worker Sally Finn. At least every five minutes, someone comes in to collect a safe use pack.

‘I wish everyone could come and spend a day here, it would really open people’s eyes about this problem,’ she says. ‘We have people in suits come here all the time, people who turn up in Rolls Royces every few months wanting hundreds of syringes, right down to people in their early teenage years – 13 and 14 year olds who have very difficult lives’.

Needle Exchange programs have had a relatively short and, reportedly, successful life span in Australia. They were first trialled (illegally) in Sydney in November 1986, and there are now more than 3,000 needle and syringe programs operating around Australia, making over a million contacts with injecting drug users each year.¹ The number of syringes distributed each year amounts to around 165 per user, one of the highest rates in the world.² As a result, Australia is considered to be a world leader in NSPs.³

While originally controversial, there have been several major reports in recent years which appear to have vindicated the use of NSPs in Australia. In particular, the *Return on Investment in Needle and Syringe Programs in Australia* in 2002

found that the programs prevented 25,000 new HIV infections and 21,000 hepatitis C infections in ten years.⁴

Last October, the Chair of the federal government’s Australian National Council of Drugs, John Herron released a statement at launch of the second Return on Investment study saying it ‘provides further validation and clearly shows the outstanding contribution to public health that NSPs have made by preventing over 100,000 HIV and hepatitis C infections in the past 10 years’.⁵

Certainly, for people like Maree, a long-term co-infected drug user who I met at the St Kilda exchange, the advent of NSPs changed the way she used drugs.

‘Back in those days (when she began injecting drugs in the mid 1980s), it was really hard to get clean needles. The only place you could get where pharmacies, it cost money and they weren’t always open. So we would run out of needles – we would re-use dirty ones and sharpen them with nail files ... we would share needles all the time, we didn’t think twice about it. We didn’t even know about things like hepatitis’.

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Maree says she hasn't shared needles in the last ten years and now gets all her syringes from the exchange in St Kilda.

However, ongoing issues remain. Between 2004 and 2008, less than 1.5% of people tested at NSPs had HIV, though among gay men who inject the figure was 37%. Out of all those tested, over 60% had hepatitis C.⁶

Part of the issue is that injecting drug users, for a variety of reasons, still share needles and equipment. Research undertaken in Australia between 2004 and 2008 indicates around 15% of injecting drug users share needles.⁷ Some users I met at the exchange tell me they think the culture of sharing needles is very much alive in some circles and also, clean needles aren't always available if they are using away from the city. Take David for example – he tells me he got hepatitis C from sharing needles with his mates.

'People still share all the time, mates who know each other. You might get some for just you and a few others and then you'll come home and some others will want to join in. There won't be enough needles to go around, but the others (who don't have needles) will chuck money so you will end washing yours out and letting them use it'.

Rachel says she was introduced to injecting drug use by a cousin when she was nine.

'On occasion I would re-use my own dirty fits and I know I didn't always wash them out properly. A few times I have let my partner use my dirty fit as well ... In the last 12 months I have seen people share needles at least a dozen times. Needle sharing is looked down upon amongst drug users, it's just that people don't get organised to get their own clean fits'.

Dr Campbell Aitken, from the Burnet Institute, is one of Australia's foremost researchers in the area and says there are

many systemic problems which lead to unsafe injecting practices.

'Although coverage in Australia is good, there are still many people who want to inject at times when NSPs aren't open and no other option is available. Vending machines are used in NSW and New Zealand and work very well; supplying needle and syringes from petrol stations and convenience stores has been talked about for years and would certainly help, but there's little prospect of that occurring'.

Sally Finn believes the situation is further complicated by the way injecting drug users often bond by sharing needles. 'I think people share in emotive situations, they share in intense relationships, they share their trust in each other, their boundaries shift and they create a kind of distorted intimacy by sharing a needle,' she says.

The real success of NSPs appears to be in the containment of HIV. The federal government looked at 778 years of data from 103 cities around the world in its 2002 *Return on Investment* report. It found that in cities that had ever had NSPs, there had been an average annual decrease in HIV prevalence of 18.6%, compared with an average annual increase of 8.1% in cities without such programs.⁸

Low HIV prevalence is considered to be the main reason why Australia has low rates of HIV/hepatitis co-infection. Nonetheless, 90% of people with HIV and hepatitis co-infection in Australia are injecting drug users⁹ – a figure largely precipitated by the very high rates of hepatitis C amongst this group.

This potentially confusing set of statistics sometimes leads to questions about why Australia's HIV levels are so low, but hepatitis levels so high.

'We think it's because our NSPs started so early in the HIV epidemic and have achieved very good coverage, especially

compared with, for example, the US, where needle and syringe coverage is much lower and HIV rates among injecting drug users are 40–50% in some cities. Whereas hepatitis was already established among injecting drug users before NSPs, and also is much more infectious,' says Dr Aitkin.

Caroline Perry, who is assistant program manager of the St Kilda NSP, says co-infected patients are rare – but they tend to show a distinct pattern of coming from backgrounds with multiple forms of disadvantage. The last two people the clinic tested and found to be co-infected were both Indigenous, homeless and injecting drug users. One was also gay, an alcoholic and suffered from schizophrenia.

'We see certain groups of people as particularly vulnerable to getting HIV and particularly hepatitis ... there a few reasons for this; poor education around sharing, less access to clean needles. Often Indigenous people, for example are not close to city resources for infection screening. Also, people in these groups are often not getting treated, they can live quite chaotic lives so they don't turn up to appointments, which means many of them are in really terrible health,' she says.

HIV, hepatitis and co-infections have been increasing amongst Australia's Indigenous population over the past few decades. Transmissions attributed to injecting are reported to have increased from 5 to 18% of HIV diagnoses within Australia's Indigenous communities over the last two decades.¹⁰

Despite the many challenges facing workers in the sector, Sally Finn says she can't help but feel encouraged by the resilience of the clients she has got to know at the exchange.

'I think if we are going to get serious about this problem we need injecting rooms (in more places other than Sydney). An injecting room is safe and sterile and people aren't going to

overdose. People can be shown how to inject safely. I think injecting rooms are really a very effective way to break down all these dangerous myths and misconceptions about safe drug use within the drug user community.’

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Luke Williams is a freelance journalist. The real names of the drug users interviewed for this article were not used for privacy reasons.



From the clinic to public health

By Jack Wallace

Over 350–400 million people around the world are chronically infected with hepatitis B; most live in the Asia Pacific region and over half the 187,000 people with chronic hepatitis B in Australia were born in the Asia Pacific Region. There is also a significant burden of disease among Aboriginal and Torres Strait Islanders, with approximately 16% of people in Australia with chronic hepatitis B coming from these communities.

While Australia developed National Strategies to reduce the impact of HIV and hepatitis C, the public health response to hepatitis B has focused on vaccination and providing clinical treatment. These are crucial in reducing the burden of hepatitis B, but they need to be embedded within a broader public health approach that acknowledges the social context of hepatitis B infection and the needs of people with chronic hepatitis B.

With Australia now developing its first National Hepatitis B Strategy, health care systems have the opportunity to develop a comprehensive response to what is a complex disease. The development of the strategy was informed by a range of documents,

and a series of consultation processes facilitated by the Australasian Society for HIV Medicine (ASHM), as part of the strategy development process. This article describes some of the issues arising during this consultation process.

Developing a community response

National Strategies responding to HIV and hepatitis C in Australia were developed from partnerships with the communities most affected by these conditions. An effective national response to chronic hepatitis B needs the same collaborative approach between the communities most affected and other key stakeholders. Communities most affected by chronic hepatitis B often have less access to participate in the development of health policy or to influence the provision of health services.

Culturally and linguistically diverse communities may have different understandings of liver disease, including the transmission of viruses, which operate outside of the

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paradigm of Western medicine. This can fundamentally affect their health literacy and willingness or ability to access medical care. Such diverse understandings of hepatitis B within communities most affected necessitate providing information and education that uses culturally appropriate methods. One health worker I spoke with for the National Hepatitis B Needs Assessment noted that hepatitis B: *'is a problem of equity and access for people who come from migrant communities and who really don't have a good understanding of the health system'*.

Preventing hepatitis B transmission

A hepatitis B vaccine is available through the Immunise Australia Program – a federal, state and territory initiative which seeks to increase national immunisation rates. Different states and territories 'value add' to the program by supporting access to free vaccine for specific groups at risk. However, this tends to vary between states and territories.

There is a lack of consistency between jurisdictions in the level of information that is publicly available through departmental websites about access to funded hepatitis B vaccination; at-risk communities are frequently not aware of their entitlement to funded vaccination. One community worker noted that there is a: *'lack of clarity about free access to vaccination for which target groups'*.

Providing effective diagnosis

A supportive diagnostic event can mean a person can integrate chronic hepatitis B infection into their lives and respond in effective ways, such as making dietary changes, reducing alcohol intake and having their infection monitored by a general practitioner or specialist. Unlike other blood borne viruses, no formal process exists for providing a diagnosis of chronic hepatitis B.

Finding out that you have chronic hepatitis B was described by several people as 'shocking'.

The National Hepatitis B Needs Assessment found most of the people with hepatitis B interviewed reported that they had not consented to the test: *'I didn't ask for it'*. Others noted that they were provided with little or no information at the point of diagnosis: *'they just told me you have hepatitis, and you try to stop the drink the beer, or eat something like diet something'*. This is an inadequate response to a diagnosis of a complex disease.

Late diagnosis can have a significant impact on morbidity and mortality and up to one third of people infected with hepatitis B are unaware of their infection. An assessment of hepatitis B knowledge found 9 of 95 people from Laos and 8 of 234 people from Cambodia had chronic hepatitis B, 79% of whom were unaware of their infection. The participants had lived in Australia for between 12–14 years, and most had contact with a health care provider (most frequently a general practitioner) in the previous twelve months.¹

The process of notifying people of a chronic hepatitis B diagnosis through the post by the Department of Immigration and Citizenship is poor public health policy. One health worker described the process as:

A standard letter which [the Department of Immigration] pop in a section [saying] 'you've got hepatitis B; you're a carrier, go and see someone at your own cost ... it's really confronting, they've just applied for asylum and they're absolutely terrified.'

Increasing access to clinical management

Only 2% of the total number of people with chronic hepatitis B receives antiviral therapy. By 2017, it is estimated that there will be a

two or threefold increase in liver cancer, with a marked increase in the number of deaths attributable to hepatitis B.² Incidence of liver cancer among overseas-born males increased by 90% between 1983 and 1996³, and another study showed liver cancer rates doubled in Asian-born patients between 1993 and 2003⁴. While cancer incidence rates in people born overseas are the same as for Australian-born (24.5%), cancer profiles vary by country of birth, and a large proportion of primary liver cancers occur in people born overseas (46%).⁵

Access to treatment services by Aboriginal and Torres Strait Islander people is poor. This is in spite of a report from Alice Springs Hospital showing that nearly 3% of all mortality in Aboriginal patients was due to end stage liver disease in the context of chronic hepatitis B infection.⁶ One clinician working in a region with a significant Indigenous population noted that Indigenous people made up *less than 1% of their patients*.⁷

General practitioners are important in reducing the burden of chronic hepatitis B. One clinician suggested they screen: *for hepatitis B (as) part of the routine health care check of populations who are high risk*. Specialists, particularly those providing treatments which suppress the immune system, need to be pro-active in checking their patients' hepatitis B status before instituting treatment.

Several clinicians in the needs assessment spoke of the challenges in treating and managing people from culturally and linguistically diverse communities. Having patients understand how treatment works and what to expect from treatment is important and helps clinicians to engage with patients in meaningful ways. One clinician noted: *'you're much more likely to get people who want to be treated and stick to their therapy if they understand what they are doing and they think it's good for them'*.

