



IMPROVING AND INCREASING ACCESS TO HEPATITIS C TREATMENT

A research project exploring barriers to treatment
for people of Vietnamese and Cambodian backgrounds

Sophie Dutertre & Stephen McNally



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This research is dedicated to the memory of Phong Chau.

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Glossary

AIDS – Acquired Immuno-Deficiency Syndrome

BBV – blood borne viruses

CALD – culturally and linguistically diverse

DHS – Department of Human Services

DIAC – Department of Immigration and Citizenship

DIMA – Department of Immigration and Multicultural Affairs

HIV – human immunodeficiency virus

HCV – hepatitis C virus

IDUs – injecting drug users

MHSS – Multicultural Health and Support Service (Vic)

NESB – non-English speaking backgrounds

NSP – needle and syringe program

PBS – Pharmaceutical benefits Scheme

PCR – polymerase chain reaction

VOMA – Victorian Office of Multicultural Affairs

Executive Summary

Hepatitis C is a significant public health problem and the most common communicable disease in Australia. At the end of 2006, an estimated 202,400 people were living in Australia with chronic hepatitis C infection, including 45,400 with moderate to severe liver disease (NCHECR 2007).

Over the past few years, anti-viral treatment for hepatitis C has improved, with the combination of pegylated interferon and ribavirin providing better results with less side-effect. At the same time, criteria for treatment eligibility have been relaxed.

Despite this, the number of people on treatment in Australia is still extremely low (approximately 1% of the total number of people with hepatitis C).

While the prevalence of hepatitis C in Australia is 1%, it is estimated that between 4 and 8% of Vietnamese and Cambodian people living in Australia have hepatitis C. It is therefore important to examine whether people from these communities are aware of treatment and recent improvements, and what may be stopping them from accessing anti-viral treatment.

This research investigates barriers to accessing treatment and care for hepatitis C for people of Vietnamese and Cambodian backgrounds. It takes as a starting point the model of the Springvale Liver Clinic. A satellite clinic of Monash Medical Centre, the Springvale Liver Clinic is the only CALD-based liver clinic in Victoria. Its objective was to reach people with liver diseases in the area where they live and work and provide easier access to specialist care and treatment.

The clinic's model gave us a point of reference to investigate factors of success when working with these two communities.

Research Objectives

The objectives of this study are to:

- Identify potential and perceived barriers to treatment for South East Asian (specifically Vietnamese and Cambodian) communities in Victoria
- Suggest appropriate hepatitis C treatment models for these communities throughout Victoria (based on the unique example of the Springvale Liver Clinic)

Methodology

The study uses a qualitative methodological approach. Two groups of people with hepatitis C were interviewed: those receiving treatment and care from the Springvale Liver clinic, and those who have never experienced treatment.

The study involves two stages, one based at the Springvale Liver Clinic and one outside the clinic. We interviewed patients of the Springvale Liver Clinic to explore their experience of the clinic and treatment, and the challenges met along the way. We also interviewed staff at the clinic about issues with hepatitis C care and treatment for this group. In order to understand what may prevent others from accessing treatment, we expanded our investigations outside the clinic's premises to local GPs and community workers in the Greater Dandenong area, concluding by

interviewing people from Dandenong, Springvale and Footscray, who do not access hepatitis C care.

Consultations with community organisations, recruitment and interviews for the project occurred between November 2006 and May 2007.

Findings

The barriers to treatment and care identified in this research can be divided in two sections: those that stop people from accessing treatment and care, and those that stop them once they have approached specialist services.

Prior to treatment

For people who may be considering treatment, the main barrier is their knowledge or perception of treatment side-effects. This is often acquired or reinforced by the community word-of-mouth, and is essentially negative when it comes to anti-viral treatment.

When a person with hepatitis C is making a decision about going on treatment, perception of side-effects weighs heavily in the decision, and is often the key element that tips the balance on the side of rejection.

