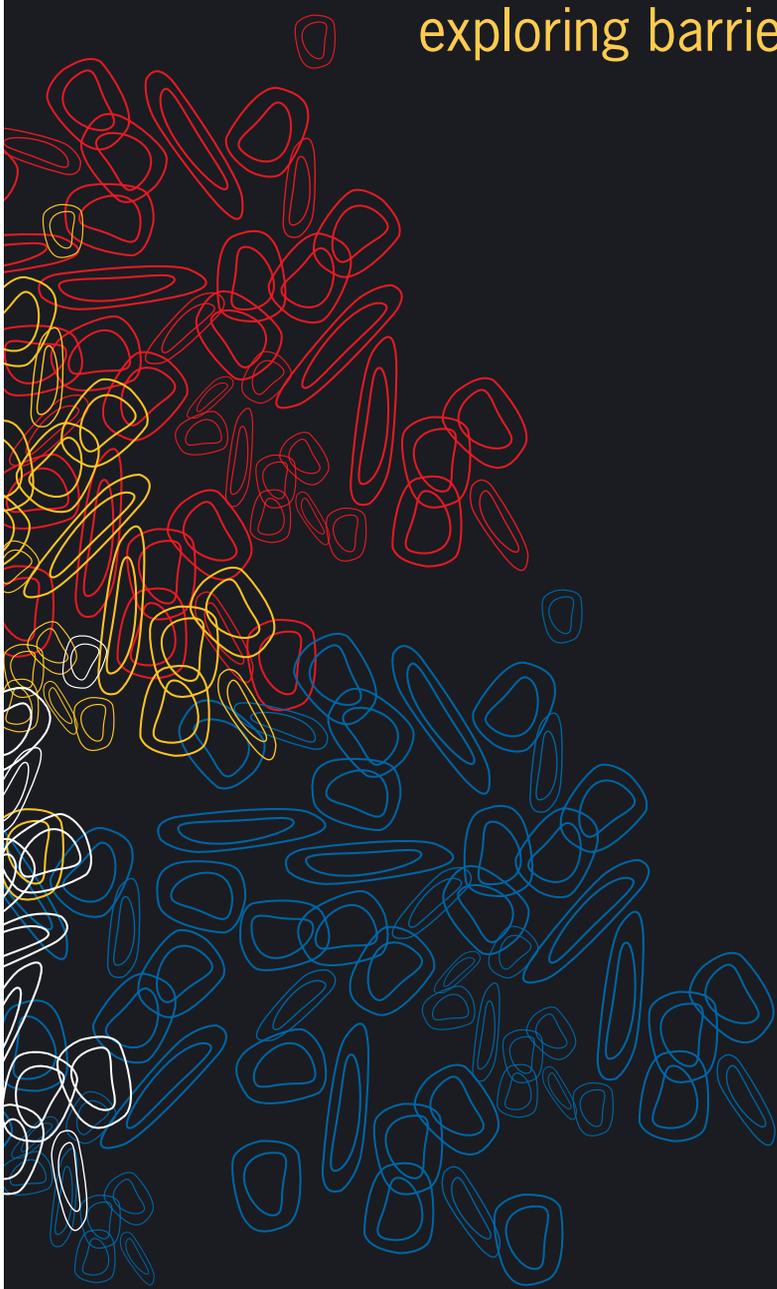


Recognising and Responding to Hepatitis C in Indigenous Communities in Victoria:

A research project
exploring barriers to hepatitis C treatment



Stephen McNally and Robyne Latham

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*This research has been conducted in partnership
with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO)*



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Introduction

This research investigates a range of issues concerning hepatitis C and Indigenous people in Victoria. Access to anti-viral treatment for hepatitis C has improved over the past few years, with over 3,500 people in 2007 accessing treatment throughout Australia; however with 207,600 people estimated to be infected, treatment uptake still remains low (NCHECR, 2008). While the goal of increasing the number of people on treatment for hepatitis is necessary, there are many other critical issues which need to be addressed if the burden of hepatitis in Indigenous communities throughout Australia is to be reduced. This research begins to address these issues.

Hepatitis C within Indigenous communities continues to challenge policy makers and health care providers. Due to the many competing issues faced by Indigenous communities throughout Australia, hepatitis C is often considered by Indigenous and non-Indigenous Australians as a low priority. Our current knowledge about hepatitis C in Indigenous communities relies on epidemiological data, which tend to be of limited value and uneven. There is very little evidence available to help policy makers and health care workers respond to the rising number of Indigenous people with hepatitis C.

This research began with the question: *How to improve access to hepatitis C treatment services for Indigenous people in Victoria*. In retrospect this is the wrong question to ask. Focusing on identifying and understanding barriers and challenges associated with accessing treatment makes sense given the recent improvements in treatment success experienced in Australia. However, findings from this study show that there are other important issues relating to hepatitis C for Indigenous communities which must be addressed. These issues are in stark contrast to the issues facing the broader Australian community. For example, very few Indigenous people access medical services that in turn provide access to information about hepatitis C treatment. The results from this study confirm this assumption. Low treatment uptake and low awareness about the virus is a result of having to compete with a range of other health and social issues. To focus solely on treatment is not the sole answer to the challenges facing indigenous communities with hepatitis C.

Hepatitis C is under-recognised amongst Indigenous communities and as a consequence, the response remains inadequate.

Background - Hepatitis C in Australia Today

Hepatitis C is a significant public health problem and the most common communicable disease in Australia. At the end of 2007, an estimated 207,600 people in Australia were living with chronic hepatitis C infection, including 47,600 with moderate to severe liver disease (NCHECR 2008).

On average in Australia, an estimated 10,000 people become infected with hepatitis C every year. Hepatitis C is transmitted by blood-to-blood contact. Most infections (89% of the 9,700) in 2005 were attributed to injecting drug use (Topp 2007). The rate of hepatitis C infection amongst people attending needle and syringe programs has been decreasing since 2000, but remained at around 25% in 2001-2005. A recent study by Maher et al (2007) suggests that despite the widespread implementation of harm reduction initiatives in Australia since the late 1980s, young people who inject drugs and initiates remain at extremely high risk of hepatitis C infection.

There are significant costs associated with the hepatitis C epidemic. Shiell (1999) conservatively estimated a lifetime cost of \$46,600 per infected person. Based on an estimated figure of 211,105 persons living with hepatitis C in 2004/05, the Federal Department of Health and Ageing estimated the prevalence cost during this period at \$156m. The number of people with chronic hepatitis C infection undergoing liver transplants almost tripled between 2000 and 2005. In 2005, chronic hepatitis C infection and chronic hepatitis B infection were the underlying causes of liver disease in 37% and 10% of liver transplants, respectively.

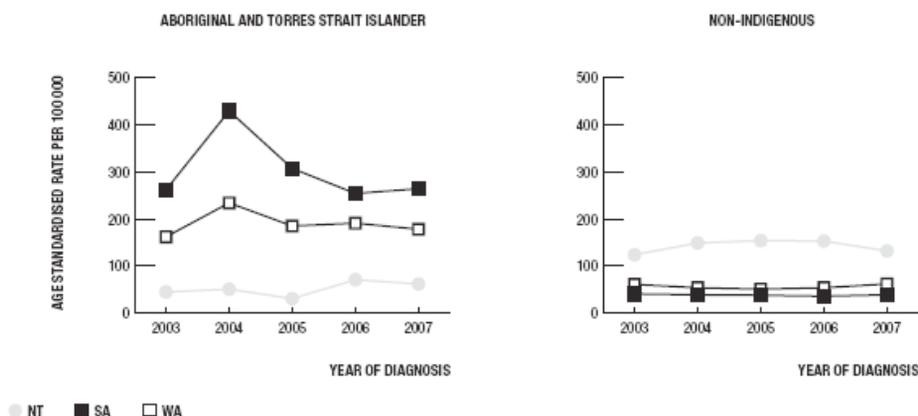
In 2002 - 2006, the rate of hepatitis C diagnosis increased in both the Aboriginal and Torres Strait Islander and the non-Indigenous populations in the Northern Territory, contrary to the decreasing trend nationally. In Western Australia, the population rate of newly diagnosed hepatitis C infection in the Aboriginal and Torres Strait Islander population was between two and three times higher than that in the non-Indigenous population. This difference was even more marked in South Australia where the rate of diagnosis was between 5 and 10 times higher in the Aboriginal and Torres Strait Islander population. In quoting these figures, it is difficult to determine accurately the level of hepatitis C infection among Indigenous Australians primarily because of the under-reporting of Indigenous status in notification data.

It is estimated 22,000 Indigenous Australians have been exposed to the hepatitis C virus, of which 16,000 are living with chronic hepatitis C. (Hepatitis C Estimates and Projections Working Group, 2006) Indigenous Australians constitute 2.4% of the Australian population while making up an estimated 8.3% of the Australian population living with hepatitis C. It appears that Indigenous Australians are four times more likely to be exposed to the hepatitis C virus than non-Indigenous Australians.

In 2007, 190 cases of newly diagnosed hepatitis C infections were notified among Aboriginal and Torres Strait Islander people. The rate of diagnosis of hepatitis C for Aboriginal and Torres Strait Islander people in 2007 was more than double for the age groups 13-19, 20-29 and 30-39 than in the non-Indigenous populations. (NCHECR 2008)

Our best insights into the level of infection among Indigenous Australians come from South Australia, Western Australia and Northern Territory. The diagnosis rate in the Aboriginal and Torres Strait population in Western Australia was more than double while in South Australia it was seven times higher than the non-Indigenous population. (Figure 1)

Figure 1: Hepatitis C by Aboriginal and Torres Strait Islander status, State/Territory and year



1 Jurisdictions (NT, SA & WA) in which Aboriginal and Torres Strait Islander status was reported for more than 50% of diagnoses

(NCHECR 2008, 37)

Our knowledge about what is happening in Victoria is poor. What we know of the impact of hepatitis C within the Victorian Koori communities is limited to data from *The Well Persons Health Check* (VACCHO 2003). This report showed hepatitis C to be a serious public health problem within the Victorian Indigenous communities with 13% of respondents infected with hepatitis C, rising to 36% in males aged 21-30. Similar findings are also evident in South Australia, where Aboriginal people are over represented among hepatitis C incidence cases to a level of 15% (Copland, 2004).