There is a perception from clinicians that people with hepatitis B were compliant and followed advice from specialists, but there was also an awareness that this may not always be the case: *'they are sitting there nodding saying "yes, yes, yes, thank you very much", but they don't understand, they won't say "what's that mean?"'*

The burden of viral hepatitis on publicly funded liver clinics is increasing, without additional resources. Existing hepatitis clinics in public hospitals often have waiting periods for new referrals, which can range from months to years. These waiting times can have a significant impact on a person's health, particularly in relation to undiagnosed liver cancer.

Research into hepatitis treatment services for people from culturally and linguistically diverse backgrounds supports community-based liver clinics that are physically accessible and respond to the specific needs of the patient group. This includes making interpreters central to the liver clinic; providing cross cultural training; employing staff from similar cultural backgrounds to patients, and showing flexibility in accommodating the difficulties patients have in attending appointments.⁸

Requiring a liver biopsy in order to access hepatitis B treatment means that people without access to biopsy services are unable to get treatment. This is a particular problem for remote indigenous communities.

Improving research and surveillance

There is limited data describing the impact of chronic hepatitis B, and how the communities most affected by the condition respond to this infection. The national research centres have recently (2009) incorporated hepatitis B related activity within their scope, without additional resourcing. Hepatitis B research has been privately funded through unrestricted educational grants

and is project-based, which limits the capacity to develop a stream of viral hepatitis research.

Cases of acute and chronic hepatitis B infection are routinely notified through public health surveillance systems in all Australian States and Territories. Chronic hepatitis B infections are responsible for virtually all deaths related to hepatitis B. However, the primary public health response to notifications of hepatitis B is to investigate acute cases while taking no action beyond keeping records of unspecified or chronic notifications.

Increasing the skills of the workforce

Chronic hepatitis B infection is a complex disease. The sectors providing care and support for people with chronic hepatitis B are diverse, and it is essential that these sectors can access accurate information about hepatitis B and have the skills to impart this knowledge in order to develop an effective national response.

The Needs Assessment showed significant gaps in the level of knowledge about hepatitis B among people with the disease, but this extended to people working with communities with higher prevalence of chronic hepatitis B. One community worker noted that even with their prior nursing experience, understanding and providing information about hepatitis B was challenging: *'I've done hepatitis B 101 three times and every time that I think I've got it, I try to explain it to someone else and I realise that I haven't got it'*.

General practice is central to the health care experience of people living with chronic hepatitis B. Assay techniques for viral levels and treatment paradigms are rapidly evolving to the point where management decisions made in the past should be revised – the decision to observe, may now become a decision to treat. The level of awareness among

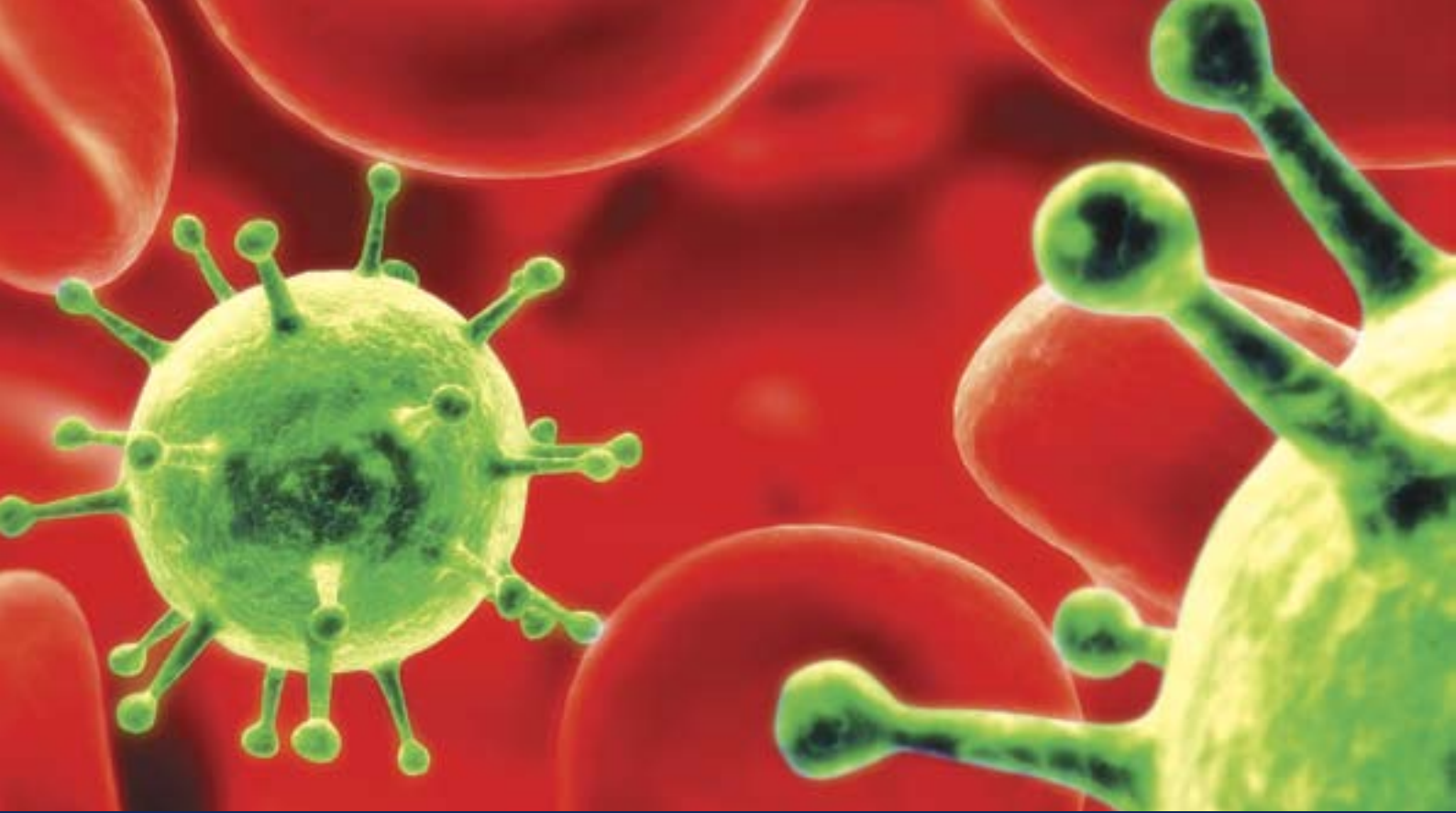
primary care physicians about hepatitis B needs to improve generally.

Until now, hepatitis B has largely been seen as a clinical or vaccination issue. The development and implementation, with resourcing, of a national hepatitis B strategy acknowledges the need for a more comprehensive and coordinated response.

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The full treatment: a brief overview of interferon-based therapy for hepatitis C

By Max Hopwood

Introduction

Hepatitis C is an infectious, resilient and stigmatised blood-borne virus. In Australia over two hundred thousand people are chronically infected with hepatitis C, and a sizeable minority of these people are at risk of life threatening illness. Many people with hepatitis C experience discrimination from the health care sector, insurance organisations and government departments, family and friends. Hepatitis C infection is stigmatised mostly because of its association with the practice of injecting illicit drugs.

While many people acquire hepatitis C through other routes, such as unsterile vaccination programs in their country of birth, injecting drug use accounts for the majority of infections in Australia. So, people with hepatitis C are often wary about when, where and to whom they disclose information about their infection, regardless of how it was acquired. Treatment for

hepatitis C is sometimes viewed by affected people as an opportunity to escape a discreditable identity.¹

Over the past 20 years hepatitis C treatments have improved considerably. Today, pegylated interferon and ribavirin combination therapy is the standard treatment. These two powerful antiviral agents can eradicate infection in approximately 50 percent of people with genotype 1 – the most common sub-type of hepatitis C in Australia – when treated for 48 weeks. In people with genotype 3 – also common in Australia – up to 80 percent clear their infection after 24 weeks of treatment.² A blood test is conducted six months after treatment to determine whether an individual is cured. Eradication of hepatitis C infection is associated with reports of improved health-related quality of life.

Because there is no vaccine to prevent hepatitis C infection and because prevention education efforts have

had limited impact on stopping new infections, treatment is the only strategy available to curb future hepatitis C-related morbidity and mortality. Since 2001, the criteria for accessing interferon-based hepatitis C treatments under the Pharmaceutical Benefits Scheme (PBS) has eased in a bid to attract more people into treatment. For example, liver biopsy is no longer an inclusion criterion and people who currently inject are entitled to access subsidised treatment. Nonetheless, treatment uptake remains low and for the past few years only about three thousand people have received treatment for hepatitis C in Australia annually.

It is expected that following implementation of innovative models of treatment delivery through general practice settings and opioid substitution treatment programs, more people will access treatment and clear infection. It is important to increase

access to treatment now, because the number of people with hepatitis C-related liver disease is projected to increase significantly over the next decade.³ Also, new treatments which use protease and polymerase inhibitors, are currently in phase 2 and phase 3 trials and should be available from 2012 or 2013. Early indications suggest they are clinically more efficacious and tolerable than current treatments.

Reported experiences of hepatitis C treatment

There is an emerging body of literature which evaluates people's suitability for commencing hepatitis C treatment. This work highlights how an individual's social context is important for maximising adherence to treatment.

During pre-treatment assessments clinicians discuss strategies that may assist patients to cope; contingency plans are developed in case of emergencies. Social workers, nurses and psychologists often collaborate with social services to assist patients to commence and complete treatment.⁴⁻⁶ Ideally, factors like the quality of a person's family and social support networks, their household incomes, and their knowledge and use of social and community services are also assessed prior to commencing treatment, as they can all influence treatment adherence and outcomes.⁷ A nurse interviewed during a recent study⁸ explained:

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 [rough] patches ... (Nurse).

While Australia has some of the leading hepatitis clinicians, who are continually refining treatment administration⁹, treatment is still often a difficult experience for patients. People's physical and psychological functioning during treatment is

reduced.¹⁰⁻¹³ It is important to note that not everyone experiences side-effects and not all side-effects are hugely problematic. But people commonly report physical impacts like fatigue, flu-like symptoms, headaches or migraine, skin problems, muscle aches, nausea and insomnia during treatment. For example, when asked to describe the way treatment felt, one study participant¹⁴ explained:

[I]'s a bit like you take the worst hangover you've had, multiply that by three and then throw in a dose of the flu ... (Man, 35).

People most commonly discontinue interferon-based treatments for hepatitis C because of psychiatric side-effects¹⁵, particularly depression. The impact of interferon-induced depression is described by a study participant¹⁶:

The major mental one I suppose is the depression. It's feeling that, you know, it's all hopeless and ... everything's meaningless and you might as well not be here. (Woman, 49).

Similarly, many people have problems with concentration, anxiety, anger and irritability during treatment and these can affect relationships and daily routines, as highlighted in the following extracts:

There was this one guy [at work], one day, he annoyed me. He did something; I mean it was quite trivial. That's the thing about this [treatment-induced] anger thing. It just came out; it was a total over-reaction, out of proportion to the incident. I did, I really walked up and slammed the desk and really went off at him. (Woman, 38).

Interferon is like that; [it] takes me hours to do what normally it would take me ten minutes. And simple tasks are awful ... Oh, I no longer can make it easily to the post office. I no longer have a desire to do the shopping. (Woman, 50).

While some side-effects are debilitating, it is important to place them in perspective: less than one percent of people in treatment experience serious problems like loss of vision, loss of hearing, congestive heart failure, induction or exacerbation

of autoimmune diseases, severe depression, suicidal ideation and suicide, and panic attacks.¹⁷ However, over 30 percent of people receiving treatment experience depression, anorexia, weight loss, irritability, hair loss, joint pain, nausea and insomnia and more than 50 percent of people experience severe fatigue, headache and muscle aches.¹⁸ In clinical trials, dose reduction and discontinuation of treatment occur in between 10 and 50 percent of people because side-effects become dangerous or intolerable.^{19,20}

According to the clinical literature, side-effects usually disappear soon after treatment stops. However, there is evidence of ongoing impact on the central nervous system^{21,22}, as well as reports of persistent physical symptoms²³. Also, in some people, an immune system disorder has developed six months after treatment was over.²⁴ A recent study into the period after treatment found that indeed some participants experienced ongoing symptoms, which they characterised as persistent side-effects, for many months and even years.²⁵ For some in this study, ongoing side-effects outweighed the benefits of viral clearance.