Other barriers identified were:

- Feeling well, and the perception that this feeling of well-being is a reflection of their liver's good health.
- Old age: older people may estimate that the risk of developing liver damage in the long term is outweighed by the potential decrease in quality of life due to treatment side-effects, or that their life expectancy is such that it is not worth undertaking treatment.
- The fear that treatment will interfere with other responsibilities. This is particularly true of people who are employed outside the home; it can also be the case for people who have family responsibilities, such as caring for their children or an elderly parent.
- The length of treatment and the commitment required; be it in terms of clinic appointments (which may be during work hours) or the fear that treatment will make them feel ill for many months.
- Lack of information about treatment: for many people, the main source of information is friends, family and acquaintances. This information may be out-of-date (e.g. mentioning the need for a liver biopsy), inaccurate or only relate to a particular person.

During treatment

For people who have taken the first step, discussed the possibility of treatment with their GP and agreed to be referred to a liver clinic, the journey only begins, and many challenges remain. Some are related to the difficulty in maintaining appointments:

- The high population mobility, with people travelling to Vietnam or Cambodia for long periods of time without re-scheduling medical appointments or notifying services.

- Need for reminders/follow-up phone calls: the number of people missing appointments is low amongst patients on treatment, but high amongst those who only attend the Springvale Liver Clinic for blood tests and monitoring. These 'reviews' take place every three, six or 12 months. Our findings show that patients forget appointments, and that a reminder close to the date would be helpful in reducing missed appointments.
- Difficulty in attending appointments during work hours: attending review appointments may mean missing work, or disclosing one's health status to an employer. This is particularly challenging for a population that typically works in the low paid, unskilled sector, on a casual basis, and has little job security.

Others are more complex:

- Lack of understanding of disease history and the need for monitoring its progression: while Vietnamese and Cambodian people are very keen to access Western treatment, some show great frustration with the fact that treatment is not always recommended or not recommended during the initial consultations. Clinic staff and GPs attributed this frustration to a lack of understanding of the natural progression of the disease and of the need for patients to have their liver function monitored even when they have no symptoms and feel well.
- Not wanting treatment: GPs and liver clinic staff suspected that failing to attend appointments may be a way for patients unwilling to contradict their referring GP to express their reluctance to attend a liver clinic.

People from Vietnamese and Cambodian backgrounds who inject drugs

For people who inject drugs, some barriers to treatment are specific to their drug addiction while other barriers are similar to those experienced by the general population. Like others, they fear side-effects that will affect their health and their appearance. Their knowledge about treatment is sometimes limited, as is their understanding of hepatitis C and its impact on their health.

An obstacle that is unique to people who inject drugs is their negative experience of the hospital system, and, sometimes of GPs. The prospect of needing to engage with clinics and hospitals in the initial phase of treatment is a significant discouraging element for some.

As for their difficulty in attending appointments, much was said by medical professionals and drug users alike about their chaotic, day-to-day lifestyle and their high rate of failure to attend appointments. As patients, people who inject drugs may have agreed to being referred to a liver clinic but may find the reality of long-term appointments difficult to commit to.

Recommendations

These recommendations assume that not one single model of care and treatment will universally increase access to hepatitis C treatment and care. It is not this study's intention to offer a clinical model that will suit all communities – such models do not, and should not, exist. The underlying principle to delivering appropriate care is to acknowledge and understand the workings of culture and context which mean a variety of care models need to be implemented to address this complexity.

It is widely acknowledged that all CALD communities are different, and within each language or ethnic community additional differences exist. A consequence of this heterogeneity is that health services need to be flexible in their models of service delivery. What works in Springvale, with Vietnamese and Cambodian communities, may not work elsewhere

The findings from this study demonstrate that there are policies and practices which can increase access and improve the experience of treatment and care for people from CALD backgrounds.

Based on the experience of the Springvale Liver Clinic, this study has identified a range of factors that can contribute to a liver clinic's success in attracting CALD communities, increasing the number of people on treatment and improving their experience of treatment and care. Some of these 'elements of strength' characterise the experience of the Springvale Liver Clinic, while some are more of a 'wish list' based on gaps identified.

1. Support the development of community-based liver clinics

The findings show that there are significant benefits associated with a community-based Liver Clinic that is not located within a hospital.

The 'small scale' approach allows for all relevant services (i.e. pharmacist and interpreters) to work interactively with specialists. A wide range of factors were acknowledged as important to people attending the community-based liver clinic. While many of these factors may appear simple, such as having available parking next to the building, or the clinic being located in a familiar and inviting Primary Health Care setting, it needs to be stressed that these practices were highly valued by people attending the clinic.