The Australian Hepatitis C Surveillance Strategy identifies Indigenous Australians at increased risk of hepatitis C transmission, compared to the general population. While exact prevalence of illicit drug use among Indigenous Australians is not known, there are indicators that the level is high. (van der Sterren et al 2002; Australian Bureau of Statistics, 2004)

The National Aboriginal and Torres Strait Islander Sexual Health and Blood Borne Virus Strategy 2005-2008 and the *National Hepatitis C Strategy 2005 - 2008* identify Aboriginal and Torres Strait Islander people who engage in risk behaviour as one of the three main priority populations for action. Aboriginal and Torres Strait Islander people are also disproportionately represented within the other two priority populations; people in custodial settings and people who inject drugs.

Hepatitis C is under-recognised amongst Indigenous communities

Hepatitis C within Indigenous communities continues to challenge policy makers and health providers for a variety of reasons. Indigenous Australians are identified to be at greater risk of contracting hepatitis C compared to the general population, however, due to competing co-morbidities, hepatitis C is often considered by Indigenous and non-Indigenous Australians as a low priority. As one health care worker in this study stated:

Unless you come in specifically with a hep C related issue, then it's not going to be even on the agenda, it will be flagged on your file, to say you've got it, but that's it. (HW31)

Hepatitis C competes with a range of health and social issues. The higher prevalence of hepatitis C occurs within a context where Indigenous Australians have the poorest health status of any identifiable group in Australia. This not only significantly increases viral transmission, but also negatively affects the ability for people to live well with the virus. Poor access to health care services minimises people's opportunity to decide if treatment is necessary.

Awareness and understanding about hepatitis C among Indigenous people, and among health and community workers who work with Indigenous people is very low. Within the broader community and within the Indigenous health sector knowledge of hepatitis C and of the availability of treatment is poor. When hepatitis C is recognised within the Indigenous communities, the shame and stigma associated with the virus and its mode of transmission can make it extremely difficult to talk about let alone manage and treat.

Hepatitis C, as is the case with all Indigenous health issues, needs to be understood in relation to social and cultural issues. Indigenous Australians experience poor access to health care in cities, regional centres and remote settings. The high rates of communicable disease in Indigenous communities are due to a number of inter-related factors which systematically limit opportunities for people to access and receive care. Perceived and real racism played out as discrimination within non Aboriginal Medical Service (AMS) health care settings, poor education, low income and poverty, generally fewer educational and occupational opportunities all directly affect the prevalence and the response to hepatitis C throughout the Indigenous community. High mobility also has consequences for accessing care and anti-viral treatment.

The prevalence of hepatitis C among all prisoners across Australian jurisdictions is 35%, while for female prisoners it is a staggering 78%. (NCHECR, 2008) Indigenous Australians are disproportionately represented within prisons; 24% of the total Australian prison population are Indigenous. (ABS, 2008) It is therefore likely that rates of hepatitis C are higher in the Indigenous population because of their higher rates of imprisonment.

Accessing treatment and care for hepatitis C

Over the past few years, access to anti-viral treatment for hepatitis C has improved. The current treatment standard of a combination of pegylated interferon and ribavirin provides improved results with fewer side-effects, and at the same time criteria for treatment eligibility have been relaxed, particularly with the removal in April 2006 of the requirement for a liver biopsy to access treatment. Despite this, the number of people on treatment in Australia is still extremely low. In 2007, 3,539 people with chronic hepatitis C were prescribed combination treatment. (NCHECR, 2008)

Recent studies show us that typically, a person with hepatitis C is most likely to be diagnosed by a GP (Gifford et al, 2003; 2005, McNally et al 2006). The most common situations which prompt GPs to test a patient for hepatitis C are:

- History of incarceration
- History of drug use
- Elevated ALT level over a period of 6 months (liver function test)
- Having a partner with hepatitis C
- Routine Sexually Transmitted Infection (STI) screening
- Hepatitis B infection

(McNally et al 2006)

Recent reports suggest that treatment early in the course of infection may be beneficial, however many GPs are unaware that referral to a specialist for consideration of treatment soon after diagnosis is preferred by specialists (McNally et al). This contrasts with earlier views that treatment should be undertaken only when there was evidence of liver damage, which often takes years to develop. There continues to be limited hepatitis C education targeting GPs and health care workers who only see the occasional patient with hepatitis C, or alternatively have not considered that their patients may have this infection.

An additional barrier to accessing primary health care for those who know they have hepatitis C are the well documented experiences of discrimination within health care settings (Anti-Discrimination Board of New South Wales 2001).

The efficacy of antiviral therapy continues to improve and barriers to treatment are reduced, however treatment uptake in Australia remains low. Understanding the potential and perceived barriers to commencing and adhering to treatment is critical to the numbers of people accessing treatment. Many issues are taken into account when making treatment decisions which often include both personal and treatment related considerations. Issues for people vary from fundamental concerns about treatment efficacy, doctor-patient relationships, side-effects and access to services, to decisions based on out-dated or incomplete information about the natural history of hepatitis C and its clinical manifestations. Other factors such as the relationship with the treating health professional and family/partner support are also rated by patients as important in making a decision about treatment.

Treatment adherence has a direct and significant influence on treatment outcome. Patients who take more than 80% of interferon and ribavirin for more than 80% of the required treatment duration are significantly more likely to achieve viral eradication than those who do not. (McHutchison et al., 2002) Adverse drug effects can impair treatment adherence and interferon-induced depression is a common cause of poor compliance.

Evidence shows that the treatment experience is improving. However, it is apparent that messages of improved effectiveness of treatment need to be well-publicised among people with hepatitis C. Negative experiences, most obviously side effects, including depression, are barriers both to treatment uptake and successful completion. However, these conditions are often successfully managed with appropriate antidepressant therapy and support services during antiviral treatment.

Barriers to treatment cannot be explored in isolation from the broader perspective on treatment access. Hepatitis C care is not limited to anti-viral medication; it involves care and monitoring of the disease. Because of the natural history of hepatitis C, monitoring of the disease and lifestyle changes are essential to maintaining good health, and can delay for several years the need for medical treatment. Hence in this report we refer not only to 'treatment' but to 'treatment and care' with regard to access and barriers.

Access is not a single point in time and consists of more than an appointment at a liver clinic. It is a journey, a continuum that may not always end in treatment. There are several 'drop out points' along the journey; such as when a referral is made to a clinic, or if treatment is not recommended and the patient is monitored. The reasons are varied and complex. As this report documents, the reasons are different for Indigenous Australians.

Research question

How to improve access to hepatitis C treatment services for Indigenous people in Victoria.

Aims

- Identify all Indigenous health programs related to hepatitis C across Australian states and territories
- Identify and document how health service providers within the Indigenous health sector respond to clients with hepatitis C
- Identify barriers and challenges associated with anti-viral treatment specific to Indigenous communities
- Identify how mainstream health services respond to health needs for Indigenous people who have hepatitis C

Australian Research Centre in Sex, Health and Society (ARCSHS) received funding from the Victorian Department of Human Services, Public Health Research Projects 2005-06 grants round.

An Indigenous Research Officer, Ms Robyne Latham, was employed on this project and undertook all interviews.

Partnership

This research has been conducted in partnership with the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), the peak body representing, supporting and advocating for their member organisations, the Aboriginal Community Controlled Health Organisations (ACCHOs) throughout Victoria. The research partners acknowledge and agree to respect each other's perspective and value each other's contributions and knowledge base. The partnership was formalised with the signing of an agreement based on recognition of the following principles of partnership and collaboration:

- Improved knowledge, information, education and training in regard to BBVs for Aboriginal people will be achieved when Aboriginal peoples and their community controlled health services are empowered to act on their own behalf.
- Aboriginal peoples have a fundamental right of ownership over their own knowledge and information.
- Improved awareness and education about BBV will primarily result from decisions about strategies developed and implemented at the local level and at a state level via VACCHO and with the expertise and experience of ARCSHS.
- Information, resources and support in relation to the project need to be shared between ARCSHS and VACCHO to ensure the development of an effective partnership and successful research project.
- Such a relationship is dependent upon the commitment of both organisations to be honest, open and frank in their communication with each other, at all levels of their interaction.
- The researchers will comply with the NHMRC guidelines: "Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research"

Ethics

Ethics approval granted by:

- La Trobe University Human Ethics Committee (No. 06-175)
- Department of Human Services, Human Research Ethics Committee (No. 02/07)

Methodology

Community Consultation Process

A presentation was made to the State Meeting of VACCHO Member Organisations. This presentation outlined and provided a rationale for the study including the background information about hepatitis C and the limited uptake of treatment and care for hepatitis C among the Indigenous community.

Indigenous health services in both rural and metropolitan Victoria were contacted and informational meetings were held, regarding the hepatitis C research project.

VACCHO member organisations were invited to participate. Posters advertising the study were given to all member organisations. Preliminary findings from the study were presented to the VACCHO board in March 2008.

Melbourne's Indigenous radio station 3KND held an interview in the health program, informing their audience of the research project. This interview included a hepatitis specialist GP, the education officer from The Hepatitis Council of Victoria and the Indigenous researcher from ARCSHS.

Stage 1: Mapping existing hepatitis C programs and resources

The research team set out to identify all programs related to HCV and Indigenous health across all states and territories including data collection and management. Key personnel were contacted. Postings were made on The Australian Indigenous Health Infonet website, e-message stick.

Stage 2: Key Informant Interviews with Service Providers (n=31)

A total of 24 in-depth semi-structured interviews were conducted by an Indigenous Research Officer. Those interviewed include Health Workers from six member co-operative of VACCHO a combination of Health Managers, General Practitioners, Aboriginal Drug and Alcohol Workers, Cultural and Spiritual Wellbeing Workers from the six participating ACCHOs. Interviews were also conducted with Koori Hospital Liaison Officers (KHLOs) and Aboriginal Liaison Officers (ALO) who work within the mainstream health sector across Victoria. The primary role of these Health Workers is to help Aboriginal people negotiate the hospital system. Five GPs were also interviewed. Two interviews were conducted with state-level Indigenous Policy Officers.