In summary, hepatitis C treatment can be difficult and unpredictable, both in terms of treatment success and tolerability. Some people sail through the regimen without trouble and clear infection, others experience only minor discomfort, through to those who have profound physical and psychiatric side-effects. However, people's social context and individualised coping strategies mediate the experience of treatment. Assistance from peers, support groups, employers, family and friends can make a substantial difference to treatment adherence and the overall experience.

Treatment for HIV and hepatitis C co-infection

A significantly more complex condition to manage and treat is hepatitis C and HIV co-infection. It is estimated that around two thousand Australians are co-infected with hepatitis C and HIV.

continued overleaf

Serious liver diseases like cirrhosis and liver cancers tend to occur sooner among affected people.²⁶ Co-infected individuals respond differently to highly active antiretroviral therapy (HAART) than HIV mono-infected people and they are at an increased risk of developing liver toxicity from HAART. Similarly, the efficacy of hepatitis C treatment in people with HIV is estimated to be around 10–15 percent lower than for people with hepatitis C mono-infection. As Matthews and Dore (2008) reported in a review of the literature²⁷, hepatitis C treatment in co-infected people is complicated by issues of drug interactions and significant toxicity. To minimise these problems, hepatitis C treatments are recommended before people commence HAART, where possible.

As mentioned earlier in this article, there is a range of new treatments currently being developed for hepatitis C, and these may increase the treatment options available for people living with hepatitis C and HIV co-infection. Innovation in the development of treatment regimens, clinical management and approaches to incorporating social support during treatment will benefit people with HIV and hepatitis C co-infection in the future.

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HIV and hepatitis C co-infection: a time for support

By Adam Hynes

HIV and hepatitis C co-infection is not widely acknowledged as a major health concern for the average Australian. Routes of transmission increase the co-infection risks for specific subcultures within the wider community, such as injecting drug users and men who have sex with men, which may be the reason that very few co-infection specific support resources exist today. This article canvasses what services are currently available for people living with co-infection, and highlights where more resources are needed.

Where we are now

Within Australia, HIV and hepatitis C prevalence have required governments and health agencies alike to be responsive and flexible when trying to support those living with either infection. However, as there are more people living with hepatitis C than

HIV¹ it becomes clear that community-based HIV/AIDS organisations are best suited to try and meet the needs of people living with both HIV and hepatitis C. It is estimated that 13% of HIV positive people are also living with hepatitis C.² Community-based HIV/AIDS community organisations therefore have a more direct link to this group than hepatitis agencies.

Resources that should be available to people living with co-infection include social support, information and education, and medical care. Very few resources that specifically address co-infection issues currently exist, but HIV/AIDS organisations are now paying more attention to the needs of those living with co-infection.

Social support is important for the health and wellbeing of people who are managing a chronic infection.³ While

HIV and PLWHA agencies around Australia run support groups for those with HIV, there are currently no social support groups specifically for those living with co-infection.

Normally support groups are combined with information and education sessions where people can share their experiences while being able to get some valuable and practical information about managing their health. Although support groups for people with HIV do not exclude people who are living with co-infection, they may not cover issues specifically relevant to them. It is therefore encouraging to know that both the Positive Living Centre (PLC) in Victoria and ACON have plans to provide support group information and education sessions

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specifically for people living with both HIV and hepatitis C within the next twelve months.

The PLC in Victoria previously ran a support information and education session for people living with co-infection, back in 2004. The session provided an opportunity for people to share their experiences and discuss issues like treatment options, where to meet potential partners and disclosure to family, friends and prospective sexual partners.

In terms of information and education, Positive Life NSW has been the only organisation to date that has created a fact sheet for HIV-positive people who are newly diagnosed with hepatitis C. This fantastic resource, which is accessible online⁴, contains information about hepatitis C and various treatment options, the importance of social support networks and personal accounts of managing co-infection, all of which aim to enhance the quality of life for people living with co-infection.

It needs to be pointed out, however, that people with HIV and hepatitis C may still find it difficult to access support and education in some contexts. For example, a support group run by the Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD) in 2006 was not utilised by people living with co-infection, mainly because of their concerns about disclosure, anonymity and confidentiality within the community. However, in Victoria and NSW where there are more people living with HIV – particularly in Melbourne and Sydney – social support information and education sessions should be made available to people living with co-infection.

There are also some extremely useful medical resources available to people living with co-infection. For example, the Alfred Hospital in Melbourne runs a specific HIV/hepatitis C co-infection

clinic out of their infectious diseases unit. The clinic is only available to people who are on treatment for both infections but it provides doctors, a nurse and a psychiatrist. The H2M clinic at St Vincent's Hospital in Sydney also provides mental health care to people who are on co-infection treatment; the clinic is not exclusively for people with co-infection, but they make up 9% of clients.⁵

The Education and Resource Centre in Melbourne, along with the H2M clinic, also provides training and information sessions for health care professionals such as doctors, nurses and counsellors who are either working with a high case load of patients living with co-infection, or who want to improve their knowledge about co-infection issues. Such training is important to improving services for people with HIV and hepatitis C.

Where to from here?

Despite the current services provided to people living with co-infection there are some evident gaps in terms of information, education and social support that is available. Filling these gaps is the responsibility of HIV/AIDS organisations nationwide.

Firstly however, more information and research is needed to help identify what the major concerns and issues are for people living with co-infection. Without a better understanding of the issues it is impossible to determine what resources are required.

Second, it would be great to see what the outcome of the social support information and education sessions are that PLC Victoria and ACON are currently proposing. The information gained through these sessions will provide a better understanding of what people living with co-infection want and need and help guide health educators.

A national online support resource specifically for people living with

co-infection would also be really helpful. This could take the form of an education/information website and also include an online forum. This combination would provide people living with co-infection the opportunity to access information and resources and also allow them to share their experiences within a community-based environment.

An online community would also circumvent the problems associated with confidentiality and with running support groups in states where numbers of people with co-infection are smaller.

In conclusion, it must be noted that there are some services available to people living with HIV and hepatitis C. Even though services for people living with co-infection are limited, the increasing attention paid by HIV services towards co-infection is extremely encouraging. With more attention being paid these issues, the future can only hold a better perspective for those currently living with HIV and hepatitis C.

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It's in the mix: HIV and hepatitis C services in small jurisdictions

By Kevin Marriott

In the smaller Australian jurisdictions it is difficult to justify the establishment of separate community-based organisations to respond to HIV and hepatitis C. This article looks at the experience of Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCAHRD).

TasCAHRD and the Northern Territory AIDS and Hepatitis Council (NTAHC) are the only AIDS Councils which are also funded specifically for the provision of community-based education and support services relating to hepatitis C. Both services also manage busy Needle and Syringe Program (NSP) outlets.

With a strong background in HIV/AIDS, bringing a new service area and new target groups into TasCAHRD presented challenges in service mix and the marketing of the organisation. It was once thought that responding to hepatitis C would be very similar to the response to HIV. Over time,

however, it became clear this is not the case. While the response to HIV included people who inject drugs, this was, in larger states at least, historically the role of peer-based organisations. The key activity that linked AIDS Councils into this target group was the inclusion of NSPs within their service mix. Given that the majority of hepatitis C infections occur through sharing injecting equipment, this posed a challenge for the AIDS Councils, who were approached by State Governments to provide hepatitis C services as well.

So the big question was 'were people with hep C prepared to access services predominantly utilised by gay men?' Initially, in Tasmania this was a significant issue that required staff to challenge stereotypes relating to both groups. Displaying materials targeting gay men in areas more frequently accessed by heterosexual people who inject drugs was an initial

barrier. There were already challenges in encouraging heterosexual men and women with HIV to engage with an organisation consistently referred to as a 'gay organisation', let alone an 'AIDS organisation'. Getting the community and other services to acknowledge TasCAHRD as being relevant to people with or at risk of hepatitis C was a greater challenge.

The funding for services was – and continues to be – unbalanced, with hepatitis C services reliant on an infrastructure base that is provided through HIV funding. The resources required to lobby for increased hepatitis C funding were also based in the HIV arena. Justifying an equal profile for each service area in a context where funding was limited seemed unachievable.

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In recent times, TasCAHRD has embraced the need to market its services at a program level rather than an encompassing organisational level. Identifying and promoting programs has so far proven effective – not only in terms of engaging people with hepatitis C but also re-engaging with gay men and other men who have sex with men. The introduction of dedicated program websites, publications and logos for *Man2Man* and *Hep in Tas* has so far proven successful. The *Man2Man* website and publication has grown through taking on a more holistic view.

Being conscious of the sensitivities for non-gay identifying men who have sex with men, a regional context, as well as including broader health issues, has allowed men previously not comfortable with an AIDS Council to access programs. The initial print runs for the *Man2Man* magazine have been doubled and website hits continue to rise. Staffing for *Man2Man* is also being increased due to the increased engagement.

Hep in Tas is the new identity for the Hepatitis C Project. This consists of a dedicated website and information line. The initial goal of *Hep in Tas* was to increase awareness of hepatitis C in Tasmania. At the time, Tasmania had increasing number of hepatitis C diagnoses and became the second highest rate (per head of population) of diagnoses in Australia. Despite this, funding still did not increase! The challenge was to re-invent the project and to increase its profile with existing funding. In January, TasCAHRD launched the *Hep in Tas* website. In the marketing of these programs, which included television advertising, the inclusion of the TasCAHRD logo has

been downplayed to enable each to develop its own identity. The increased profile of the programs has primarily focused on prevention and access to information.

While these strategies appear to be increasing engagement with at-risk communities, how do you promote care and support services to an increasingly diverse communities? This is where the TasCAHRD brand continues to be relevant.

The provision of care and support does not target subcultures or groups of people living with either HIV or hepatitis C. Care and support services are accessed by HIV positive women and heterosexual men and people living with hepatitis C who may have never injected drugs. Creating a public profile to engage these diverse client groups is equally important.

In general, people living with either disease often have defined needs and access, through referral pathways or seeking out the support. The priority is to ensure that referral pathways are effective and the services are relevant to them. There is increasing pressure on more generic services to become more relevant and accountable to people living with HIV and/or hepatitis C. In recent times TasCAHRD's HIV Care and Support Program has taken on much more of a case management approach incorporating elements of chronic disease self-management. There is also scope to apply this approach to hepatitis C, though the diseases and their treatment are quite different.

So, is the challenge now to dispel myths about the original organisational profile? Promoting 'TasCAHRD' as a service provider for all people living

with HIV or hepatitis C and breaking down community stereotyping is a major part of addressing this.

A further challenge is identifying where NSPs fit in the changing profile of the organisation. NSPs were originally introduced as an effective response to HIV, but hepatitis C has become the primary focus of interventions outside of vein care. As a separately funded activity it may be possible and appropriate to shift the activity under the hepatitis C banner and be managed by the hepatitis program rather than a HIV funded position. While relevant, this means putting more strain on an underfunded program. TasCAHRD is about to make such a change and will be monitoring the impact.

The TasCAHRD Board is currently looking at the future direction of the organisation. Should the organisation attempt to grow? Should it become more specialised? What needs to change to make these things possible?

While a number of AIDS Councils have broadened their focus into LGBTI health which encompasses HIV, this will not be the case for all of them. The initial development of AIDS Councils in Australia grew out of the gay community response to HIV and it is important to acknowledge this heritage. For TasCAHRD, it is likely that any shift into broader LGBTI health issues will follow a similar format to the *Man2Man* Program and *Hep in Tas* branding. As an organisation working in the area of blood-borne viruses, it may well be the case that a broader focus could also include more involvement from the drug and alcohol sector.

Kevin Marriott is the Chief Executive Officer of TasCAHRD.