2. Adapt the service to the cultural needs of the patient group

The findings show that running a Liver Clinic which has a significant number of CALD community members requires considerably more administrative support than a mainstream clinic. The uniqueness associated with a clinic that works with CALD communities also requires:

- Interpreters as central to the running of a Liver Clinic
- Cross cultural training of staff
- Recruitment of staff of similar cultural background to client group
- Flexibility in the delivery of care to accommodate patients' difficulties in attending appointments

3. Address the treatment drop out rate and the 'failure to attend' rate

Patients dropping out of care or failing to attend appointments were identified by most staff at the Liver Clinic as a significant barrier to care and treatment. A range

of strategies were suggested by the health care workers to reduce the number of 'drop outs' and 'failure to attend'. These include:

- Finding ways to better explain the need for monitoring and the natural history of the disease. It is important for patients to understand that treatment is not the sole aim of a Liver Clinic
- Increasing the role of GPs in keeping patients involved in managing their hepatitis
- Increasing administrative support to provide more patient follow up
- Promoting a collaborative approach between staff to maximise chances that patients concerns and hesitations are noticed, recorded and addressed
- Developing relationship with local D&A services (drop-out is high for IDU) including needle and syringe programs and methadone prescribers
- Supporting a free psychiatric service to increase the number of patients accessing treatment who are considered 'vulnerable' due to mental or emotional health issues
- Acknowledge and support the pivotal role of Clinical Nurse Consultants to provide treatment and care education and support, with the help of interpreters.

4. Develop culturally appropriate information about hepatitis C and hepatitis C treatment. Support sustainable means for this information to reach the broader community.

The study found that there was very little information available about hepatitis C generally, and about hepatitis C treatment, for people from CALD backgrounds. Most in-language material about treatment available to patients attending the clinic was provided by drug companies and most information about hepatitis C has a strong focus on safe injecting drug use, which is not always relevant to CALD communities.

Information needs to be developed specifically for communities with a high prevalence of hepatitis C. In addition:

- Sufficient funding needs to be provided for regular updates to mirror constant treatment or treatment access developments
- All relevant information needs to be accessible to GPs
- Audio-visual medium needs to be used to address illiteracy
- Ethnic media need to be used to promote this information

5. Counteract the negative image of treatment in the community

The findings from this study show that people's knowledge about hepatitis C treatment comes from their doctor AND from within their community. Stories that circulate within the community about treatment tend to reflect outdated information and negative experiences of treatment. Treatment success stories need to be promoted throughout the community, including ethnic organisations and workers and ethnic media. Other means to promote up-to-date information to the community may include taking part in community run forums/festivals and utilising the informal and extremely effective 'grapevine' to circulate up-dated and positive information about treatment by supporting patients with positive experiences to become advocates.

It is imperative that GPs are used to circulate positive information about hepatitis C treatment and the role of Liver Clinics in managing the well being of people with hepatitis.

PART ONE
PROJECT BACKGROUND

Introduction

This research investigates barriers to accessing treatment and care for hepatitis C for people of Vietnamese and Cambodian backgrounds. It is estimated that between 4 and 8% of Vietnamese and Cambodian people living in Australia have hepatitis C (Caruna 2005, Razali 2007) – much higher than the 1% prevalence in the overall Australian population.

Over the past few years, access to anti-viral treatment for hepatitis C has improved, with the current standard being a combination of pegylated interferon and ribavirin providing improved results with less side-effects. At the same time, criteria for treatment eligibility have been relaxed, particularly with the removal in April 2006 of the need for a liver biopsy.

Despite this, the number of people on treatment in Australia is still extremely low (less than 1% of the total number of people with hepatitis C). The particular difficulties encountered by people of culturally and linguistically diverse (CALD) backgrounds in accessing health care have been well-documented. In this context, it is important to investigate the barriers to treatment and care experienced by communities where hepatitis C is particularly prevalent.