Stage 3: Interviews with Indigenous people (n=19)

Interviews were conducted by an Indigenous Research Officer with 19 Indigenous men and women who have hepatitis C.

All in-depth, semi-structured interviews, using open questions were used to collect data. Interviews were audio taped and transcribed. No personal identifying information was collected. The analysis of the data involved the progressive establishment of key issues, concepts and themes through which the data was examined. The data was analysed through the creation of typologies and associations between themes.

Quotes referenced throughout this report have been categorised into three 'groups'

P=people with hepatitis C, GP=general practitioner, HW= health worker, including workers from member co-operatives of VACCHO, Koori Hospital Liaison officers and Aboriginal Liaison Officers.

**Findings:
Barriers and Challenges,
and Ideas for Change**

Hepatitis C as a priority for Indigenous people

This study confirmed that hepatitis C competes with a range of health and social issue. Hepatitis C is only one of many health concerns for Indigenous communities across Victoria and indeed Australia, as reflected by the following comment from a manager of an Aboriginal Health Service with:

I think a lot of Aboriginal people are just sick of the negative, you know, about how bad our health is, how bad our educational standards are, how bad the housing issue is, there's so much drug and alcohol, domestic violence; ...Can I say that some people become complacent, as well as numb. (HW16)

It was repeatedly noted by respondents that there needed to be a focus on reinforcing people's interest and commitment in self-care and not separating hepatitis C from other health issues.

There is an urgent need to improve general diet and general health, which has a direct link not only with illnesses such as diabetes but also with maintaining a healthy liver. Supporting people to eat well and look after their liver may have a greater impact on the health of someone with hepatitis C than finding the best way for Indigenous people on to go on anti-viral treatment.

For some people the option of treatment is not viable, it may be the wrong time or simply not as serious as other health and social issues being confronted:

... When Aboriginal people are told our health is so bad, because of this thing, this thing, this thing, and that thing, a lot of people just go, frigg'n 'ell, what haven't we got? It's just another thing, added on top. I think that's a real worry, they're exhausted. (HW10)

it's not even a problem in their eyes, like they've got it, big deal, it's not going to affect them for between ten and forty years. Forty years is when it does most damage, by that time most Koori people have died. They supposedly live to forty-five or fifty, what's the use of going through the pain of the treatment? (P10)

One challenge a GP identified from working with Indigenous people with hepatitis C is that "they need to get followed up, at least annually." (GP24) As these findings show, there are many issues which make it extremely difficult to follow up people:

There are multiple problems within an Aboriginal person's life. Complacency can be a problem too; it's just another thing on the list. (HW10)

For people managing their hepatitis C, the three biggest things to reduce the development of liver disease other than anti-viral treatment are:

1. Hepatitis B vaccination
2. Reducing alcohol intake
3. Eating well

Hepatitis C and shame

The significance and complexity of the notion of 'shame' is poorly understood by non-Indigenous Australians. Shame for Indigenous Australians has distinct cultural meanings; it can not be characterised as guilt or embarrassment alone. Shame incorporates negative ways of being perceived by others, both inside and outside the community. Shame impacts on how a person is received and treated. Shame and shyness, which are intrinsically linked, do influence people's interactions with health workers. The workings of shame have implications on health and health care outcomes and are evident in the various barriers to accessing hepatitis C care and treatment. All study respondents, both health workers (Indigenous and non-Indigenous) and people with hepatitis C, talked about hepatitis C and its association with shame, but more notable was the association with shame with almost every issue relating to hepatitis C.

The association of hepatitis C with shame, or what many respondents referred to as 'a shame job' was a concern raised by most health care workers and people with hepatitis C. The stories people shared in many interviews suggest that you could not begin to understand the significance of hepatitis C within the Indigenous community without acknowledging the centrality of shame. As one health care worker remarked, *shame, just shame about it all.* (HW10)

Acknowledging and understanding shame and how it manifests in relation to hepatitis C reveals the challenge in finding ways to increase access to hepatitis C care and treatment for Indigenous Australians. Shame runs through all the identified barriers and challenges to hepatitis C care and treatment. The importance of trust and confidentiality, the ramifications of the practice of singling out individuals from their group to offer care and treatment can not be understood without understanding and acknowledging the working of shame. It is arguably the central issue when tackling the challenges associated with hepatitis C.

Morgan and colleagues (et al 1997) give us a sense of the cultural complexity which forms the concept of shame:

'Shame', for Aboriginal people, is more than an individualised awareness of 'guilt' or a sense of 'disgrace'. It is a powerful emotion resulting from the loss of the extended self, and it profoundly affects Aboriginal health and health care outcomes.

Shame might be experienced by, or for, a person who acts, or who is forced to act, in a manner that is not sanctioned by the group and that is in conflict with social and spiritual obligations. (Morgan et al, 1997, 598)

As the findings reveal, shame associated with hepatitis C has stopped health workers talking about hepatitis C and stopped people accessing information about hepatitis C. Morgan and colleagues (et al 1997) explain the complex positioning of the individual in relation to the group and how shame can be result:

The fulfilment of obligations to the group is more important in Aboriginal society than isolated individual behaviour, especially individual assertiveness. Given their commitment to the extended social self, group cohesion and cooperation are not driven by economic and political expediency, they are the expression of life itself.

Shame might also be experienced when an individual is singled out from the group, for either praise or blame. It is the act of making a special case of individual behaviour, rather than its associated value, which causes shame. Individual recognition separates a person from their extended identity and ultimately from life.

Shame is perhaps the most complex and sensitive Aboriginal concept and practice to deal with in a health clinic. (Morgan et al, 1997, 598)

Many health workers and community workers noted that there are simply too many barriers to treatment. The challenges associated with poverty, poor access to health care in cities, regional and remote settings, the high mobility for some Indigenous people and the high consumption of alcohol and drugs appear overwhelming. But the greatest challenge is finding ways to deal with the shame.

Shame and shyness stop people from talking about hepatitis C; it stops people from asking questions and asking for help, and ultimately exploring the option of treatment. Shame makes it extremely difficult for health workers to raise the topic of hepatitis C:

Cultural Shame is always there, so sometimes people do not want to mix with their community, because they are "shamed up" by their lifestyle. (HW12)

Hepatitis C and its association with drug use is not unique to Indigenous communities. Unsterile injecting is the leading cause of hepatitis C transmission throughout the community, and the connection between hepatitis C and drug use is often a cause of discrimination. Shame and shyness can make reaching and supporting people a challenge for Indigenous people and for people providing support and care. The following quote from a non-Indigenous health worker who works with people who inject reflects an awareness of shame within Indigenous communities and what she sees as an obvious heightened sense of shame that often accompanies everyday experiences of drug users:

Around the issue of shame, I don't think that it is particularly Aboriginal. I think it might be more intense, it might be more palpable. In general, drug users feel a lot of shame. Sometimes it's overwhelming, when something happens as a consequence either directly or indirectly, of their drug use, you just see people so distraught. (GP25)

Shame and stigma is a constant issue. Respondents interviewed refer to it in answering their perceptions of the barriers to care and treatment. People also refer to shame and stigma when reflecting on how existing successful programs have evolved and also what they believe will work in helping to provide successful models of care for people with hepatitis C.

People with hepatitis C

Respondents described how it can be extremely difficult to deal with hepatitis C without confronting shame and the stigma associated with hepatitis C. Shame, for one participant from regional Victoria, was so present that she had not told her partner that she has hepatitis C:

I'm just too ashamed, it's a dirty thing ... In a way I'm scared because everyone out here, they've lived out here all their lives, they don't really know a lot of things. I believe that everyone would think about it as AIDS. I'm too scared to let anyone know. (P19)

She goes on to relate some of her past experience of drug use, and that she is not ashamed about using drugs. 'I'll talk to anyone about using.' But having hepatitis C makes her feel dirty, to the point where she has stopped looking after herself:

I even dress down now, I don't put the makeup on anymore like I used to, because I feel dirty ... I wish I could turn back the clock and... never have used ...or never got tattoos. (P19)

"There is a fear of going back and talking to partners about stuff," as highlighted by a health care manager at an Aboriginal health service in Melbourne. (HW16) Shame has a lot to do with people not coming out or disclosing about their hepatitis infection:

I don't like telling people I have hep C, because I'm embarrassed what they'll think...I was too embarrassed to ask questions about whatever it may have been I wanted to ask about. (P7)

No one really admits to it, it, cause they're ashamed of it...Its always on your mind, and in your mind, hep C and everything like that, like when people use, no one admits that they've got it, its like saying you've got AIDS or something. (P15)

While acknowledging shame and shyness as a barrier for people getting help, this wasn't the case for everyone. One respondent talked about how he always tells people he has hepatitis C, so the other person won't get it. He is not ashamed at all about having hepatitis C - everyone's got it, so who cares. (P3)

Shame was not a problem for one person currently on treatment who had not personalised the virus. For him, hepatitis C can not be separated from broader social issues which are not confined to the Indigenous community. Some people take their illness on not as a sign of weakness, but as evidence of strength and surviving. He did, however, go on to comment on the association between hepatitis C and shame acknowledging that it is a barrier to getting people to find out and think about the possibility of treatment:

There are that many diseases in this country now, and there weren't when our people come, so it's no shame on me, it's a shame on white fellas! It seems really hard to get people to think about it (treatment) because of the shame factor and all that kind of stuff that goes with the Koori community. And a lot of our people don't like talking about anything about illness and all that, so it's pretty kind of hard. (P10)

Health and community workers

Shame makes it difficult for Indigenous health workers to raise the topic of hepatitis C and to engage with clients and the broader community about the issue:

A lot of them will talk with me about their other issues, but they never, ever bring up about hep C ... and I tend to avoid it too, because I'm there to support them, not alienate them. (HW23)

I think there is a bit of a stigma with hep C...I believe that there's this feeling around that it's not good...I think more about, what might I have been doing to have caught hep C, whereas a lot of people have a liver problem, and if they talk about it in public, that's what they'll say, I've got a liver problem...and everybody will assume its alcoholic liver disease, or hep B or something else. B is apparently okay, but hep C seems to have more of a stigma attached to it.