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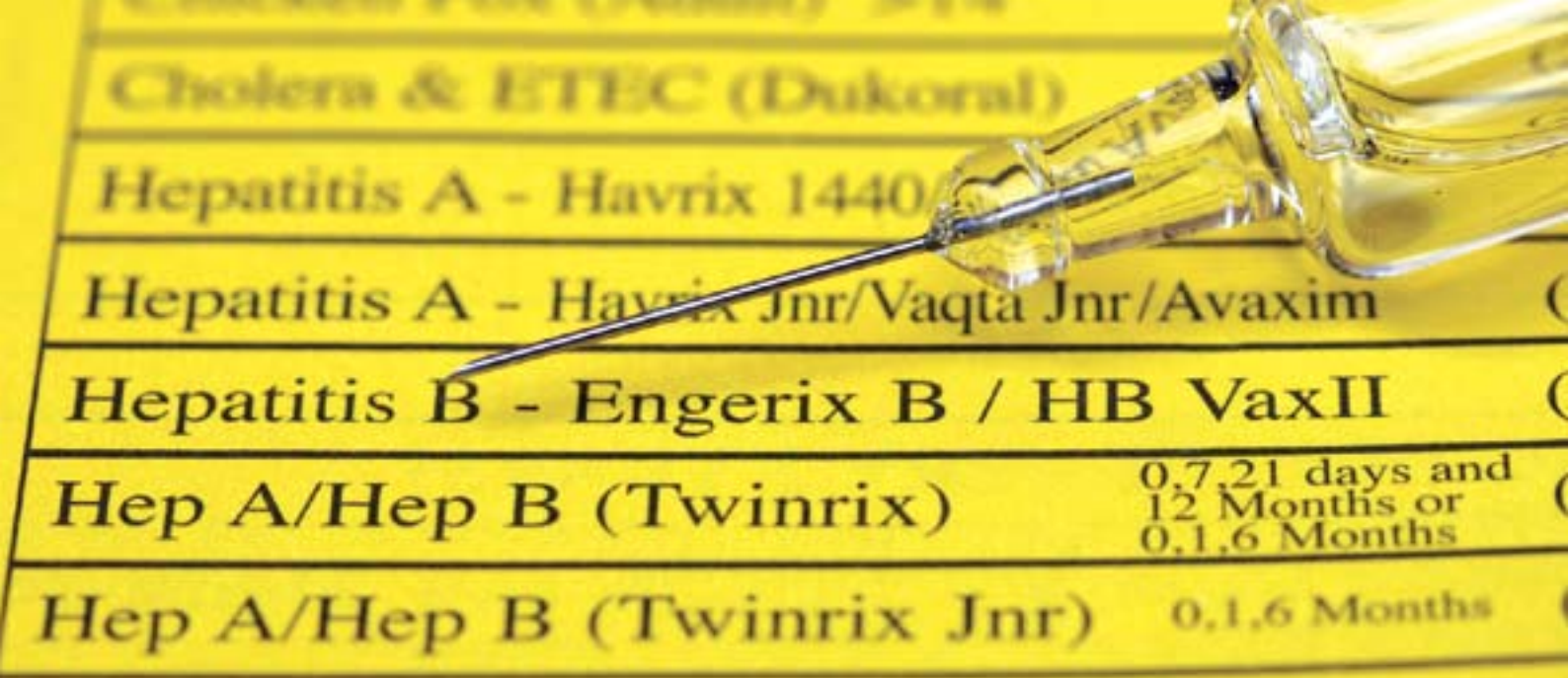
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A good dose: preventing hepatitis B through vaccination

By Jason Appleby

Hepatitis B is a potentially life-threatening liver infection caused by the hepatitis B virus. It is a major global health problem and the most serious type of viral hepatitis. It can cause chronic liver disease and puts people at high risk of death from cirrhosis of the liver and liver cancer.

Worldwide, an estimated two billion people have been infected with the hepatitis B virus (HBV), and more than 350 million have chronic (long-term) liver infections.¹

In Australia, an estimated 90,000 to 160,000 people have chronic hepatitis B, more than half of whom are people born in highly endemic countries of the Asia-Pacific region. Other high-risk groups include people born in other highly endemic regions, Indigenous people, men who have sex with men, and people who inject drugs.²

Transmission of hepatitis B virus results from exposure to infectious blood or body fluids containing blood. Possible forms of transmission include (but are not limited to) unprotected sexual contact, blood transfusions, re-use of contaminated needles and syringes, and vertical transmission from mother to child during childbirth.

The hepatitis B virus enters the body and travels to the liver via the bloodstream. In the liver, the virus attaches to healthy liver cells and multiplies. This replication of the virus then triggers a response from the body's immune system. People are often unaware they have been infected with the hepatitis B at this stage.

Most people recover from the acute infection but may still carry the hepatitis B virus long after recovering from symptoms. Some people develop chronic hepatitis, which can lead to liver failure and cancer. Chronic infection is more common if infection occurs at a young age.³

Vaccination

Hepatitis B can be prevented with a safe and effective vaccine that has been available since 1982. The initial strategy for the control of hepatitis B in Australia commenced in 1988, targeting groups at particular risk of infection for vaccination at birth. In addition to vaccine, hepatitis B immunoglobulin (HBIG) was given if the mother was a hepatitis B carrier. In 1990, universal infant vaccination commenced in the Northern Territory.

In 1996, the NHMRC recommended a universal hepatitis B vaccination program for infants and adolescents. The adolescent program commenced in some States and Territories in 1997 and the universal infant program, with the first dose given at birth, began nationally in 2000. The adolescent program will continue until those immunised for hepatitis B in the childhood program reach adolescence.⁴

The Australian Immunisation Handbook recommends that the following groups are vaccinated against hepatitis B:

- Household contacts of acute and chronic hepatitis B carriers
- Sexual contacts
- Sexually active men who have sex with men
- Haemodialysis patients, HIV-positive individuals and other adults with impaired immunity
- *Injecting drug users
- Recipients of certain blood products
- *Individuals with chronic liver disease and/or hepatitis C
- *Residents and staff of facilities for people with intellectual disabilities
- Individuals adopting children from overseas
- *Liver transplant recipients

- *Inmates and staff of long-term correctional facilities
- Healthcare workers, ambulance personnel, dentists, embalmers, tattooists and body-piercers
- Others at risk
(* Individuals should consider the combined hepatitis A/ hepatitis B vaccine.)

Vaccination in men who have sex with men

Sexually active men who have sex with men should be vaccinated, unless they have previously been exposed to hepatitis B or have serological evidence of immunity. The combined hepatitis A/ hepatitis B vaccine may be appropriate for men who have sex with men, if they are not immune to either disease, as they are at increased risk of both.

People with HIV

It is estimated that 10% of the 40 million people infected with HIV world-wide are coinfecting with hepatitis B.⁵ Although hepatitis B infection appears to have a minimal effect on the progression of HIV, the presence of HIV markedly increases the risk of developing

- Police, members of the armed forces and emergency services staff should be vaccinated if they are assigned to duties which may involve exposure.
- Funeral workers and other workers who have regular contact with human tissue, blood or body fluids and/or used needles or syringes.
- People travelling to regions of intermediate or high endemicity, either long-term or for frequent short terms, should be vaccinated.
- Staff of child day-care centres will normally be at minimal risk of hepatitis B. If advice on risk is sought, the enquiry should be directed to the local public health authority.
- Contact sports generally carry a low risk of hepatitis B infection. Vaccination is nevertheless encouraged.
- As the risk in Australian schools is very low vaccination of classroom contacts is seldom indicated. Nevertheless, vaccination of all children and adolescents should be encouraged.
- Sex industry workers.

hepatitis B-associated liver cirrhosis and hepatocellular carcinoma (a cancer of the liver). A recent meta-analysis of studies examining overall mortality showed an increased death rate among HIV-positive people due to coinfection with hepatitis B, both before and after commencement of highly active antiretroviral therapy (HAART).⁶

HIV Futures is an anonymous, cross-sectional survey of a sample of people living with HIV/AIDS in Australia. In *HIV Futures 6* (which ran from October 2008 through to April

2009, surveying 1106 people with HIV), people with HIV were asked about their hepatitis B status and whether they'd been vaccinated. They found that:

A total of 23.4% of respondents had at some time been diagnosed with hepatitis B. Of these, 77.5% had cleared the infection, 16.0% had an ongoing infection and 2.9% had a chronic infection. In addition to those who

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‘Which comes first – the chicken or the egg?’: HIV/hepatitis C co-infection and injecting drug users

By **Fiona Poeder**

People who inject drugs and are co-infected with HIV and hepatitis C (HCV) have a range of issues, not least of which is an increased risk of being subject to stigma and discrimination. Co-infected injecting drug users face a double stigma: they are marginalised and discriminated against on the basis of their drug use as well as their hepatitis C status.

While the research is still in its infancy, some of the physical effects co-infected people who inject drugs and those who are on pharmacotherapy (opiate replacement therapy [ORT]) may be subject to include: a speeding up of the metabolism (particularly relative to those on HIV treatment and ORT) – thereby increasing the risk of precipitated withdrawal; HIV infection in a person who is also infected with hepatitis C can result in higher levels of hepatitis C in the blood, more rapid progression to hepatitis C-related liver disease, and increased risk for cirrhosis and liver cancer; hence a ‘speeding up’

of the progression of hepatitis C; and, most relevant to this article, increased risk of liver damage.

When researching this article it became apparent that little research has been conducted nationally or internationally in relation to HIV/hepatitis C co-infection as it applies to people who inject drugs. There is a significant body of research on HIV and injecting drug use; and research on hepatitis C and injecting is steadily growing. However, if you put the two viruses together with injecting drug use, there is an obvious disparity.

Most available research is either of a scientific/quantitative or of a medical nature (detailing, for example, the interactions between the viruses and disease progression). Research of a qualitative and/or ethnographic nature is rare. HIV research exists – particularly relating to men who have sex with men (MSM), while ethnographic research into hepatitis C is starting to appear. But ethnographic

research into the triad of HIV/hepatitis C/injecting drug use appears notably absent.

I found that this disparity in relation to research into HIV/hepatitis C co-infection and injecting drug use transposed itself into other areas. The two blood-borne viruses are viewed differently by researchers, medical professionals and the general community alike. Hepatitis C continues to be the ‘poor cousin’ to HIV; when it relates to injecting drug use, hepatitis C is the ‘junkies’ disease’. When it comes to co-infection and injecting drug use, the disproportionate gap takes on a whole different – almost sinister – meaning. As ‘Anonymous’ (the pseudonym is telling in itself) wrote: *‘The part of living with HIV and hep C that I find ironic is that everyone is more concerned about how I had become infected than how I am managing to live with both conditions ... (but) I also think to myself ‘what’s the silence about hepatitis C?’ ... I often feel it’s easier to*

*talk about having HIV than it is to tell someone you have hep C ...*¹

My intention here is not to disparage the work that has been done in relation to HIV in this country; in fact, if it weren't for that work and the dedication of many, particularly within the homosexual movement, the work of hepatitis C advocates wouldn't have a platform now. Rather, the intention here is to draw attention to the plight of injecting drug users who are co-infected with HIV and hepatitis C, and to examine the situation from a behavioural standpoint, as an attempt to humanise the issues. Let us get the 'elephant out of the room': if one has HIV it is largely assumed (in this country, at least) that it was contracted through sex.

However, if one has hepatitis C it is assumed that it was contracted through injecting drug use. Injecting drug use is not 'natural' and by extension, injecting drug users become second-class citizens. This viewing of the viruses from a moral perspective can lead to an unequal allocation of resources and has significant impacts on injecting drug users who are co-infected.

Injecting drug use and HIV/ hepatitis C co-infection in the Asia-Pacific

When one compares the situation in Australia to that of our near neighbours in Asia – in relation to co-infection and injecting drug users – the picture is frightening, and again relates back to the disparity between the viruses mentioned above. Co-infected injecting drug users in Asia have definitely got a life and death struggle ahead of them. While increased access to HIV treatment would usually be regarded as a positive step in the fight against blood-borne viruses, in the Asia Pacific region this must be seen in context of some unique circumstances.