This research takes as a starting point the model of the Springvale Liver Clinic. By interviewing staff, patients and referring GPs, we explore the uniqueness of this community clinic, and what elements can be replicated by other liver clinics aiming to attract people of CALD backgrounds. We also interview people who inject drugs, a group at high risk of hepatitis C but where treatment uptake is low, in order to identify ways to make treatment and care of the virus more accessible to them. Finally, we suggest models of care that could improve hepatitis C treatment access for other CALD communities.

The journey of accessing treatment and care

Barriers to treatment cannot be explored in isolation from the broader perspective on treatment access. Hepatitis C treatment is not limited to anti-viral medication; it also 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 by 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 (such as stepping into a liver clinic) but a journey, a continuum that may not always end with medical treatment. There are several 'drop-out points' along this journey. Looking at these 'drop-out points', and the reasons why they occur, help inform models of care that can best meet the needs of people with hepatitis C.

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 2006, an estimated 202,400 people in Australia were living with chronic hepatitis C infection, including 45,400 with moderate to severe liver disease (NCHECR 2007).

The World Health Organisation estimates that about 170 million people, some 3% of the world's population, are infected with hepatitis C virus (HCV), 130 million of whom have chronic HCV and are at risk of developing liver cirrhosis and/or liver cancer (WHO 2007). WHO has described hepatitis C as a 'viral time bomb'.

The hepatitis C virus was identified in 1989 – prior to this date it was classified as non-A / non-B hepatitis. In 1990, a hepatitis C antibody test became available to help identify individuals who may have been exposed (Hepatitis C Council, 2005). In Australia, on average, an estimated 10,000 people become infected every year.

Hepatitis C is transmitted by blood-to-blood contact. Infected blood must enter the body of a person through being injected directly in the bloodstream or through a rupture or skin opening (National Hepatitis C Resource Manual 2001).

In Australia, hepatitis C transmission occurs predominantly among people with a recent history of injecting drug use. Of the 264,000 infections in 2005¹, 80% were attributed to injecting drug use, and 89% of the 9,700 new infections that year occurred among injecting drug users (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 IDUs and new initiates remain at extremely high risk of hepatitis C infection.

The hepatitis C epidemic may be 'silent', but it is costly. Shiell (1999) gave a conservatively estimated lifetime cost of \$46,600 per infected person. Based on an estimated figure of 211,105 persons living with hepatitis C in 2004/2005, the Federal Department of Health and Ageing estimated the prevalence cost for 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.

Hepatitis C in the Vietnamese and Cambodian Communities

The prevalence of hepatitis C in Vietnamese and Cambodian communities in Australia is not clearly known. However, several studies indicate a higher rate than in the general Australian population. Available figures are based either on infection rates in Vietnam and Cambodia, or on modelling of the virus in Australia.

In research conducted in Melbourne with immigrants from the Mekong region (Caruna 2005), Cambodian participants were tested for hepatitis C, and 8% of participants were found to be hepatitis C positive (twice the reported rate of Cambodia).

Data from the Hepatitis C National Database population reveals that 28.5% of the total non-Australian born group came from Vietnam (Batey et al 2002).

Out of the estimated 9700 newly diagnosed infections in 2005, 7.2% were among migrants from countries of high HCV prevalence (Razali 2007). In 2005, out of the 517 new migrants from Cambodia arriving in Australia, it is estimated that 2.4% were hepatitis C positive. Out of the 2,470 new migrants from Vietnam arriving that year, the estimated rate is 6%. Hepatitis C prevalence in Cambodia is estimated at 4% and 6.1% in Vietnam (WHO, 1999).

1 This includes people who later cleared the virus

While most hepatitis C infection in Australia and other developed countries can be attributed to sharing contaminated injecting equipment, in developing countries, such as Vietnam and Cambodia, 'inadequately sterilised medical equipment, transmission of infected blood and cultural practices have been implicated' (Dev 2004). In people diagnosed in Australia but born in Asia, South America and Africa, injecting drug use is an infrequent source of HCV infection (Batey et al 2002). According to research conducted at the Monash Liver Clinic in 2004 (Dev et al 2004), risk factors in patients from South East Asia (Vietnam, Cambodia and Laos) were injection therapy, dental therapy and surgery. Only 10% of the patients interviewed had a history of injecting drug use – compared with 89% of Caucasian patients. As well as these well-known routes of transmission, less well-known modes were identified, such as cosmetic tattooing, acupuncture or traditional practices like coin rubbing and 'cupping'. This was also the finding of Caruna (2005). In her study, people from the Mekong region who had hepatitis C had no history of blood transfusion or injecting drug use.