Cultural shame is always there, and it's everywhere in terms of my work. The cultural shame is there as some people will not mix in their own community, because there's such a level of shame about what they are doing, and they're so embarrassed themselves, and their sense of self is so shattered, they tend not to want to mix in the community...I think it almost freezes people, in terms of the element of shame. (HW12)

[There is a] shame of getting treatment, and then just all the things that stop people, Indigenous people, wanting to come to a GP service, being judged, not trusting their GP, especially in a small town. (HW6)

Sharing is an important cultural practice. Sharing happens without fuss or acknowledgement. Everyone shares, no matter how intimate, as the following quote shows. A Melbourne based community worker commented that she was surprised there had been such an increase in Indigenous people with hepatitis C:

It's not being talked about, due to the shame around drug use, which is much more underground...the basic knowledge of the consequences of "sharing practices" alcohol, drugs, needles, toothbrushes, is just not there. (HW12)

Health services: relationships, confidentiality and trust

Tied to the notion of shame is the need for autonomy. There was a perception that having other people know your private business is wrongful and humiliating. Many Indigenous Australians do not tell anyone their personal happenings. To have a third person talk about your private life can be very humiliating. Support provided by health care workers can be complicated by shame and the interactions with relatives who may be working in a health care setting.

People with hepatitis C

Many respondents talked of the challenge in negotiating their illness amongst existing relationships as a real concern. *Confidentiality is a huge issue. (P3)*

Past experiences of confidentiality and trust being breached were recalled by a few respondents. Obligations with relatives within health settings can complicate

access to care. For example, a health care worker who is a relative may not be able to tell the patient what to do, to take the medicine or to have the blood tests.

Confidentiality goes much further than the doctor or the nurse maintaining levels of professionalism. As one respondent recalled from a recent bad experience with a Community Health Check, it includes all staff including *drivers for the health centre maintaining confidentiality*. (P3)

Another respondent from regional Victoria mentioned the importance of maintaining confidentiality. She commented on:

...being able to trust people that are working around you, that they're not going around talking about your business...that happened in the last gig (P18)

Consistency with health care workers helps to reassure people's level of trust that confidentiality is maintained. While it was important that the GP knew everything about hepatitis C, for one respondent it was more important that the same doctor was the only professional he saw about his hepatitis C infection. It was important that the same doctor took his blood, told him about the results, talked on the phone with him:

I wasn't seeing twenty people; I wasn't referred from one person to another. I was with one person that I had established a relationship and a trust with. I believed what she told me. (P3)

One person commented that he would not go to an Aboriginal health centre for his hepatitis C. The primary reason was clear, *it wouldn't take them long to work out what you are going there for*. (P17)

Health and community workers

A past breach of confidentiality makes it difficult for health and community workers to gain trust with clients particularly around issues where stigma and shame exist. A manager from an Aboriginal health care centre talked about one of the problems with hepatitis C in the Aboriginal community as simply, *the fear of other people knowing*. (HW16)

Connected to shame is the need for respect and confidentiality. An additional layer of complexity is added to the challenges of maintaining confidentiality and trust when relatives work in the local health service. Running into relatives in a health service is common experience for many Indigenous people and ensuring that no one finds out about their hepatitis C infection is a real concern. Going to an Indigenous health service can be problematic and stressful for an Indigenous person with hepatitis C and seeking health care from a familiar service can ultimately be a barrier to care and treatment. Some people choose to go to a service where they are not known. Running into relatives has consequences and can be complicated. The following quotes from health workers in regional Victoria repeat the perspectives expressed by people with hepatitis C:

Shame, embarrassment which would be the most common [barrier] to a lot of the people in the community, because they don't want people knowing that they have the symptoms, or that they have the illness, so that'd be one of the biggest barriers. Especially within the Aboriginal communities, that we have Aunties and Uncles working in some of our services. So that would be another

barrier, having relatives working in services. Because if you're a young person in the community, you don't want to go into a service knowing Aunt or Uncle's going to be in there, and then the whole family finds out from that. (HW11)

You will get a group that will only go there (Aboriginal Health Service) and you will get a group that wouldn't go there if their life depended on it... (HW12)

For some, the anonymity that comes with a larger health centre that is not a designated Aboriginal health centre is important and may mean the difference in seeking out health care. One nurse commented on what she has done in the past when patients have concerns with confidentiality and don't want to attend an Aboriginal health centre:

I will ... try to get them referred through to a liver clinic through St Vincent's. St. Vincent's is usually the more user-friendly, the area and everything and people have often presented there at some time in their lives.

What makes St V's more user-friendly?

Location, they've got the ALERT (Assessment, Liaison and Referral Team) team there, they've got an Indigenous Liaison Officer there, the Austin's really good but they're too far away. And it's easy [for someone] to get there themselves if they really needed to ... The larger hospital setting provides a cover. There is also the option to say that they are just visiting someone.

They can walk past and say hi, I've just come to visit so and so, or I'm just passing through, I'm going to an out patients clinic, it could be for their heart, it could be for their lungs. (HW5)

One GP commented on an Aboriginal group at a general community health centre that meets weekly. The GP believes that this group may have helped establish some trust in the staff and the service as a whole by the Indigenous clients. When asked if she thought some people would rather go to this service rather than an Indigenous health service, the GP commented:

Some people will only go to Aboriginal services and other people don't want that recognition, they want to go somewhere completely different. This is not an all-Aboriginal organisation so I guess some people feel that they're not being segregated...I heard sometimes there's some politics, and um personal things that go on in an Aboriginal health centre... if an Aboriginal person attended an Aboriginal Clinic, well often somewhere down the line, everyone knows everyone sort of thing, so they may think, I want to attend my own service, in my area...There are many concerns around confidentiality. (GP29)

Building trust and relationships takes time but is important in improving access to health services, particularly for stigmatised health issues:

It's what Indigenous women specifically look for, once they trust you with one thing, they feel comfortable to come back and trust you with contraception, or their pap screening ... that [trust] only comes over a period of time. Because I've been here for so many years, and I live here, and I grew up over the river, I'm going to the same school as all the kids from the mission, and all the girls I went to school with are grandmothers in the Indigenous community now, so even though I'm not Indigenous, there is that connection there. The fact

that I've been in this position here for seven years, that continuity makes a big difference...It's that continuity of care, that makes the difference, and the trust that they know somebody, which is a hard thing to guarantee in our health services. (HW7)

It seems to me, that when there's a new health professional, for Indigenous patients, it often takes up to a year, for them to suss out whether or not this is someone they can really trust. (GP26)

A health care worker with experience working with Indigenous clients with hepatitis C identified trust, respect and being non-judgmental as each being important:

It was about developing a strong human bond in the professional setting and so part of the attraction, I think, of continuing on treatment was that relationship. People liked coming back, not only because they had a blood test, but because they wanted to hang out and talk. (GP24)

Mistrust and fear of treatment for hepatitis C was raised by one health care worker as a legitimate fear by some clients. One client believed he would be experimented on if he agreed to treatment:

When you mention treatment, why don't you go and see the GP and see what kind of treatment, you know, "No they're not going to experiment on me, let them experiment on some white fellas." It's just that everything's all an experiment and why should they be used as a guinea pig? (HW1)

Diagnosing hepatitis C

People with hepatitis C

For the 19 people with hepatitis C who were interviewed, diagnosis occurred between 4 and 16 years ago. In most cases, diagnosis was 'incidental' - the person was tested in jail, or when pregnant. Few people were tested in connection to current or past drug use. Reference was made to the lack of support and lack of information provided at that critical time of diagnosis. The most common reaction upon hearing of diagnosis was 'scared'; 'huge shock'; 'embarrassed': 'I just cried'.

Some commented that they were not told anything about hepatitis C at the time of diagnosis. As one person described:

They didn't tell me nothing, absolutely nothing... "You've got hep C" and that's it. (P13)

Another person described the impact of the lack of information and care provided when being diagnosed:

The doctor didn't even let me know what it does, like when he told me I've got hep C. I just sat there in his office and I just cried. He didn't tell me, do you know about your hep C, do you know what it does, do you know how you can control it, and you can get rid of it. (P7)

Others recall being diagnosed with hepatitis C and the missed opportunity to find out about care and treatment. People remember the lack of support and information at a critical time:

How I found out that there's medication for it is through my neighbour. We were talking about hepatitis and that, she said 'I'm on medication for that' and I was just shocked! I said 'what? I didn't know there was such a thing', you know...it's more about being ashamed of the unknown, you don't know what it is, and so you don't go talk'n about it. I've been diagnosed 13 years ago, it's only in the past couple of years, that I've been openly able to talk and enquire about it. (P13)

All that sort of stuff, like I've sort of just found it out on my own... And that's pretty upsetting for me, 'cause it feels like its my own fault that I've got it. (P7)

The poor level of information that was provided to people when they were diagnosed led one person to think that *I felt as though I shouldn't have had children having hep C. (P7)*

The two reoccurring settings where diagnosis was reported was prison and during prenatal care:

During her pregnancy, she was monitored by the midwife at the hospital, who runs groups at the co-op, so she told her about the hep C. It was important that the response was non-judgemental (P12)

Found out when I was inside (P2)

Was diagnosed when I went inside (P3)

Health and community workers

A Melbourne hospital-based Aboriginal Liaison Officer (ALO) reported most of their clients being infected with hepatitis C. However, at the time of diagnosis, hepatitis C had a low priority for their patients with little room for follow up. There were too many other competing issues:

That's the last thing on their minds, they've got housing, family problems, addiction, and at this stage of their life they're feeling okay, so the hepatitis is the last thing on their mind. (HW13)

What people know about hepatitis C

A lack of information or incorrect information about hepatitis C was evident from the stories people with hepatitis C shared, and by some health care workers admitting their lack of knowledge. There are critical times when information and support can play an important role in dealing with a diagnosis and learning to live with the virus and then in being given the opportunity to explore the possibility of treatment.