Firstly, in Asia injecting drug use is a major mode of HIV transmission. It is estimated that there are between

two and nine million injecting drug users in the Asia Pacific region², with some 750,000 living with HIV (30% of HIV infections in Myanmar, 40% in China, and most infections in Vietnam, Indonesia and Malaysia)³. The few studies on co-infection in the region estimate that hepatitis C infection prevalence is near-universal among injecting drug users, and co-infection is on the rise.⁴ Interestingly, a Thai study found that while HIV transmission through sexual intercourse may be decreasing, transmission through injecting drug use was increasing.⁵

Secondly, the only treatments available in the region are first generation antiretrovirals (ARVs), which are routinely provided to people with no access to hepatitis C testing, treatment or support. The irony is that for co-infected people who inject drugs, this might be exactly which is causing their demise: '*... Patients with HCV co-infection may experience increased rates of hepatotoxicity during antiretroviral therapy compared to patients without HCV ... one of the widely available ARVs in the region ... (is) associated with ... life-threatening hepatotoxicity. In many countries in Asia, second line regimes consisting of protease inhibitors of newer classes of antiretroviral agents simply do not exist ...*'⁶

The first generation antiretrovirals are toxic to the extent that some co-infected people are dying of liver disease and cancer – before they die of HIV and before they 'succumb' to their abuse of drugs; the ARVs heralded as 'saviour' become their demise!

The health issues related to co-infection for people who inject drugs in the Asian region are further compounded by a number of factors, including:

- The general lack of awareness of hepatitis C as a health issue: given that many hepatitis C positive people do not experience symptoms, or that for people who inject drugs these symptoms can be misconstrued for withdrawal or symptoms related to other disorders
- That hepatitis C is given a lesser priority in comparison to HIV: when one looks at the funding, media attention, health dollars and general priority given to both of these viruses, without a full understanding of the full health and social implications, it appears that hepatitis C is less 'deserving' of concern

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Co-infected injecting drug users in Asia have definitely got a life and death struggle ahead of them. While increased access to HIV treatment would usually be regarded as a positive step in the fight against blood-borne viruses, in the Asia Pacific region this must be seen in context of some unique circumstances.

- Lack of access to hepatitis C testing and treatment: apart from a lack of awareness in relation to hepatitis C in the Asian region, there is also an inadequate health infrastructure which includes a lack of skilled and trained staff able to deal with the complex health issues for which co-infected drug users are likely to require the services of health professionals
- Criminalisation of people who inject drugs and mandatory ‘treatment’ for drug users: in many Asian countries drug users are unlikely to come forward for health treatment as this is likely to result in compulsory ‘detoxification and rehabilitation treatment’ for their drug use. In countries where HIV treatment is available, it can also be routinely interrupted when drug users are forced into ‘drug treatment’, and
- Costs associated with hepatitis C testing and treatment: while some Asian countries have initiated HIV treatment (which is discussed below) and a few have introduced limited testing for hepatitis C,

the costs associated with hepatitis C treatment are extreme: *‘The medications used in hepatitis C treatment, pegylated interferon and ribavirin, are expensive. A six month course costs between US\$4,000–5,000; the lifetime income of some Indians. Unlike HIV, where first line antiretroviral therapy (ART) is provided free, there is no government support or subsidy for hepatitis C treatment ...’*⁷

Currently the UNODC, WHO and UNAIDS are working to set target guidelines for the inclusion of hepatitis B and C testing and treatment. In addition, the Global Fund for AIDS, TB and Malaria are advocating or the provision of hepatitis C testing and treatment in Asia. There is a limited amount of funding going toward testing and treatment for hepatitis C in some Asian countries and advocacy is happening in relation to releasing the patents on second generation HIV treatment drugs – which are less toxic to the liver, and thereby less harmful to co-infected people who inject drugs.

There is a limited amount of funding going toward testing and treatment for hepatitis C in some Asian countries and advocacy is happening in relation to releasing the patents on second generation HIV treatment drugs – which are less toxic to the liver, and thereby less harmful to co-infected people who inject drugs.

There is no easy answer or solution. All I know is that WE, in Australia, those working in this field, and we in the ‘developed’ world need to be aware, to listen and to speak out, because regardless of our blood-borne virus status we are ‘the lucky country’ and will remain so until the situation changes for co-infected people who inject drugs.

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Silent partner: acute hepatitis C infection and HIV

By Jason Appleby

had experienced hepatitis B infection, 69.9% had been vaccinated against this virus. This means that 6.7% may currently be at risk of being infected with hepatitis B.⁷

It is currently recommended that HIV-positive individuals and other adults with impaired immunity should be given a larger than usual dose of hepatitis B vaccine. At least one study suggests that hepatitis B vaccination is less effective in patients with HIV.⁸

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Recent evidence suggests that the epidemic of sexually acquired acute hepatitis C (HCV) infection in HIV positive men reported from Europe and the States, as well as from within Australia, is continuing. The reasons for this increase in cases acquired through sexual exposure rather than through traditional routes of infection (such as injecting drug use) are unclear. Studies have suggested that the risk may be greater with certain types of sex, the use of other (non-injected) drugs, and sex with multiple partners – although the mechanisms behind transmission remain unknown. Whether people living with HIV are more likely to have hepatitis C virus in semen and/or at higher concentrations, particularly in the setting of acute hepatitis C infection, is also unknown.

The incidence of hepatitis C co-infection amongst HIV-positive people in Australia is estimated to be 13.1%¹, while the incidence in the general Australian population is estimated to be 1.4%².

The latest *HIV Futures* study asked a cohort of people with HIV how they believed they had become infected with the hepatitis C virus; 44.0% said injecting drug use, 23.2% during sex, 7.9% blood transfusion or the receipt of blood products, 1.5% through tattooing and 3.8% through other means. 18.9% of respondents did not know how they were infected.³

Acute infection

Acute hepatitis C refers to the first six months of hepatitis C infection, while those lasting more than six months are known as chronic hepatitis C infections. 60% to 70% of people infected with

hepatitis C develop no symptoms during the acute phase. For the minority of patients who experience acute phase symptoms, these are generally mild and nonspecific, and rarely lead to a specific diagnosis of hepatitis C. Symptoms of acute hepatitis C infection include decreased appetite, fatigue, abdominal pain, jaundice, itching, and flu-like symptoms.

The hepatitis C virus is usually detectable in the blood within one to three weeks after infection by polymerase chain reaction (PCR)⁴, and antibodies to the virus are generally detectable within three (3) to 15 weeks. Some people will clear the hepatitis C virus without treatment during acute infection; this is known as spontaneous viral clearance. Spontaneous viral clearance rates are highly variable and between 10–60% of persons infected with hepatitis C clear the virus from their bodies during the acute phase. However, persistent infections are common and most patients develop chronic hepatitis C. Rates of spontaneous viral clearance are reduced in people with HIV compared with HIV negative individuals.

Treatment and acute infection

Treatment in acute or early infection demonstrates a greater chance of success with reduced periods of treatment. The greater challenge for many patients is detecting hepatitis C infection during the acute infection.

However, it has been recognised that people with HIV who are engaged in regular clinical monitoring are more likely to be diagnosed with hepatitis C during acute infection.

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Last year, at the 60th Annual Meeting of the American Association for the Study of Liver Diseases, Dr Fierer presented data from 51 HIV-positive men who have sex with men (MSM) who experienced 53 episodes of acute hepatitis C (some were infected twice). Acute hepatitis C infection was defined as newly identified hepatitis C antibody seroconversion, marked elevation in liver function tests (ALT > 5 times the upper limit of normal)⁵, or large fluctuations in HCV RNA level (>1 log in four weeks).

'Treatment is highly successful when initiated in the acute phase, but may be less successful if initiated soon after,' the investigators noted. 'Thus, it is crucial to detect hepatitis C infection in the acute phase to allow successful treatment and prevent further progression of the already significant liver fibrosis.'

*'We therefore recommend ALT testing every three months and hepatitis C antibody testing every 6–12 months for all HIV-infected men who have sex with men,' they advised. 'Promotion of safe sex is also warranted.'*⁶

This finding mirrors local data collected during the ATAHc study (conducted at St Vincents Hospital through the National Centre for HIV Epidemiology and Clinical Research).⁷ The ATAHc study had some surprising findings, which include:

- Presumed sexual transmission accounted for the majority (56%) of hepatitis C infections among HIV-positive patients, compared with only 8% among HIV-negative participants
- Overall, 44% of patients treated with pegylated interferon plus ribavirin had undetectable hepatitis C RNA⁸ at week four (rapid virological response or RVR)
- 95% of patients had undetectable hepatitis C RNA at week 12 (early virological response or EVR)
- 90% had undetectable hepatitis C viral load at 24 weeks (end of treatment response)

- 80% still had undetectable hepatitis C RNA at week 48, or 24 weeks after the completion of treatment (sustained virological response or SVR), and
- RVR at week four had a positive predictive value for SVR of 100% and a negative predictive value of 33%.

Based on these findings, the study authors concluded, 'Significant differences were demonstrated between HIV-infected and HIV-uninfected individuals enrolled in ATAHc'.

'Treatment responses among HIV-infected individuals with both acute and early chronic infection are encouraging and support regular HCV screening of high-risk individuals and early treatment for recently acquired HCV infection'.

Starting hepatitis C treatment

Current treatment is a combination of pegylated interferon-alpha-2a or pegylated interferon-alpha-2b (brand names Pegasys or PEG-Intron) and the antiviral drug ribavirin for a period of 24 or 48 weeks, depending on the hepatitis C virus genotype. Treatment is generally recommended for patients with proven hepatitis C virus infection.

The treatment may be physically demanding, particularly for those with a prior history of drug or alcohol abuse. It can qualify for temporary disability in some cases. A substantial proportion of patients will experience a range of side effects ranging from a 'flu-like' syndrome (the most common, experienced for a few days after the weekly injection of interferon) to severe adverse events including anaemia, cardiovascular events and psychiatric problems such as depression.

A recent study looked at factors which affected HIV/hepatitis C coinfecting patients' decision making around initiating treatment for hepatitis C.⁹ The following were key factors which influenced treatment decisions:

- Stability of HIV disease
- Perceived need for hepatitis C treatment
- Treatment readiness
- Willingness to deal with side-effects
- Absence of substance abuse
- Stability of mental health
- Overall life circumstances.

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Hepatitis: Get Treated

In many cases, hepatitis B and C can be treated effectively



If you think you could be infected with hepatitis B or C, consult your doctor immediately. If you have already been diagnosed with hepatitis B or C, talk to your doctor about the most effective treatment option for you.

There are many factors that will affect whether you should start treatment and an open and honest dialogue with your doctor will help you make the right choice.



This is **hepatitis...**



Food for thought: HIV/hepatitis C co-infection and nutrition

By Lia Purnomo

It is estimated that 13% of people living with HIV in Australia are co-infected with hepatitis C.¹ Current evidence suggests there is an increased risk of progression to fibrosis and end-stage liver disease in HIV/hepatitis C co-infected patients.² It is not clear whether hepatitis C has an effect on HIV, however, a recent meta-analysis shows higher mortality among people with HIV/hepatitis C co-infection.³

Given the efficacy of highly active antiretroviral therapy (HAART), Australians with HIV are living longer. However, lifestyle related co-morbidities are now becoming increasingly evident among HIV/hepatitis C co-infected patients. The co-morbidities are attributable to a range of factors, some of which can be addressed by dietary changes.