While injecting drug use has not traditionally been the main cause of infection in the Vietnamese and Cambodian communities, injectors with CALD backgrounds are seen to be especially vulnerable to HCV infection (Maher et al 2007). This is particularly the case for people who have only recently started to inject. A study conducted in Melbourne in 2003 of ethnic-Vietnamese who inject drugs found that out of a total of 127 participants, 81% had been exposed to hepatitis C, and 71% had on-going infection (Hellard et al 2006). It also reported a worrying trend of injecting drug use during travel to Vietnam: half the study participants had travelled to Vietnam in the past five years, often to get away from drugs and detoxify. However two-thirds of participants had used drugs in Vietnam. The prevalence of chronic hepatitis C amongst IDUs in some part of Vietnam is as high as 75% (Quan et al 2004).

The Vietnamese community in Victoria

In 2006, Victoria had a Vietnam-born population of 58,877 people (36.8% of the overall Vietnam-born population in Australia), a slight increase on the 2001 figure of 56,664 (ABS 2006).

The Vietnam-born population in the state is essentially urban, with 98.6% living in metropolitan Melbourne. More than half the population lives in the Local Government Areas (LGA) of Brimbank, Greater Dandenong and Maribyrnong. This refugee community settled in Victoria in the past twenty-five years, with 75% of Vietnam-born Victorians arriving between 1981 and 1995.

The Vietnamese population in Victoria is predominantly young, with more than 40% of all Vietnam-born people aged between 15 and 34 years, and another 25% aged 35 and 44 years old. More than half live in a 'couple with children' setting. The two main religions are Buddhism and Catholicism (VOMA 2003).

According to the 2006 census, 72,162 people (born in Vietnam or of Vietnamese ancestry) in Victoria spoke Vietnamese at home. The Vietnamese Australian community is characterised by a high number of non-English speakers (more than 40% estimate that they speak English 'not very well' or 'not at all'). This is a significantly larger proportion than in other CALD groups and this has direct implications for communication campaigns. Only one in five self-assess as speaking English 'very well'.

Another characteristic of relevance for health promotion purposes is the low level of post-school qualifications for this community: almost three-quarters (72%) of Australians of Vietnamese ancestry have no qualification higher than secondary school (53.7% for total Victoria). This can be attributed in part to the low English proficiency of this group and to disrupted education in Vietnam due to conflict and displacement.

This is also a community with a high level of unemployment: 20.4% (compared with 6.8% of total Victoria) and overall lower income levels.

The Cambodian community in Victoria

In 2001, 9,003 Cambodia-born people lived in Victoria – 39.2% of the total Cambodia-born population in the country (VOMA 2003). Almost all people of Cambodian birth live in metropolitan Melbourne, mainly in Greater Dandenong. This is a predominantly adult population, with one in two Cambodia-born people aged between 25 and 44 years old. There are few children (only 4.5% aged 0 – 14 years compared with 20.3% for total Victoria) and few older people (12.9% older than 55 – 22.4% for total Victoria).

People born in Cambodia speak a variety of languages other than English at home: Cambodian (66.3%), Cantonese (10.4%), and Mandarin (4.8%). Less than 4% speak English only. This poses some challenges for the provision of LOTE information to this group.

Over three-quarters of Cambodia-born Victorians are Buddhist, with small percentages of Western Catholic and Baptists respectively.

The 2001 census draws the picture of a community at high disadvantage in terms of access to information and services. More than three-quarters (78.3 %) of the Cambodia-born community had no post-school qualifications compared with 53.7 % for total Victoria, and their unemployment rate was 17.2%. (2001 census) A high number of people in the community self-assess as having no or little proficiency in English (44.8%, almost one in two Cambodian-born people).

Treatment In Australia Today

Treatment uptake in Australia remains at a worryingly low level, with only an estimated 1% of people with chronic hepatitis C infection accessing anti-viral treatment (Batey et al, 2002). However, treatment uptake has increased in recent years, and 2006 saw the highest number of people on treatment to date: 2,847 people (1.4% of the total number of people with chronic hepatitis C) were prescribed anti-viral combination treatment for hepatitis C in Australia that year (NCHECR 2007).