People with hepatitis C

There was clearly the desire by participants to know more about hepatitis C. Some questioned why they had not been told more about hepatitis C by health care workers when they were diagnosed. Some felt that health services have let them down.

I don't know a great deal about it, I would like to know more. I was diagnosed with hep C six years ago. I've only just found out today that I can go and get treatment from the liver clinic; I didn't know that before today. I think there just needs to be more awareness and places where I can go to find out research about it, because I'd like to know more about it, and what its doing to my body and what I can do to help it. (P7)

All I knew was that it would eat my liver away and one day I would die. (P2)

People commented that generally there is a lot of incorrect information about hepatitis C throughout the community with several comments from people reflecting confusion with HIV and/or AIDS:

The older people, when they hear you've got hep C, they think you've got AIDS. (P17)

A lot of people thought that hepatitis was AIDS. (P6)

Incorrect information about how people are infected with hepatitis C and the impact of infection was offered in some interviews. For example one person commented: *I caught mine by using a silver spoon...that's how I caught the virus. (P6)* The connection between hepatitis C and HIV was incorrectly made by a few people. One person made the following connection: *If you have all the 5 brothers, hep A, B, C, D and E, then that's AIDS. (P5)*

Health and community workers

Some health care workers did not know about ways hepatitis C is transmitted or what hepatitis C does to the body. Very few health care workers were aware that hepatitis C treatment is available. Most health care workers recalled stories about clients and how little people knew about hepatitis C:

I had once someone with hep C, who didn't really realize how they got it, they thought they got hepatitis because their house wasn't clean. (HW3)

I think people generally know of it (hepatitis C). In terms of details...I think there's a lot of misinformation. My hunch is that around transmission, people generally know it's around bloods. But, in terms of symptoms, and how it's likely to play out, and treatment options, I think there's not a lot of knowledge. (HW4)

There are a lot of myths; most of my Indigenous patients think hep C's incurable. (GP26)

When asked about the general knowledge of most people around hepatitis C, an Aboriginal Health Worker commented on the lack of information about hepatitis C, how information about hepatitis is understood and delivered, and the impact that this has on people:

They can't distinguish between A and B and C, they hear the word and it just scares the hell out of a lot of them. [It's] the unknown factor, our grapevine is quicker than the internet, so it's the stigma that goes with it as well. So people don't like to disclose anything. (HW18)

Lack of knowledge about hepatitis C by health care workers can have major consequences. Two health care workers talked about patients who were misdiagnosed and believed they were positive:

For my patients that have hep C, I also always do a PCR and genotype, because lots of them have actually cleared it, and I think that lots of Aboriginal people with hep C don't know they've cleared it. (GP26)

I've screened 120 people for hepatitis C, 18 of those people were PCR negative, which means they didn't have hepatitis C, and they were told they did, based on an antibody test ... I have four or five guys, that have thought they've had hepatitis C for fifteen years, and so that's cost them jobs, that's not to mention walking around thinking they have this for fifteen years, and they didn't. (HW17)

A Melbourne based community worker commented on people's lack of understanding around transmission of hepatitis C and there is very little information about the dangers of some practices:

People are sharing toothbrushes, so I think that even the basic knowledge around the sharing practices, not just needles and stuff like that, is not there, there needs to be more education. (HW12)

A regional Aboriginal health worker commented on the fact that there is limited information about hepatitis C for people, including the broader community:

I don't think there's a good understanding about hep C, I think there is a reasonable understanding about how you get it ... but I don't think there's good information out there, for people to understand what hep C is. If it were a bit more in your face, it would be a bit better understood, and I think that's part of the problem. Why haven't we got it on TV in ads? You know, it's those sorts of things. That's where people see it, that's what people mostly watch, is the tellie, so why haven't we got it on there? You know, back in the 80's we had the big AIDS scare; you were drowned in the grim reaper. (HW14)

I think most people have heard of it and know a little bit about it... They know it's transmitted by sharing needles... I think people are a bit scared of catching it, but no one really talks about it much. (HW20)

Lack of knowledge about hepatitis C is not confined just to the Indigenous community; there also is a general lack of knowledge by health care workers about hepatitis C. High turnover of health workers in Indigenous health settings and the fact that there are many other health issues that need to be dealt with add to the problems created by a low level of knowledge about hepatitis C:

As workers, most of us workers are all covered against hepatitis C, because we all receive our [vaccination] needles as well. (HW6)

Two Aboriginal Liaison Officers from a city hospital admitted to knowing very little about hepatitis C:

Interviewer: What do you know about hep C?

ALO 1: Buggar all.

ALO 2: I know it's a virus. People catch it from using needles.

ALO 1: Hygiene issues

ALO 2: Yeah hygiene issues. I think they catch it through intercourse too, but I'm not sure about that one... Well what I've heard is that they go yellow. Doesn't it muck their liver up? (HW8&9)

One Melbourne based non Indigenous GP working with a few Indigenous patients, remarked that she had only in the last 12 months discovered that anti-viral treatment for hepatitis C was available:

I've had one (patient), I met him after he had the treatment, that was when I was really surprised that he had actually had a complete disappearance of the virus... I used to think that there was just no treatment for hepatitis C, and that you have to avoid toxins to your liver. (GP 29)

A non-Indigenous practice nurse knew very little about hepatitis C treatment and did not know that the type of genotype can affect the treatment regime. When asked about what she thought were the main barriers which could be stopping people going on treatment she commented:

... just not knowing about treatment. Lack of health workers knowing themselves, so they can pass on the information... (HW6)

One health care worker commented that what is needed most is education for staff:

It wouldn't hurt for us to have more education about hep C ... I'm aware of all that sort of stuff [around modes of transmission] but treatment, I'm way behind. Obviously when people get sick I liaise with the doctor but I don't know a lot myself and it wouldn't hurt to read up more, especially when you're at the coal face, so that we can do more, like we do with the diabetics or with other chronic diseases...because it's left behind a bit when you think about it. (HW2)

Support

The following section documents views given by community and health providers and by Indigenous people with hepatitis C about finding ways around the barriers to treatment and care for Indigenous people with hepatitis C. Suggestions are made about how to improve existing practice to provide better access to services for Indigenous people and making community services and health services more responsive to the needs of people with hepatitis C. While one important aim is to find ways to support people to make an informed decision about undertaking treatment, it is acknowledged that this option will only be used by a minority of Indigenous people. Finding ways to support people to live well with hepatitis C is arguably a more pressing need to be addressed in the short term.

Anti-viral treatment is not a viable option for many Indigenous people. As identified in the previous section there are many barriers which stop people from talking about hepatitis C and ultimately from knowing very much about the virus. However, this section provides a range of measured ideas grounded in years of practice, often not in tackling hepatitis C, but in supporting Indigenous people with a range of health issues related to chronic illness which carries a great deal of stigma and shame.

Attention needs to be directed not to how best to open the door at the liver clinic, but what are the most effective ways to reduce people's harms, such as alcohol, drugs, poor diet and housing. How best to provide support and how best to deal with shame associated with hepatitis C.

People with hepatitis C

The need for support was identified by some people with hepatitis C. There was also interest in a support group, preferably gender specific, although one person said that was not necessary:

Even though I have hep C, I couldn't explain to my family what it was. You know. I said to her [GP] what do I do with this, and she said, "here's a booklet". This big book; like this you know! You do really need your family support through this, there's no way of getting through it on your own. Not with our people. (P17)

Having safeguards in place, where people can feel secure about their privacy would be one of the top five issues that need to be addressed before people would seriously step up and seriously look at having treatment. (P16)

Someone who's been living with hep C for ten years has got a lot of information to give someone that's just been diagnosed. They're just going through all that guilt and shame, and what ifs. Someone who's been living with it for ten or twenty years can go; 'Mate, it's not the end of the world'. (P15)

One person from regional Victoria was not aware that anyone else around where she lives has hepatitis C. She is not sure if she would want to be involved in a support group, although she believes that if she did know someone *'it would be a lot easier'*. (P19)

When the idea of a support group was suggested to one young mother of 6 children she liked the idea. She said she would go. She suggested a support group, for parents with hepatitis C. They could have a group for parents with hep C; they could have a few different groups. When asked what would she like to get out of that group, she answered:

More knowledge on hepatitis C and what it does to my body, how I can help prevent it getting worse, the treatment, and hopefully come out clean, I mean after my treatment and the support groups, that's what I would try to work at doing. (P6)

One woman has been attending a drug and alcohol service for check ups, including liver function tests. She is now attending a support group meeting at this centre to find out more about hepatitis C. There are 12 people in the group which meets once a fortnight, and she goes once a month. She made the suggestion that a support group could become a peer support group, helping get to appointments, baby sitting, etc. And that it is also important for people's families to know about hepatitis C:

They actually make you feel comfortable up there, about the whole thing and everything that happened. If you've got any disease at all, like hep B, they're really good...It would be good if we could have like a program or something here [local Aboriginal health service] for us Aboriginals. [Also] a professional hep C doctor to talk to us, who can relate to Aboriginal people. That would be really really good. And a group also that's going on, so that Aboriginal people can sit down and talk about it. (P7)

Most people interviewed believed that counselling and support groups would be a good idea. Through counselling, support and group-work shame can be acknowledged and managed. Support groups in whatever form they are offered can provide opportunities for people to share experiences about living with hepatitis C. A similar suggestion was made by one man from regional Victoria. He thought an information centre and support groups, where people who have not been through treatment can talk to people who are thinking about doing it. He sees people as being frightened of hep C, as they are of HIV/AIDS, the shame attached to it.

Different models of service delivery were suggested. One woman talked about wanting to see a community women's health group established. The community group could support educational programs and host general health days with guest speakers, discussion groups, to open up discussions around how to improve one's health:

I'd like to start a community women's group that would be just for starters.