HIV and hepatitis C co-infection: nutrition issues

Alcohol

Heavy alcohol intake is associated with an increased risk of liver damage. Research also shows that alcohol adds extra kilojoules to the diet and may increase energy intake further by increasing appetite⁴, which may affect an individual's tendency to gain weight⁵. High alcohol consumption and being overweight are two factors that might lead to a poorer health outcome in people co-infected with HIV and hepatitis C.⁶

Current guidelines recommend that generally, both men and women should not drink more than two standard drinks per day (20g/day) – a standard drink being one schooner of light beer,

one middy of full strength beer, one standard glass of wine or one nip of spirit. These guidelines are not suitable for people living with HCV, who should consider avoiding alcohol altogether – particularly people with hepatitis C who have evidence of liver damage.⁷

Body weight

The incidence of being overweight and obesity is increasing in people living with HIV, both in Australia and internationally. This means that the incidence of obesity-related disorders, such as cardiovascular disease and diabetes are also on the rise among people living with HIV. The transition appears to be a result of effective anti-retroviral treatment, poor eating choices and low levels of physical activity^{8,9}

– similar trends to those in the general population.

In chronic hepatitis C infection, obesity is associated with: inflammation, insulin resistance, fatty liver, progression of fibrosis, and non-response to treatment with interferon or peginterferon alpha and ribavirin.¹⁰ Modest weight loss increases the chance of better response to treatment and improves liver enzymes and serum insulin levels.¹¹

Maintaining a normal weight by monitoring food intake and physical activity is important in people with HIV/hepatitis C co-infection. Successful weight management requires establishing a life-long commitment to a healthy lifestyle.

Some tips for effective weight management include:

- aim for slow weight loss (0.5–1kg a week)
- focus on eating healthy foods
- cut back on refined sugars
- eat less takeaway and processed foods
- reduce the size of portions for calorie reduction
- aim for at least 60 minutes or more of moderate intensity physical activity on most, if not all, days of the week (eg. 30 minutes walking and 30 minutes lifestyle activity), and
- forget crash diets, as the lost weight is most likely regained within years.

Insulin resistance and metabolic syndrome

Insulin resistance is the condition of decreased tissue sensitivity to the actions of insulin. It is associated with Type 2 diabetes as the pancreas cannot keep up with the body's need for insulin and excess glucose builds up in the bloodstream.

Type 2 diabetes and insulin resistance are becoming more common in

people living with HIV due to the adverse metabolic effects of highly active antiretroviral therapy (HAART – particularly protease inhibitors), the effect of lipodystrophy and the impact of the obesity epidemic.¹² The hepatitis C virus, regardless of genotype, has also been shown to induce insulin resistance.¹³

People with HIV/hepatitis C co-infection who are on HAART have been reported to have a higher incidence of insulin resistance¹⁴, and lower total and low density lipoprotein (LDL) cholesterol than HIV mono-infected individuals¹⁵. HIV and hepatitis C have been linked to metabolic syndrome – a collection of manifestations including high body mass index, low high density lipoprotein, high triglycerides, insulin resistance and high blood pressure – as they demonstrate similar pathophysiologic pathways. Metabolic syndrome is a risk factor of cardiovascular disease. The similar risk factors for metabolic syndrome are also associated with hepatic and metabolic dysfunction leading to fatty liver and other complications.^{16,17}

There is no 'quick fix' solution that is effective for the management of metabolic abnormalities. Studies have shown that lifestyle modification focusing on healthy eating, weight management, smoking cessation, and increased physical activity is essential to reduce risk of cardiovascular disease and type 2 diabetes in high-risk populations.^{18,19,20,21}

Diet and HIV/hepatitis C co-infection

Although most people living with HIV/hepatitis C co-infection do not need a special diet, they are best advised to maintain a healthy diet. Healthy eating for people who are co-infected with HIV and hepatitis C is the same as recommended for the general population.²² However, dietary choices should be based on individual circumstances and will depend on any symptoms being experienced at a particular time.

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What is a healthy diet?

A healthy diet contains the right balance of foods from each of the five major food groups. Choosing a variety of foods within and across food groups is essential. Healthy eating also means following a regular meal plan which provides the body with a constant supply of protein, carbohydrate, fat, vitamins and minerals.²²

Healthy eating for people co-infected with HIV and hepatitis C should generally be:

- high in fibre from wholegrain foods, vegetables (including legumes) and fruits
- high in unsaturated fats such as fish, nuts, avocados, canola, olive and sunflower oils
- low in saturated fats, which commonly come from animal fats, high fat dairy products and highly processed convenience foods
- low in added sugars, such as that which is found in soft drinks and lollies
- adequate in calcium – low fat dairy products are excellent source of calcium, and
- low in alcohol.

Living with HIV and hepatitis C co-infection: symptoms related to eating and nutrition

Symptoms experienced by co-infected individuals may impact on nutritional status by affecting the amount or

range of foods eaten. Appetite may be reduced and the taste of foods can be altered, changing the types of foods consumed and affecting absorption and utilisation of nutrients.

There are many strategies to manage these symptoms, but in general the best way to meet nutritional needs is through eating regular small portions of food and drinks that are high in calorie and nutrient density, such as smoothies, yoghurt and milk drinks, and high energy snacks (nuts and dried fruits, cheese and crackers).

Fatigue

Recent research suggests that fatigue is among the most common presenting symptoms associated with HIV and hepatitis C coinfection.²³ There is no nutritional 'quick fix' for fatigue, however, these suggestions may help manage fatigue:

- focus on adequate energy intake
- stock up the pantry when feeling well, cooking in bulk and freezing meals for use another time
- reduce highly processed foods
- incorporate light exercise into daily routine, and
- have support systems of family and friends to prepare meals.

Poor appetite

Lack of appetite may cause insufficient dietary intake, making it difficult to maintain adequate supply of nutrients.

Dietary strategies include:

- eat small amounts often, rather than relying on appetite to prompt eating
- eat most when feeling the best
- separate consumption of liquids from meal times
- eat meals with family or friends
- make meals as tempting as possible by varying tastes, colour and texture
- eat in well-ventilated room
- rinse the mouth before meals, and
- light exercise before meal-time may stimulate appetite.

Nausea and vomiting

Nausea can occur as a result of skipping meals, feeling hungry or having gastrointestinal disease. Prolonged cases of vomiting can lead to symptoms of dehydration.

Dietary strategies include:

- avoid having an empty stomach
- avoid fatty foods (eg. fried foods, pastries)
- rest after eating
- nibbling on salty foods (eg. crackers) or dry toast
- sip on ginger ale, and
- try small, frequent sips of nourishing fluids after the vomiting is controlled and gradually introduce small amounts of solid foods.

Weight loss

Unintentional weight loss occurs because the body is using up more nutrients than it is absorbing from food. There can be many causes of weight loss in people co-infected with HIV and hepatitis C. Some causes include increased metabolism and mal-absorption associated with HIV; symptoms associated with each condition; and drug treatments that affect appetite.

Symptoms experienced by co-infected individuals may impact on nutritional status by affecting the amount or range of foods eaten.

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Me, myself and I: self-management programs for HIV

By Neil McKellar-Stewart

HIV is increasingly seen as one of a number of manageable chronic health conditions. Because of the efficacy of highly active antiretroviral treatments (HAART), mortality attributable to HIV infection and AIDS has reduced dramatically since the mid-1990s. Recent data from public health databases and cohort studies indicate that life expectancy for people with HIV has been extended to near-normal levels.^{1,2}

HIV meets several chronic disease criteria: an uncertain course, a prescribed treatment regimen, requirement for self-care, significant stigma, changes in personal relationships, identity changes, and psychological distress.³ The goal of chronic illnesses healthcare is to control symptoms and prevent disability rather than cure the disease – certainly this is the case with HIV.

Because of the success of treatments for HIV in developed countries, people living with HIV are ageing. Many have lived with HIV for many years. Decades of low to moderate immunosuppression pose significant health issues for people with HIV. These, along with concerns about long term HIV-specific drug toxicities, are revealing a growing body of evidence of early onset of metabolic, cardiovascular, renal, hepatic, bone, and central nervous system degenerative diseases, as well as non-AIDS associated malignancies.^{4,5}

Self-management: an imperative for people with HIV

In order for people with HIV to best maintain their health it is advisable that they adopt a range of behaviours which include:

- being the principal caregiver for themselves

- engaging in day-to-day ‘illness work’ (this includes taking medications, managing treatment side effects, attending to their mental health and to lifestyle issues such as exercise, diet, drug and alcohol intake, etc.)
- changing behaviour to improve symptoms and maintain, as far as possible, immune functioning
- working in partnership with treating doctors to make treatment decisions, maintain ongoing HIV monitoring and attend medical appointments, manage emotional responses to illness, treatment, and discrimination, and
- minimising the risk of transmissible infections including HIV and other sexually transmissible infections (STIs).

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People with HIV have a pivotal role in assuming an active and informed role in managing the physical, psychological and social aspects of their HIV infection. Increasingly, models of care for people with chronic diseases like HIV have included formal programs which aim to enable people to manage their own health conditions in partnership with their health care providers. The World Health Organization⁶ suggests that best practice involves educating and supporting patients to self manage their conditions to the greatest extent possible. Self-management programs have been developed across a range of chronic diseases.

The situation for people with HIV who are also living with hepatitis C virus (HCV co-infection) is more complicated. Issues for such people include when to start treatment and for which viral infection. A recent article on hepatitis C self-management⁷ indicated that people with hepatitis C selectively used a range of strategies in addressing multiple goals, which may be categorised as: fighting the virus, strengthening the body, and managing consequences. These involved ad hoc and individualised interventions made by people with HIV and hepatitis C outside any formal framework. We are unaware of any formal programs which provide a self-management framework for people who are living with both HIV and hepatitis C, but believe the key elements of self-management for HIV can also be applied to hepatitis C.

Some recent reviews

The New Zealand National Health Committee reviewed a number of these programs in their report Meeting the needs of people with chronic conditions.⁸ In particular they discussed two which are suitable to meet the needs of people with HIV. These

are the Positive Self-Management Program for HIV (PSMP)⁹, (one of the self-management modules developed by Stanford University, School of Medicine), and the Flinders Program of Chronic Condition Self-Management¹⁰ (developed by Flinders University, Human Behaviour and Health Research Unit). These two programs are discussed in more detail below. They suggest that there is now a body of evidence on the effectiveness of self-management in terms of improved health outcomes and health system efficiencies.

The UK National Institute for Health and Clinical Excellence¹¹ similarly reviewed the evidence for the benefits resulting from implementation of self-management programs, including peer-led programs. They discussed at some length the Arthritis Self-Management Program (ASMP), which is an analogue to the Stanford PSMP. The UK researchers concluded that promoting self-management and helping individuals to manage chronic conditions better has the potential to enable such people to achieve better health outcomes.

A recent, extensive review¹² of self-management programs for HIV and other chronic diseases identified some common elements. They discussed a number of HIV-specific programs and argue that self-management education: enables people to proactively address predictable challenges in their HIV disease; sustains long term changes in everyday behavioural routines; allows HIV-positive people to identify with a larger population of people diagnosed with chronic diseases, and; facilitates the continued mainstreaming of care for people with HIV.

Two programs suitable for people with HIV

The Stanford PSMP is specifically adapted for people with HIV. The

program is a group-based intervention in which people with HIV attend a closed group for two and a half hours per week for seven weeks. Workshops are facilitated by two trained leaders, one or both of whom are living with HIV and working outside of the health sector. The program is based around the eight subject modules:

- 1) Integrating antiretroviral drug treatments into daily life to maximise adherence
- 2) Managing issues such as frustration, fear, fatigue, pain, and isolation
- 3) Establishing appropriate and effective exercise programs
- 4) Communicating effectively with family, friends, and health professionals
- 5) Nutrition
- 6) Evaluating symptoms
- 7) Establishing advanced care directives, and
- 8) Evaluating new or alternative treatments.

A textbook¹³ is supplied as part of the program. The course structure and content are set and permission is needed from Stanford University to make alterations. Living Well UK has gained permission to alter specific language and stylistic features to make the course more appropriate to the UK context.

The PSMP course is a peer-led initiative facilitated by past participants. The peer-led process is one of the most important aspects of the course and having facilitators who are themselves living with HIV is a key feature. Participants are provided with 'positive role models' and shown that the techniques covered are effective. Each PSMP course has at least one facilitator who is living with HIV. Facilitators are accredited to conduct the program after successfully completing a four and a half day intensive training course.