People of Vietnamese background represented 16% of the total treated population in 2002 (Batey et al 2002). There is no comparable data available for people of Cambodian background.

Recent improvements offered by pegylated interferon have increased treatment efficacy and reduced side effects: depending on genotype, long-term viral eradication following anti-viral therapy is achieved by between 50% and 80% of patients. Another improvement has been the removal of the mandatory liver biopsy prior to accessing treatment.

While the decision to pursue medical treatment for Hepatitis C remains an individual choice, little is known about why, to date, the choice to take up treatment has been so low. Although side-effects are experienced by many, the benefits of treatment potentially outweigh the costs for the majority of those eligible for treatment (McNally et al 2006).

Aim Of Treatment

The aim of antiviral treatment is to prevent progression of the infection and reduce the serious consequences it may bring. For many this may mean frequent periods of illness, with periods of time when the quality of life and the ability to work are severely affected. For some, treatment prevents the advancement to cirrhosis, liver failure and liver cancer.

There is evidence that the motivation of people with hepatitis C to undergo treatment is not only to prevent future health problems, but also to remove the virus that may cause feelings of anxiety about potential transmission to others, experiences of discrimination or even shame (Australian Hepatitis Council 2003). Successful treatment also benefits the general population, as it removes a source of transmission from the population.

Successful treatment does not, however, confer immunity from further infection by hepatitis C. People who have viral clearance following treatment continue to be at risk of re-infection, possibly with a different genotype, if re-exposed to hepatitis C.

As the clear majority of cases in Australia have been acquired through injecting drug use, it has been suggested that the development of harm minimisation strategies would be a more successful approach to the reduction of hepatitis C transmission (Dore 2001b).

Current Treatment Protocol

Antiviral therapy for hepatitis C uses interferon, a synthetically manufactured protein that mimics the interferon naturally produced by the body in response to any viral infection. The synthetic version is given in much higher doses than the body would normally produce, thereby boosting the body's immune response and inhibiting viral replication.

For many years, interferon was used alone as a treatment for hepatitis C. This was known as monotherapy, and was administered as a thrice weekly subcutaneous injection for a period of up to 12 months. In 1998, studies showed that a higher sustained virological response was achieved when treatment with interferon was combined with ribavirin (Poynard et al 1998; McHutchison et al 1998).

The current international gold standard for hepatitis C treatment is a combination of pegylated interferon², which is administered by a single weekly injection, and ribavirin taken orally daily. The dosage of these two drugs will vary according to the patient's genotype and weight. Treatment generally lasts for 6 or 12 months. For patients with genotype 2 or 3 hepatitis C without hepatic cirrhosis or bridging fibrosis, the treatment course is limited to 24 weeks. For hepatitis C patients with genotype 1, 4, 5 or 6 and those genotype 2 or 3 patients with hepatic cirrhosis or bridging fibrosis, the treatment course is 48 weeks.

The decision to complete the course of treatment is based on the patient's virological response at particular time intervals, which have been shown to be predictive of success in clearing the virus.

There is no association between genotype and the progression of disease, however, genotype is the most significant predictor of the success of interferon-based treatment (Poynard et al, 1998; McHutchison et al, 1998). Patients with genotype 1 usually respond less well to treatment than other genotypes (Sievert, 2003). Treatment outcomes have improved markedly and an 80 – 90% sustained virological response (SVR) rate is expected for people with genotype 2 or 3. 50% of people with a genotype 1 or 4 infection should achieve SVR with current treatment schedules (National Hepatitis C Strategy 2005 – 2008).

Most hepatitis C acquired in South-east Asia is genotype 6 (Dev et al, 2002; Nguyen and Keeffe, 2005). People from South-east Asia who acquired the virus in their country of origin therefore have potentially higher chances of a sustained virologic response when treated. Better treatment response is also associated with being female, younger (less than 40 years), and with shorter duration of infection (Dore 2001b).

Eligibility For Treatment

Access to hepatitis C treatment has improved over the past six years through the broadening of eligibility criteria.