No one wants to talk about this sort of stuff with the opposite sex around

It's just a matter of being able to air those sorts of things out. When I first found about hep C, there were so many people I didn't want to share it with, and then I find out there are so many out there that have it. So how lonely are they? And they can't speak to no one. (P12)

Health care workers

Many health workers talked about the need for support and acceptance and minimising the shame factor. The need for people to feel secure and safe is a universal need. By normalising hepatitis C, the blame and the fear is taken away. An outreach worker for homeless people commented that critical to providing support is building trust with a patient:

Whenever you are working with someone, Indigenous or non-Indigenous, don't ever promise something you can't do. And if you can't deliver then you need to be mindful that the community will know about your non-delivery within five minutes. Being really mindful of what your responsibility is, [what] you can and can't do, and not entitled to overstep that because, if you can't deliver the trust can be broken from that...Don't say you can do it, when you don't know that you can do it, or there's not funding, or there's not stuff available. (HW4)

As soon as you say, sexually transmitted infection, it's all a big yuk yuk. With my girls I often say you've got a sexually transmitted bug, and it plays it right down and, it can be treated, it can be managed... if you play it down a bit so that its not this big yuk factor, or shame factor. We need to focus on that a bit, with the words we use with our young ones, makes a big difference to how they perceive the condition and themselves, or how they think other people are going to perceive them...If you normalise it as much as you can, take the shame, yuk factor out of it, and I think the young ones are much more comfortable with it...Take the blame and the fear out of it, just makes a huge difference to whether they're comfortable to come back and tell you other things. (HW7)

You need to be thinking medium to long term when planning models of service delivery for an Indigenous client base... [For someone to be ready for

treatment] I have to be confident that their substance use is stable, and that they are within a treatment program, alcohol is something that they shouldn't be using. If they are drinking excessively, either binge drinking or in a dependent fashion, I won't put them on [treatment] because the evidence is that they don't get a good result. ...their mental health needs to be stable as well, so they need to be in treatment, adhering to treatment, and they need a little bit of social support; be it a case worker, or family or friends. They need to be adherent to their appointments and stuff, so if they never rock up, we would be less likely to start them, because we don't have confidence. (GP24)

This GP talked about the necessity for providing a friendly and welcoming environment to ensure that Indigenous people feel safe enough to access the service:

There is no doubt that the lack of Indigenous faces, in a standard drug and alcohol treatment agency does impact on people's unwillingness to come. (GP24)

Another strategy for reducing shame was to rename the health care being done with Indigenous people which acknowledges and strengthens cultural norms:

What we really need is one male health worker that the community can get to know, they can go; 'this is the one you can go to see about men's health'. Don't even call it sexual health, call it men's health, they can come in and talk to him about anything. If we can get one person trained up, who becomes confident of his own knowledge, enough to talk comfortably with these young guys, they're going to talk to each other out there, and they'll start coming in. And I really think that would be the secret. It's just people talking to people. (HW7)

Support groups and education about hepatitis C

Providing information to people with hepatitis C through groups which are set up specifically around hepatitis C was suggested by some people, while others believe that to reach more people it is necessary to broaden the context within which the support group operates. Supporting people with hepatitis C doesn't have to be set apart from other health and wellbeing issues and many of the issues associated with living well with hepatitis C relate to other health issues:

There is an opportunity for information sharing sessions at some of the focus group discussions....The availability of anyone with an illness, to be able to access a program, a support program. Like they do at the elders' group, but young people go into that group too. If they're doing water aerobics and hydro therapy and they are also going to the gym and building body mass index, or they're just going to walk around the park, do a couple of laps of the park, and our staff organise that for those groups. Why can't other people fit into that too? Why can't we, as an organisation, refer to these support groups, instead of having a support group for that, and a support group for that, because there are a lot of issues, health issues? It's that thing about changing your mind set, it's that thing about, and why do we only have to eat well when we are sick. Shouldn't we be eating well and exercising all the time? I just think that sort of thing would work. You take away stigma stuff. (HW16)

One person suggested that if you bring people together to educate and support them about hepatitis C, it needs to be done in a much broader way than by only addressing hepatitis C. Many structures exist that bring people together to educate and support them including women's groups, youth groups and elders groups:

Elders' group, and the men's group ... all of those groups, they could be the vehicle to disseminate educational information, about hep C. So that may be an avenue, looking at running workshops and forums and stuff maybe a bit more problematic because you may not have the interest there. Plus there's also the jump back to the stigma attached to turning up to a forum that's about hep C. Indigenous people are very quick to label people. It's not just an Indigenous thing, it's a wider community thing, so there's the danger of getting labelled if you turn up to a lecture, unless you're actually working in the health field, where you can say I'm coming from the health unit to attend this. (HW10)

Suggestions were made to run groups with a recreational approach such as going away for weekends:

You can maybe run a few groups, and maybe even run it around something recreation-wise ...if you could possibly take the guys fishing for a day, and women a workshop or something, and have it as health information, that sort of thing, tag it on to the specific thing. (HW5)

Don't stick people in a room, like AA and that meeting mentality, it needs to go a bit deeper than that. Do lifestyle stuff, that's getting people to be proactive about what they're eating. (P15)

Workshops and forums may be problematic because of being identified with hepatitis C. One person interviewed felt that it would be necessary to have workshops outside of the Indigenous community, so that people's status is not compromised. A nurse practitioner working in regional Victoria felt that a support group can be problematic. Confidentiality can be difficult. (HW15)

Providing information about hepatitis C to the broader community

There's not enough information and flyers and that, circulating around, in like health communities, about this thing, like AIDS is there, and all that kind of stuff, but not hep C. (P5)

Most health care and community workers interviewed were unaware of materials about hepatitis C to pass on to their clients. Brochures and written materials were not thought to be the most appropriate way to get information about hepatitis C to the broader community. At the time of the interviews an Indigenous play, *Chopped Liver*, presented by Ilbiggerri Aboriginal and Torres Strait Islander Theatre Co-op and VACCHO was touring Victoria. Two respondents had seen the play and were very supportive of it as a way to spread information about hepatitis C through many communities:

I think "Chopped Liver" was a key, I really do; something like that, because the community don't read stuff, brochures and that they are really not interested

in. And I've found that they've had basic brochures for other stuff, they'd read it, and they'd get back to me about it, but they never did with hep C stuff. NEVER, but I think that's part of Shame job and that. (HW23)

That show, "Chopped Liver" that spread it around, that went into the next people... but there was no follow up. So it needs to be done again, regularly in the gaols and that kind of stuff. Access through the prisons is easy. (P11)

When asked about the role of peer support groups, one GP was not so sure that support groups specifically for hepatitis C would be a good idea. She felt that opportunities exist with groups involved in social activities, for example art groups, sports groups. She went on to talk about a community based project called "Hoops Health, C the Goal" from Darwin:

See the goal is about minimising and managing the effects of hepatitis C... Because you're not going to get young people into workshops, not on a regular basis. If you are thinking about targeting young people, and probably in terms of like, issues to do with alcohol and hep C for instance, the most impact that would have, would be on young adults, if you are talking about trying to prevent transmission. (GP25)

[The support group] probably wouldn't be just dedicated to hep C; it would be a three-pronged approach around HIV, Hep C and STIs. Having an educative, informative look, at each of those areas, and how to guide; how young adults and teenagers can avoid putting themselves at risk. It would look at strategies that they can put in place for themselves, to minimise their risk-taking behaviour. (P16)

Develop the web site of the ACCHO service, [developed by the kids, and relevant to their age group] ...With links to other web sites, where they can do more research for themselves, discreetly, without going to an adult. Pages from this could be printed off for circulation in the community newsletter. (P16)

An Aboriginal Liaison Officer working at a Melbourne based hospital talked of a healing circle, where people can informally join the group. The group has an educational focus where information is shared. The group is open to children and mothers and to all ages:

We are on about getting knowledge to the patients and the families, educating them about their rights, and building up their health, physical and emotional and spiritual health. (HW8&9)

There were a range of suggestions for support groups to provide the opportunity for a group of people to come together to deal with the same issues. One respondent thought a support group at Victorian Aboriginal Health Service (VAHS) would provide an opportunity to learn more about the virus, especially for pregnant women with hepatitis C. Another person suggested establishing a peer support group for people who have just been diagnosed.

Groups and treatment

People with hepatitis C

One respondent commented that it would be helpful if there is an information centre and support groups, where people who have not been through treatment can talk to people who are thinking about doing it.

A person who attends a hepatitis C related support group at an alcohol and drug service and also attends a D&A support group talked of the challenges associated with undergoing treatment and the role for a support group and specifically an Indigenous support group:

It [treatment] brings up everything, all the childhood stuff, all your colonization stuff, it brings up everything, it's all out on the table...It's pretty hard to do that, [to take responsibility for your health/addictions] in this society when you are not accepted as anyone that's worthwhile. Being a drug addict, being an Aboriginal man or woman, or being anything, you can find a thousand excuses for not partaking in this society and getting out of it. My break, after years of drug abuse, was fitness. (P10)

He talked about the possibility one day of having a Koori specific support group. The groups don't have to be gender specific; he believes that the mix of men and women gives a balance:

Eventually it would be good to have our own support groups...I've been in support groups with both men and women, non-Koori and, and they work... they're fine. (P10)

Health care workers

Providing treatment in a small group was suggested by one GP. He believed that even a small group of three people being on treatment at the same time could provide invaluable support to each other. By bringing together at least three people information could be shared and people would get an idea of what treatment is all about. Most importantly, people would not be tackling treatment alone, but in a shared and collective way:

People don't all have to start in the same week. We had this hep C support group going, and that was really useful. People met every week, and some people, not everyone, started at the same time. There was a bunch of people who were starting, and a bunch of people who were sort of in the middle and a bunch of people who were coming to the end. So, it was really useful for people to see where people were at different stages, and people who had come to the end you know, they come and give the people who were just starting some advice. It was really useful. I think it gave clients a sense of being in it together, which I think is really important. Hep C treatment is difficult. (GP24)

He thinks clients should be given the option of a support group, or a support worker or seeing their own doctor, while also seeing the doctor and nurse responsible for administering the treatment:

I thought the level of honesty and communication was high, higher than usual. There was that, but, our part of the bargain was, we are not going to let you go, we are going to do the best we can for you, but you've gotta be honest with us, and you've gotta come to the table with us.