The PSMP has been critically evaluated as it has been offered in the USA and in the UK. (Details at the PSMP website referenced above.)

The Flinders Program of Chronic Condition Self-Management is a one-on-one program whose aim is to develop a 'Self-management Care Plan' which documents any related medical investigations, self-management approaches undertaken by the patient, and self-management education and allied health and community services accessed by the individual during a twelve month period after they commence the program. It will normally include:

- 1) Identified issues around living with HIV
- 2) Agreed goals
- 3) Agreed interventions
- 4) Shared responsibility signified by sign off by both the patient and health professional, and
- 5) Review process including dates.

The following three tools are used to inform the individualised Care Plan: Partners in Health Scale (PIH), Cue and Response Interview (C&R) and Problem and Goals' (P&G) Assessment. Details of these and examples of how the Flinders Program has been applied and evaluated are available on the Flinders website (referenced above).

Adoption of self-management programs in Australia

To date the Stanford and Flinders programs have not been delivered to people with HIV in Australia. Individual State and Territory AIDS Councils, and people living with HIV/AIDS Organisations, including the National Association of People Living with HIV/AIDS (NAPWA), are currently considering the adoption of self-management programs for people with HIV.

People with HIV already adopt self-care strategies for a range of issues, including depression.¹⁴ It is uncertain to what extent people with HIV in Australia might be interested in participating in such structured self-management programs. However, Australia has a strong track record of developing and implementing peer-led interventions which aim to improve the health and well being of people with HIV.

Based on past performance of an active, informed, empowered and empowering model of service delivery and program development by and for people with HIV, Australian-based community organisations are already in a strong position to adopt and implement one or more of these programs.

A range of interventions which utilise self-management elements, including life coaching (which is offered by ACON's Positive Living Centre and Western Australian AIDS Council), have been used in the Australian HIV sector. Details of such interventions can be obtained from relevant HIV community and government agencies in individual States and Territories.

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DON'T FORGET
TO REMEMBER!

Stop the Drama Downunder! – multimedia campaign targets rising STI rates among gay men

By Ben Wilcock

The Drama Downunder is a campaign produced by the Australian Federation of AIDS Organisations (AFAO) to address rising rates of sexually transmitted infections among Australian gay men. There is particular concern that rising rates of sexually transmitted infections (STIs) are partly driving new HIV diagnoses: having an STI can dramatically increase the potential for HIV transmission during sex, as sores and other irritations provide an effective gateway for the virus to pass from one body to the next.

The Drama Downunder multimedia campaign aims to encourage homosexually active men in Australia to improve their knowledge about sexual health, and to get regular sexual health checks. Originally launched in 2006, AFAO has built on the success of the initial campaign by recently launching a new phase of the campaign.

Getting an individual to change their behavior takes time and is part of an ongoing process, explains AFAO president Graham Brown. 'Increasing rates of STIs are still a major concern for gay men. For maximum impact and to get more men going for regular sexual health checks, a campaign such as this needs to be sustained over an extended period of time,' he said.

STIs are a particular concern for people living with HIV. The campaign provides information specifically for HIV-positive men, about the impact of having HIV and another infection such as hepatitis B or C. It includes information about the effect STIs can have on HIV viral load, about how HIV can make the STI more difficult to treat, and how to reduce the impact that STIs have on the health of people with HIV. Tips include having full sexual health checks when HIV monitoring blood work is done, getting vaccinated for hepatitis A and B, and using condoms. As Robert Mitchell, President of the National Association of People Living with HIV/AIDS (NAPWA) said, 'Having an STI can have a large impact on the health of someone living with HIV and also make it easier to pass on HIV. This campaign explains what these impacts are and shows why regular sexual health checks are important for all HIV-positive people.'

The campaign materials feature a model in various poses representing different messages about sexual health. In some of the images he is in various states of drama, downunder. In some, his underpants are on fire; in others he has swirls of smoke rising up; and in others he appears happy. This range of images represents the fact that, while

many STIs are all too obvious – being painful and/or irritating, others can have no symptoms at all. This makes regular sexual health checks vital for all men who are sexually active.

The campaign also features a website, www.thedramadownunder.info. It provides comprehensive information about STIs, testing and treatment and also features two interactive services. The first is a reminder service, where users can sign up for SMS or email reminders to book in for their sexual health checks. The second is a partner notification service, where people who have recently been diagnosed with an STI can notify their partners via SMS or email – anonymously if they wish – in order to look after the health of their partners.

The Drama Downunder man will be seen throughout Australia in the coming months, on billboards and Adshels, on public transport, in press ads, on gay chat-sites and other websites. He will also appear in a booklet, posters, cruise cards and postcards. Copies of the campaign materials are available from state-based AIDS Councils and People Living with HIV organisations.

Ben Wilcock is an HIV Education and Health Promotion Officer for the AFAO/NAPWA Education Team.



From the ground up: community-based HIV advocacy in Laos PDR

By Matthew Tyne and RD Marte

Laos Peoples Democratic Republic (PDR) shares borders with five other countries (Thailand, Cambodia, China, Myanmar and Vietnam). It is landlocked and one of the most sparsely populated and least developed countries in Asia. Nearly 80% of the country's population lives in rural areas and about half the country's gross national product (GDP) comes from subsistence agriculture.¹ Much of rural Laos is still directly affected by unexploded ordnance, a legacy of conflict between the United States and North Vietnam some forty years ago.

Laos PDR is a low HIV prevalence country. By the end of 2007, there were an estimated 5,500 people living with HIV and an adult prevalence rate of 0.2%.² However, there is some evidence to suggest a growing epidemic among sex workers, their clients and men who have sex with men (MSM). Migrant workers are also a vulnerable group. While the rate of infection among sex workers remains relatively low, at 0.5% in 2008, a study of 540 MSM in Vientiane indicated that 5.6% of those surveyed were HIV-positive.³

The country's response to HIV is led by the National Committee for the Control of AIDS (NCCA). The NCCA is supported by Committees for the

'Before we just implemented activities, followed instructions [as handed down to us by our organisations] but we did not know the reason behind those activities. We also did not know how to develop plans to address the issues. Now we know ... we know how to analyse issues, how to look at the root causes of problems and how to develop plans to address them.'

— Waii, MSM Outreach worker, Lyap TBC

Control of AIDS at both the provincial and district levels. In 2006, the NCCA coordinated the development of the country's current National Strategy and Action Plan (NSAP). The focus of the plan, which is currently under review in preparation for the next NSAP, is on scaling up Universal Access, especially for sex workers and their clients, and men who have sex with men.⁴

Antiretroviral therapy (ART) was first made available in Laos in 2003 by *Medecins Sans Frontiers*. Treatments are currently available at three sites: Vientiane, the country's capital; Luang

Prabang in the north, and Savannaket in the south.⁵ The Ministry of Health manages and operates treatment services. While by the end of 2008, there were approximately 1000 people receiving free ART, by 2012 it is expected that there will be 3,500 people on ART.⁶

The NSAP aims to include people living with HIV as participants by appointing them to 'advisory roles in all HIV/AIDS

continued overleaf

decision-making bodies, including NCCA and Country Coordinating Mechanisms (CCM).⁷ In addition to scaling up prevention efforts and treatment access, the NSAP includes aims to put 'supportive policies' in place to facilitate 'interventions focusing on the most vulnerable and marginalised groups'.⁸

An important dynamic in the Laos HIV response is the way in which the dominant government sector interacts with civil society. As the current NSAP makes references to increasing the participation of people living with HIV and other affected communities, the relationship between government agencies and their non-government counterparts requires careful monitoring and negotiating.

In Laos, it is difficult to form autonomous community-based organisations (CBOs). Instead, government-sponsored mass organisations auspice many projects and organisations to work directly with communities. Civil society is represented by mass organisations, including Lao Women's Union (LWU), Lao Revolutionary Youth Union (LYU), Lao Front for National Reconstruction (LFNR) and Lao Federation of Trade Unions (LTU).⁹

The Laos Youth Union (LYU) has been particularly active in its support of community based groups working in HIV prevention, care, support and advocacy. LYU auspices the Laos Youth Action for AIDS Program (LYAP), the in-country partner of the Community Advocacy Initiative (CAI). The CAI is a three-year¹⁰ program, which aims to expand and strengthen the capacity of local and regional CBOs. Funded by AusAID through the HIV Consortium for Partnerships in Asia and the Pacific, CAI is implemented by AFAO and APCASO in partnership with in-country CBOs. Currently CAI operates in Indonesia, Vietnam and Laos.

CAI implementation began in Laos in 2009. It was guided by the advice AFAO and the Asia Pacific Council of

AIDS Service Organisations received from consultations with stakeholder groups: CBOs, international NGOs, government, the United Nations (UN) and funding agencies. A unique feature of the Laos program is the need to constantly keep in check the balance of having community groups as the focus and owners of the program, while keeping relevant government agencies involved and supportive of the program. The in-country experience, network base and expertise of the local implementing partners have proven valuable in negotiating this balance.

The program in Laos is led and coordinated by the Laos Youth Action for AIDS Program, a 12-staff and 60-volunteer members strong local organisation, which provides peer outreach programs to men who have sex with men and transgender people and care and support services to people living with HIV and their families. With the leadership of LYAP, the CAI program has brought together a diverse range of community-based groups whose members include men who have sex with men, people who identify as transgender, sex workers, women, young people, and people living with HIV. The program has also facilitated joint advocacy capacity development, identification of critical local HIV/AIDS issues¹¹, and the development and implementation of advocacy plans in response to these critical issues.

Program activities, to date, include a series of advocacy workshops and ongoing technical and financial support for CBOs to develop, refine and implement advocacy plans. The Laos translation of the CAI *HIV Advocacy from the Ground Up* toolkit¹² serves as key reference material for the program. The toolkit is a practical resource for trainers of advocacy capacity development. It is intended to broadly elaborate on the concept of advocacy and how it plays a key role in effective HIV interventions and AIDS services and, wherever possible, builds on actual experiences and work already being carried out by local NGOs and CBOs.

Slowly, CAI is seeing the development of a very new and small but committed movement of community-based advocates in Laos. We are really beginning to, as the title of the toolkit suggests, do advocacy from the ground up.

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'It must be kind of weird being you'

A review of *Sordid Truths: Selling My Innocence for a Taste of Stardom* by Aiden Shaw, Alyson Books, 2009

By Jennifer Power

The second instalment of Aiden Shaw's memoirs reads like a boys' own adventure, albeit a grown up adventure for gay men. The tale carries us on a rollicking ride with Shaw's friends, lovers and clients, each chapter revealing a new encounter, presumably the characters—most-memorable in Shaw's life of many encounters.

Aiden Shaw was the highest paid, and arguably most famous, porn star of his generation, starring in over fifty films through the 1990s which won him numerous awards, including the accolade of having one of Carrie Bradshaw's *Sex in the City* boyfriends named after him. He now makes his living as a novelist and poet.

Sordid Truths ... is the prequel to Shaw's original, best-selling memoir *My Undoing: Love in the Thick of Sex, Drugs, Pornography, and Prostitution*. It follows Shaw's life from the mid 1980s, when he was working as a rent-boy in London, through to 1991 when he travels to the US to meet renowned film producer Chi Chi LaRue, who would go on to make him a star.

The title of this memoir, *Selling My Innocence for a Taste of Stardom*, is deceptive in some ways. It suggests the story could be one of regret. But apart from the occasional reference to 'Little Fella', the name Shaw gives his childhood inner-self, there is very little



sense of regret or loss in the book. In fact, Shaw seems to be having a grand old time navigating his world of sex and drugs and the book is fun as a result. It's not until the self-reflective epilogue that a hint of uncertainty and sadness emerges:

Thinking about my life – the hustling to be paid for sex, on streets in various cities, on porn sets in California surrounded by naked bodies, shooting up crystal meth at some grungy dealer's pad, lying in a hospital ward with some HIV complication – I've asked myself why I did it the way I did.

Shaw uses some fairly obvious pop-culture markers to situate his text in the 1980s – setting his VCR to record the first-ever episode of *The Simpsons*, deciding he doesn't like the new Swatch watches everyone is wearing and discussing whether or not this new singer Madonna will take off. There is something self-conscious about this, as though Shaw is concerned his readers will forget what decade he is talking about. Or perhaps it is just that, as it is for many of us, the reference points for his memories are grounded in the music and television (or hairstyles) of the time. Either way, a bit of '80s culture spotting certainly adds to the fun of the book.

This is a story told with good humour and a healthy sense of cockiness. Shaw is popular with the lads and his eccentric parade of clients are quite fascinating in themselves, from the wealthy and famous to the downright strange. There is no doubt that Shaw has lived a life-less-ordinary. This is expressed most succinctly in the prologue to the memoir by a young fan who Shaw meets in a San Francisco bar in 1997. 'It must be kind of weird being you,' says the fan. 'Sometimes,' Shaw replies.

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HIV AUSTRALIA

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Dietary strategies include:

- never skip meals
- increase healthy fats (eg. add extra olive oil, avocado, nuts and seeds to salads), and
- avoid eating ‘junk food’, as this is not the best way to gain weight. Instead, increase intake of nutrient dense foods such as starchy vegetables and dense wholegrain breads and cereals.

Diarrhoea

Diarrhoea is the passage of three or more loose or liquid stools per day, or more frequently than is normal for the individual.²⁴ A variety of bacterial, viral and parasitic organisms, HIV itself, side effects of HAART (and some other medicines, such as antibiotics) can cause diarrhoea in HIV positive people who are co-infected with hepatitis C.²⁵

Dietary strategies include:

- drink plenty of fluids
- limit consumption of highly spiced, fatty foods, and of alcohol, caffeine, and carbonated drinks
- limit food with insoluble fibre such as wholegrain cereals, brown rice, raw vegetables, nuts and seeds
- increase soluble fibre intake, such as oats, bananas, apples, fibre supplement (psyllium husk)
- reduce high fructose foods such as fruit juice, and
- try soymilk or lactose free milk until diarrhoea ceases as diarrhoea can cause temporary lactose intolerance (yoghurt and cheese in small amounts are usually tolerated).

Once bowel function returns to normal, it is important that the diet returns to a balanced diet which includes fresh fruit and vegetables and wholegrain cereals.

It is recommended that people with HIV/ hepatitis C co-infection consult a HIV/HCV specialist dietitian to ensure all dietary requirements are met and obtain advice on suitable dietary changes.

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WEB WATCH

The Hepatitis C Education Project: An online resource for health professionals <http://hepc.ecu.edu.au>

The hepatitis C online education website is an online resource designed to give users a solid overview of the hepatitis C virus from a clinical perspective. Although the site is primarily aimed at healthcare professionals, it is very accessible and so is a valuable resource for anyone wanting to learn more about hepatitis C.

The site is maintained by the Systems & Intervention Research Centre for Health (SIRCH) and funded by the Department of Health Western Australia. It provides information about all aspects of the hepatitis C virus through a program made up of three discrete learning modules.

Importantly, sequential completion of the each module provides a professional development opportunity for health workers, such as GPs, nurses, and ambulance professionals. Through successful completion of each module on the site, users gain credit points towards accredited training endorsed by professional bodies including the Royal College of Nursing (RCNA), the Australian College of Rural and Remote Nursing (ACRRN) and the Royal Australian College of General Practitioners (RACGP). A test and a certificate of completion is provided to users after the successful completion of each module.

To access the modules, users must first complete a free registration process to obtain a username and password



to log in to the site. After successfully registering, users are given access Module One.

A test is required for registered health practitioners before undertaking any modules, to assess their existing knowledge about hepatitis C. Successful completion of a test at the end of each module is also required in order to progress to the next stage. Each module takes around four hours to complete, assuming that the user accesses and reads all the content provided within each stage, including links to external resources that the site provides.

Module One provides an overview of hepatitis C, including prevention and treatment strategies; Module Two focuses on assessment and management of hepatitis C along the continuum of

care and Module Three offers advanced management of hepatitis C, including antiviral therapy. Access to modules varies depending on the occupation of the individual using the site. The information in Modules One and Two can be accessed by both health professionals and the general public. Module Three is restricted to specialist medical practitioners and nurses.

The topics contained within each module are easy to navigate, allowing users to get a broad overview of what each module contains before exploring them in-depth. The clean interface and clear chunking of information throughout the site provide a thorough and enjoyable learning experience about hepatitis C for users of this innovative and interactive educational tool.



HIV Australia online includes additional content not published in the printed edition.

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Suppressive antiretroviral therapy slows progression of atherosclerosis

Antiretroviral therapy that reduces viral load to an undetectable level was linked to slower progression of sub-clinical atherosclerosis, as indicated by carotid intima-media thickness, researchers reported last week at the 17th Conference on Retroviruses and Opportunistic Infections (CROI), in San Francisco.

Atherosclerosis ('hardening of the arteries') is an inflammatory condition in which plaques (accumulations of lipids, immune cells, scar tissue and cell debris) build up in artery walls. This leads to narrowing of the arteries, and ruptured plaques. The resulting clots can block blood vessels, causing a heart attack or stroke. Several studies have shown that people with HIV have more rapid atherosclerosis progression than HIV-negative people, but data has not always been consistent.

Jason Baker and fellow investigators evaluated artery changes amongst participants in the SUN study, an observational cohort of HIV-positive people in four US cities enrolled during the modern antiretroviral therapy era (2004–2006). Most (78%) were men, about 60% were white and the median age was 42 years.

The researchers measured sub-clinical or pre-symptomatic atherosclerosis using ultrasound to assess the thickness of artery walls – known as intima-media thickness or IMT – in the carotid arteries that supply blood to the brain.

Many of the participants had traditional risk factors for cardiovascular disease when they entered the study. The median body mass index was about 26 (considered overweight), about 40% were smokers and about 30%

had high blood pressure or metabolic syndrome. However, total cholesterol and LDL (bad) cholesterol levels were generally low and within recommended ranges. The median Framingham Risk Score (a frequently used indicator of cardiovascular risk) was low, at 2, but 30% had a score of 5 or higher.

The investigators concluded that 'Maintaining a suppressed HIV viral load decreased progression of sub-clinical atherosclerosis (carotid IMT) ... Factors related to both HIV infection and the type of antiretroviral therapy independently associate with the rate of carotid IMT progression.'

Dr Baker said that the study found changes in atherosclerosis 'at the level of the arterial wall' that are consistent with the elevated risk of cardiovascular events like heart attacks seen in the D:A:D observational cohort and other studies.

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— Liz Highleyman, *Aidsmap*

Studies confirm that drugs that penetrate brain control HIV better and improve symptoms of brain impairment

A number of different studies presented at the 17th Conference on Retroviruses and Opportunistic Infections (CROI) confirmed that antiretrovirals (ARVs) that penetrate the blood-brain barrier more fully are better at suppressing HIV replication in the cerebrospinal fluid (CSF) and help to improve symptoms of neurological impairment.

It is clear from previous studies that being on suppressive HAART (highly

active antiretroviral therapy) improves neurocognitive symptoms but it has not been clear whether drugs with better brain penetration produce greater improvements in measures of cognitive function. The consensus of studies presented at this conference was that they do.

A number of studies made use of what is called the CNS Penetration Effectiveness (CPE) scoring system, a way of ranking ARVs for the levels they reach in the CSF. The total CPE score is achieved by adding up the scores for the individual drugs the patient is on.

A new CPE system was issued this year, adding some new drugs and giving drugs a penetration score from one (poor) to four (best), where there had previously only been three ranks. The two commonly used drugs in the highest rank are nevirapine (*Viramune*) and AZT (zidovudine, *Retrovir*, and the most commonly used drugs in the lowest rank are tenofovir (*Viread*) and boosted saquinavir (*Invirase*). Some of the studies presented at CROI used the old system and some the new, but results are broadly similar.

Findings from CHARTER

Scott Letendre, principal investigator in the largest study investigating neurocognitive impairment, the CHARTER study, looked at factors associated with a detectable CSF viral load in a cross-sectional study comparing viral loads in 1221 simultaneously taken CSF and blood samples.

31% of the patients were not taking HIV therapy. Three-quarters of these patients had detectable CSF viral loads compared with 16% of those taking HAART.

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In multivariate analysis the factors significantly associated with CSF viral load on HAART were high plasma viral load, white ethnicity, non-adherence, and lower CPE score. Twenty per cent of white patients had detectable viral loads compared with 9% of non-white patients. Some of the association with white ethnicity was explained by age, but not all.

Factors associated with a higher CSF viral load off HAART included viral load and CD4 count as well as older age, and a trend towards association with white ethnicity and male sex. In multivariate analysis only blood plasma viral load and older age remained significant.

Detectable CSF viral load (over 50 copies/ml) was not associated with poor performance on neuro-psychological (NP) tests, but having a CSF viral load higher than plasma viral load was. In this study 15% of subjects off HAART, and 4% of subjects on HAART had a higher CSF viral load than they did in plasma. Mean NP test scores were not significantly different with these patients, but in patients off treatment the proportion with very poor scores was.

Letendre commented that in another study the same had been shown of patients on HAART when a more sensitive viral load test was used that could detect CSF viraemia down to two copies/ml.

Other studies

Two more studies looked at the effect of ARVs on psychological performance.

In the first, psychologists from Cotugno Hospital in Italy administered a battery of psychological tests to 45 patients without being told what ARV regimen the patients were taking. All patients had to have viral loads under 50 copies/ml in plasma and to have been on the same HAART regimen for at least six months. Patients at high risk of impairment were excluded. These exclusions were age over 60, poor education, diagnosed depression or other psychiatric or neurological conditions, and drug use.

Thirty of the patients were on regimens with a high CPE score and the remaining 15 on ones with a low CPE score. Patients with a high CPE score showed better performance in language performance, namely tests measuring verbal memory, verbal fluency, and ability to manipulate symbols. Other psychological domains were unaffected.

In the second study, a team from the University of New South Wales conducted a substudy of a larger study called ALTAIR, which compared cerebral function and physiological indicators of neuronal damage in patients on a randomised controlled study of three different regimens: tenofovir/FTC (*Truvada*) plus either efavirenz, boosted atazanavir, or an unconventional quadruple-NRTI

regimen of *Truvada* plus abacavir and AZT. The CPE scores of these three regimens are 7, 6 and 11 respectively.

Patients taking the quadruple-NRTI regimen had an improved psychological test performance over 48 weeks, whereas patients on the efavirenz-based regimen showed more signs of recovery from neuronal damage.

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— Gus Cairns, *Aidsmap*



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April

8–9

The 11th Social Research Conference on HIV, hepatitis C and related diseases

Sydney, Australia
<http://nchsr.arts.unsw.edu.au/>

29–1 May

Health in Difference: doing diversity

Sydney, Australia
www.lgbthealth.org.au/health-in-difference-2010

May

24–27

Tackling stigma: pride, prejudice and prevention – AFAO HIV Educators' conference

Sydney, Australia
www.afao.org.au/conference10/

30–2 June

Walking the talk together: partnerships in health promotion – Australian Health Promotion Association conference

Melbourne, Australia
<http://www.conferenceco.com.au/AHPA/>

31–2 June

6th International HIV and hepatitis co-infection workshop

Tel Aviv, Israel
www.virology-education.com/

June

7–9

Diversity in Health conference

Melbourne, Australia
www.diversityinhealth.com.au

16–18

4th International Conference on Peer Education, Sexuality, HIV and AIDS

Nairobi, Kenya
www.nope.or.ke/conference.php?id=33&parent=33

July

15–16

5th International Workshop on HIV Transmission – Principles of Intervention

Vienna, Austria
www.virology-education.com

18–23

XVIII International AIDS Conference

Vienna, Austria
www.aids2010.org

September

6–8

The 7th Australasian Viral Hepatitis Conference

Melbourne, Australia
<http://hepatitis.org.au>

Diary