Part of the education process was realizing what needed to be done to get through treatment, and realizing the only way to get through treatment is by forming a really strong partnership with your treatment team....and you go through it together. (GP24)

It wasn't just about us saying, you gotta do this, it was about a partnership, the only way we get through this treatment, is if we both work together, that was the implication. (GP24)

One regional based GP talked about treating patients in small groups and some of the rules that been developed around this process:

We won't treat partners at the same time ...because they'll rip each other's heads off! Support groups quite often help. They can bounce off that "Oh yeah, I'm getting that as well...Oh woe is me", and they can "Oh woe is me" back, so support groups is not a bad idea.

What about in a country area?

The main issue that actually is blocking to that is that; a lot of them don't want anyone to know they've got hep C... That's got to do with stigma, of having hep C, and everyone associated with intravenous drug use. And there's huge stigma about people having that problem. (GP28)

Another GP commented on the idea of small groups of people going on treatment at the same time. She saw many benefits in this approach:

Absolutely, as long as it was done respectfully and each person was invited. Like how shall we set this up, would you like to meet other people, because I think there is so much shame around having hep C. (GP26)

For hepatitis C management, the GP believed that opportunities to learn about the virus help empower people to better manage their health and the impact of hepatitis C on their everyday activities. She supports the idea of small groups of people going on treatment at the same time, forming support groups would be a good model and suggested the need for someone to liaise with the group, to be proactive with the group and to organise transport. Phoning people the day before to remind them when the group will meet would also be necessary and this could be done by an ALO type position. Other suggestions made by the GP included the ALO taking a group of people together to the liver clinic. Support would be even more meaningful and may even increase the odds of people getting to their appointments and staying on treatment if food was made available, and people's children were allowed to come. On a practical level, this would mean making car seats available for kids and toys to play with.

A support group for carers of people on treatment was another alternative raised by an Aboriginal Health Worker as an idea that should be considered. She does think that there would need to be gender specific groups for support groups:

I think all groups would need to be that way, I don't think people talk openly enough in mixed groups. (HW14)

Appointments and transport issues - getting people to a clinic

Appointments

I think people are prepared to be referred, the question is more whether they will turn up for the appointment and that's not just for people with hep C... and that usually involves the clinic being involved in making sure that they've got transport. (GP27)

The complexity of people's lives can make it problematic to follow up not only with doctors' appointments, but also with necessary medical check-ups. Keeping an appointment can be a barrier to treatment:

Coming in all the time; getting check ups, that was hard, because I can't keep appointments...I forget a lot, and I can't read or write properly. (P8)

Appointments! No one keeps appointments, some people make their appointments, but they are so rigid, in this, appointment times, they [the patient] miss one and they're too shamed to ring up again... and most people's telephones are mobile phones, they put you on hold, it's too hard. (HW13)

Associated with the challenge of making and keeping appointments is the fear people have with going to the hospital. Hospitals are seen as places where people die, unless it is an emergency, people will often put off going to the hospital. Another barrier is simply getting an appointment. Appointment times from hospitals are often notified by mail, however, a stable address where mail can be sent is not always available:

One of the first barriers is actually getting an appointment, because often they get mailed out, and lots of my Indigenous patients are actually very transient, and they might never receive the appointment in the mail. (GP26)

There are cultural imperatives and responsibilities that impact and take precedence on the capacity of people to attend appointments:

Death will take over as a higher priority to any thing. If something happens in community and there are appointments and things, for people to follow up appointments and things, just forget it, because it won't happen. (HW18)

One of the hardest things for one person who needed to monitor his hepatitis C was to keep his appointments. He found it difficult to keep appointments because he can't read. It was difficult to remember to get check-ups. The health service calls his mum to make sure he remembers his appointment:

This service does not have ANY appointment times, except to tie in with the transport time. (HW19)

One health worker noted the benefits associated with flexibility of appointment times, around counselling. At VAHS they create the opportunity for "walk-ins". To manage this, they schedule regular appointment times, with breaks between to accommodate walk-ins. So they actually schedule in advance walk-in appointments, whether they are there or not:

We're not restricted to appointments; we also make the opportunity for "walk-ins", because I think that's really the key, it's optimistic. (HW16)

Transport to appointments

The inability to access transport stops people keeping appointments; *If it is not an emergency then people will put it off. (GP25)*

Transport is an issue as well. We had one fella coming to the group, but then he lived down in Frankston, and it was hard for him to get around ... he didn't have a car. So I mean there are practicalities. It's not a rich group for people who are on hep C treatment. (GP24)

Transport is another big issue, around the place as well, because we're relying on our Aboriginal co-operatives to get people to and from appointments.

If there's no transport, they don't get there?

That's exactly right.

So people need to be picked up and dropped home?

And that's where it's good with your health workers and that's why they need to be fully trained up, because you can talk to these people while they are in the cars. We don't want health workers that just drive a person to and from places. I wouldn't want my health workers just to be a driver. I'd want them to be informing people on the way. (HW18)

In rural and regional areas, transport is a priority given the distances and time taken for travel:

Transport is a huge problem here, for everything. Because of all the different areas, from Robinvale down to Wentworth, and anywhere in between, that access our service, transport is a huge problem. (HW10)

An Aboriginal Liaison Officer commented that given people's complex lives, they often are unable to access transport to get medical treatment:

Might be that they're unable to get transport, to actually get some testing done. Especially if it's a female, she may be looking after four or five kids at that time. She's got to try and drag four or five kids onto a bus, and into a community to get some tests done, especially if she's a single mother, which is very common in the rural areas. (HW11)

There needs to be someone to liaise with the group, to be proactive with the group and to organise transport. For a service to work there needs to be transport available or taxi vouchers. Some health workers commented that there is a real need to be proactive and even creative about how to shape the service to make it more accessible to the client. One community worker spoke about an existing mobile health service in Melbourne:

With services like a health bus, or a GP project that we are just establishing, where people are able to actually meet with doctors in their own environment.

And their environment might be ...?

The park, it might be the rooming house...confidentiality of course is a big

issue, but its not always about someone coming from the hep C clinic, it could be a generalist nurse or doctor that they are going to see about a sore thumb. And then that then engages the process. And it's an opportunity to have a look at what's happening for the individual...I think that if there's hep C clinics, that the hep C clinic needs to be a lot more Indigenous focused, it needs to be that you've got an appointment and you go and see the doctor and you're out of there very quickly and that there's transport available, for that to happen. (HW12)

It comes back to being able to access appointments and things, so the ability to actually find transport to actually come in. We kind of pick up in that area quite well I believe, because we offer transport, so people have only got to ring and say I need a ride into the clinic and we will pick them up and drop them home again. (HW15)

As soon as an Aboriginal person gets referred to any therapist in this section of the hospital, where I am at, I want to know about it. I've got a calendar on my thing here [computer] that says you can lock people in on calendars even, and say this is their appointment time, and I put it in a day before, and say ring this person and remind them about their interview. And sometimes it's going to be a week or two weeks down the track, and I book the car as well for them, if they haven't got a vehicle. So I ring the medical clinics and say, I need this car for this time, and if that person doesn't come up, I want that therapist to put it in my pigeon hole, or email me to say this person didn't turn up, don't tell me why, because I'm going to find out why,... if they don't know why, and I note it in that person's file. Why they didn't turn up, because a lot of the reasoning for them not turning up is, because the medical car turned up late, and they only have a certain amount of time to sit here, because our clinicians have appointments after appointments. (HW18)

Mobility

When asked what might stop people from accessing care about hepatitis C, the transient nature of Indigenous lifestyles was seen as an ongoing issue and certainly relevant to accessing care and treatment. It was seen as problematic for health conditions in general. One GP suspected that most doctors would not have the time to manage the issues that could arise from mobility while another GP noted that mobility had not been an issue for him with his clients. Clients prioritized the treatment, or arranged to have an extra dose of their medication if they knew they were going to be away: *once they were on treatment that was a high priority. It was impressive. (GP24)*

A regional based Aboriginal Liaison Officer commented that perhaps hepatitis C did present additional challenges to keeping in touch with clients. Suggestions were made by both health workers and GPs that perhaps additional planning would be needed:

People that move from community to community, we can chase them up quite easily with other health issues, I'm not sure if hep C or HIV, we would really be wanting to chase them up over the phone, because umm, we do have health worker networks, the only way you could get around that would be on your first consult asking them where they are likely to be if they're not in town. (HW18)

This issue obviously raised problems with confidentiality, particularly in rural areas:

They do tend to move up and down, but around here they usually move between Tyers, Morwell and Drouin... so if you actually know what you are doing, and have it set up right, it shouldn't actually make a difference, all you need is people in each zone, or who can access each zone, and you would probably do Drouin and Warragul as part of Latrobe Valley, so if they are moving, as long as you know they have moved, you just pass them onto the other team. (GP28)

I always think that it is people's own responsibility to take their medication but it's our responsibility to make it possible for them to do so. (GP26)

What we are trying to develop with the refugee community, and it would be similar with Aboriginal and Torres Strait Islanders (ATSI), is to give them a summary of what tests they've had and the general health issues and the treatment. So that then they can find a doctor wherever they go, so the doctor can see what's happening, and they can get follow up where ever they go. (GP29)

Programs and Resources on Hepatitis C and Indigenous People

One aim of this project was to identify programs throughout Australia specifically targeting Indigenous communities in relation to hepatitis C.

Programs

- Northern Territory AIDS and Hepatitis Council, ***Hoops 'n' Health, C the Goal, a healthy lifestyle*** (2007): *Hoops 'n' health* is a healthy lifestyle basketball program for youth. The goal is to increase healthy lifestyle choices among youth by encouraging participation in the sport of basketball. Some of the aims and objectives of the *Hoops 'n' health* program are: to create a network that will link young people to other organisations and support services i.e. join the local basketball competition; to develop in these young people a range of attitudes through sport such as sportsmanship, the benefits of teamwork and discipline, and cooperation and responsibility that readily transfer into other environments such as home and the workplace; and to create an awareness of the risks of smoking and alcohol abuse.
- AIVL, ***Dulangirr Gubbynidgel Aboriginal Peer Education hepatitis C/IDU workshop kit project***: presented at the *National Hepatitis C and Aboriginal & Torres Strait Islander Communities Workshop: Engaging Communities* on 7th June 2007, this project provided workshops and peer education to current and former Aboriginal drug users on how to inject safely. The project is run by *The Connection*, a peer-based Indigenous Youth Service which is open four days per week based in Canberra. *The Connection* provides peer education, support and referral through their peer-based Drop-In centre.
- SA Aboriginal Drug & Alcohol Council, Hepatitis C Council of SA and Nunkuwarrin Yunti '***arts in health***' programs produced ***Tune into your health, it's in your blood*** (2005). The *Tune into Your Health* program combines education and conversation with music and song writing to give young Aboriginal people a voice about important preventable health issues that affect their lives. In 2004, Nunkuwarrin Yunti in partnership with the Hepatitis C Council of South Australia began a series of statewide workshops that focused on hepatitis C (It's in your blood). The Aboriginal Drug and Alcohol Council (ADAC), Kamangka Aboriginal Youth Service, and the Kurrur Indigenous Youth Performing Arts were also key organisations that collaborated in the project. An opportunity was created for young people to communicate with other young people and the wider community about hepatitis C and a 12 track CD was produced and launched in Youth Week 2005.
- SA Aboriginal Drug & Alcohol Council provides ***weekly barbecues*** for homeless Indigenous people in Adelaide where health education (including hepatitis C education) is provided as well as referral pathways to appropriate services
- Nunkuwarrin Yunti (SA) runs a ***weekly liver clinic*** with a visiting specialist and a clinical nurse. This has raised the priority of hepatitis C as an issue within the organisation, and increased the capacity of the agency to provide hepatitis C education and referral pathway for their clients. The clinic aims to increase access to hepatitis C treatment for Indigenous people.

- Department for Correctional Services, South Australia, **Hepatitis C awareness workshop** at Port Augusta prison for Indigenous inmates. A paper presented at the Best Practice Interventions in Corrections for Indigenous People Conference convened by the Australian Institute of Criminology, 2001, reported on a series of hepatitis C awareness workshops run at Port August (SA) prison for traditional Anangu men. Indigenous men are overly represented in the SA prison population, where they make 20% of prisoners.

Available resources

- **Don't Be Bunta (Hep C Don't let it Be)** A DVD produced by Hepatitis C Council SA (2008) in partnership with Centacare, Wodlittinattoai and Gawler Health Service and Kaleteeya Aboriginal Health Team
- Aboriginal Health and Medical Research Council of NSW, **STI & BBI Manual**: a manual for improving access to early detection and treatment of Sexually transmissible Infections and Blood Borne Infections for Aboriginal People and Communities in NSW
- **Chopped Liver** (Vic): An Indigenous play presented by Ilbijerri Aboriginal & Torres Strait Islander Theatre Co-Op and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO). This powerful play has been scripted and is performed by Ilbijerri to educate Koori people about hepatitis C among the Indigenous community. Through comedy, *Chopped Liver* explores a number of issues of relevance to the Koori community including drug use, relationships, discrimination, bullying and health.
- WA Department of Corrective Services' Health Services, **Sistas Staying Strong - Rosie's Story (DVD)**, It is believed to be the first prisons hepatitis C resource for Aboriginal women in Australia, and has already attracted significant interest from other states. The script was developed in collaboration with prisoners at Bandyup Women's Prison and the superintendents of Bandyup and Boronia Pre-release Centre for Women in WA. Included is information on hepatitis C transmission, treatment, symptoms and support services available to prisoners during imprisonment and on their release.
- The Kirketon Road Centre (2003), **Health for all - drug, alcohol and STD pamphlet series**, Kings Cross. This series of 9 pamphlets has been designed specifically for an Indigenous audience, and addresses HIV prevention, sexual health, and illicit drug use issues.
- Victorian Aboriginal Community Controlled Health Organisation (2003) **VACCHO sexual health and hepatitis C pamphlets**: VACCHO has produced a series of sexual health pamphlets specifically developed for Aboriginal people. The series contains the following titles: Hepatitis C, Condoms, Genital herpes, Syphilis (the pox), Gonorrhoea, Warts on pippi, mutja and moom (genital and anal warts). The pamphlets also list details of places to get more information, including a listing of rural STD clinical services in Victoria.

- Australasian Society for HIV Medicine (ASHM) (2004), ***Talking together: contemporary issues in Aboriginal and Torres Strait Islander health: HIV, Hepatitis and Sexual Health. A distance learning package for those working in Indigenous health.*** This resource was developed in collaboration with the Indigenous Australians' Sexual Health Committee (IASHC) and funded by the Office for Aboriginal and Torres Strait Islander Health (OATSIH), Department of Health and Ageing. It was designed for use by general practitioners and other interested clinicians and health care workers. The package contains a copy of the video (a CD version is available) 'Talking Together', a users guide with training materials and activities, and a copy of the ASHM monograph HIV/Viral Hepatitis - a guide for primary care. The manual offers practical advice for risk assessment, testing, diagnosis, and basic principles of management of HIV and viral hepatitis. The incorporation of viral hepatitis reflects the trends in public policy and medical practice towards locating HIV/AIDS within the broader public health and sexual health context.
- Relationships Australia (2003), ***Yarnin' up hep C. A hepatitis C education resource for Indigenous communities:*** The 'Yarnin' up hep C' education resource was developed as part of a project run by Relationships Australia, South Australia. Its purpose is to increase awareness, encourage conversation, and prevent infections of hepatitis C. The resource consists of a small wallet-sized information leaflet, and a larger information booklet with information wheels, and has been designed specifically for educational use with Indigenous communities in metropolitan Adelaide. It is colourful and informative, with easy-to-understand language that explains the hepatitis C condition, its transmission, treatment and care, and provides community contacts.
- Hepatitis Council QLD, ***Torres Strait Island HIV/AIDS and Hepatitis Information in Creole*** (first edition 2007): resource produced as part of the TSI project, a partnership between the Queensland Association for Healthy Communities (QAHC) and the Hepatitis Council of Queensland (HCQ). One of the outcomes of the TSI project is to translate resources into the common language of the Torres Strait islanders, with the aim to increase understanding, education and communities' awareness on health issues, including hepatitis C. Prior to the publication of this booklet, there were no health resources in Creole addressing viral hepatitis or HIV/AIDS.

Conclusion and Recommendations

In addition to preventing transmission of hepatitis C, a great deal of attention by public health officials and health care workers across Australia is directed towards increasing access to liver clinics to monitor viral activity and if appropriate begin anti-viral treatment. The most effective response for Indigenous people with hepatitis C is not necessarily finding ways to get them into a liver clinic. Barriers and challenges to accessing treatment which have been identified within the broader community, such as perception of effectiveness of treatment and concerns with side-effects of treatment, were not identified within this study. Without doubt hepatitis C competes with other health issues and socioeconomic issues affecting Indigenous communities. However, our findings show that there are policies and practices which can help improve the level of care and support for Indigenous people with hepatitis C.

For the Indigenous people interviewed in this study, one identifiable barrier stopping them accessing care and treatment is the limited knowledge they have about the virus. Stigma and shame associated with hepatitis C transmission and infection stop people talking about hepatitis C, and ultimately seeking support and health care. Stories were told of people being misdiagnosed and as a result living with the assumption of having chronic hepatitis C. Some were not aware that treatment was an option. One of the most worrying outcomes from this study is the general lack of knowledge by health care workers and by Indigenous people with hepatitis C about the virus.

Finding the most appropriate and sustainable ways for Indigenous people with hepatitis C to live well with the virus will achieve far more in reducing the burden of the disease than attempting to find a model to increase the number of Indigenous people in liver clinics across Australia. This may mean providing support and information to Indigenous people and health care workers to understand more about what the virus does to the body and about the benefits of eating well and reducing intake of alcohol. For this to happen conversations about hepatitis C need to begin between health care workers and patients within mainstream health services and Indigenous health services and also outside the health system within the broader Indigenous community.

1. Health care workers and community workers working with Indigenous communities need to be provided with training about hepatitis C

Training about hepatitis C is critical for health care and community workers. It is important that the training addresses stigma and how to reduce the impact of shame associated with hepatitis C.

2. Provide information about hepatitis C to the broader Indigenous community

There is a clear lack of information about hepatitis C within Indigenous communities. The study shows that people don't like to talk about hepatitis C. There is a great deal of stigma and shame associated with the virus. Shame and lack of understanding make it very difficult for health care workers and for Indigenous people with hepatitis C to talk openly about the virus and about options available to manage the virus.

Information about hepatitis C needs to be provided in a way that is culturally appropriate and accessible to Elders and to young Indigenous people. Programs such as the production of "Chopped Liver" need to be supported and their reach broadened.

3. There is no one model best suited for managing the health care of Indigenous people with hepatitis C

The findings show that some people prefer to seek out support and health care within an Indigenous health care setting while others state very clearly that they prefer the anonymity that comes with the use of larger mainstream health care settings.

4. Group treatment needs to be explored as an alternative option for Indigenous people

The findings show that the dominant medical model based on treating the individual does not allow for alternative models which favour providing antiviral treatment for people within a group setting. The findings demonstrate that there is support from the non-Indigenous health care sector, to providing care, support and anti-viral treatment within a group setting.

5. Health care workers and community based workers within Aboriginal Health Settings need to be provided with appropriate and up to-date information about hepatitis C

The findings show that hepatitis C is not well understood by health workers working within the Indigenous health care sector. The understanding of hepatitis C as a disease with serious consequences within the Indigenous community needs to be increased.

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