In 2001, current injecting drug use was removed as an exclusion criteria for government-funded treatment. This measure was followed by other government actions to subsidise testing and treatments through Australia's Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefits Schedule (MBS). In August 2002, pegylated interferon was listed under Section 100 (Highly Specialised Drugs Program) and in April 2005 the requirement for an elevated liver enzyme test (Alanine Aminotransferase – ALT) to access hepatitis C treatment was removed.

In April 2006, the Commonwealth Government removed criteria around level of scarring of the liver and the requirement of a liver biopsy to gain access to subsidised treatments. While a liver biopsy is still frequently recommended, the removal of this criteria has resulted in an increase in referrals to specialist services. The NCHECR's Annual Surveillance Report (2007) claims that 'the increase in the number of people dispensed drugs for treatment of hepatitis C infection between the first and second quarter of 2006 [is] attributable to a removal of the requirement for biopsy-proven liver damage prior to treatment' (NCHECR, 2007, 32).

The current (September 2007), criteria for eligibility to access anti-viral treatment for hepatitis C under the Pharmaceutical Benefits Scheme are as follows:

1. Patients must be 18 years or older.
2. Blood tests: people must have documented chronic hepatitis C infection (repeatedly antibody positive and PCR positive).
3. Treatment history: people must not have had prior interferon or pegylated interferon treatment.
4. Contraception:

- Women of child bearing age undergoing treatment must not already be pregnant nor breast-feeding, and both a woman and her male partner must use effective forms of contraception (one for each person).
- Men undergoing treatment and their female partners must use effective forms of contraception (one for each person). Female partners of men undergoing treatment must not already be pregnant.

(Australian Government – Department of Health and Ageing)

Treatment Decisions

The decision to commence treatment is not straightforward. Treatment for hepatitis C is often debilitating, with severe side-effects (see table below) and no guarantee of efficacy (Harris et al 2006). Treatment involves a heavy time commitment, with monthly visits to a hospital or clinic for 6–12 months. Motivation, severity of side-effects, the impact of treatment on work and personal relationships, issues around drug and alcohol use all play a part in a person's willingness or ability to undertake antiviral treatment (McNally et al 2006). There is also the possibility of significant financial commitment (time lost from work, travel costs and costs of medication to control side effects).

Side-effects of antiviral therapy

While the side-effects of pegylated interferon are far less marked than for non-pegylated interferon, they are still present. Side-effects of interferon fall into the following categories:

- Systemic: flu-like symptoms including fever, headache, rigours and coughing, nausea, weight loss, diarrhoea, temporary hair loss, exacerbation of existing conditions such as diabetes
- Neurological: loss of concentration, loss of sensation, insomnia, visual and auditory loss (rare), exacerbation of epilepsy
- Psychological: anxiety, depression, irritability, psychosis
- Myelosuppression: low white blood cell count, thrombocytopenia
- Induction of autoimmunity: overactive thyroid, psoriasis or worsening of these
- Cardiac: arrhythmia, congestive failure
- Susceptibility to infection
- Haematological: haemolytic anaemia
- Respiratory: cough, breathlessness, pharyngitis, sinusitis
- Rash
- Embryonic development: possible birth defects

(National Hepatitis C Resource Manual 2001)

Given the potentially serious nature of some of the side-effects associated with treatment, it is important that those considering treatment are able to make a properly informed decision, and are adequately assessed for suitability. Once they are on treatment, patients require access to ongoing emotional support as well as management for side-effects.

Psychological side-effects of treatment can be a serious concern. The potential impact of treatment induced depression is an issue; some studies have estimated between 22% and 28% of people with untreated Hepatitis C are already suffering from depression (Dwight et al 2000).

There is an emerging body of Australian research about the psychological and social factors associated with decisions to take up treatment. *'Now, Later or Never, Challenges to hepatitis C treatment'* (McNally et al 2004) was the first study to explore a range of different perspectives on treatment: those of people with hepatitis C (currently and previously on treatment, and those who had never experienced treatment), general practitioners (GPs) and specialist physicians. This study showed that people's relationship to their doctor/specialist was critical in making the decision to start treatment. GPs play a critical role in testing and referring people for treatment, but face many decisions such as: when should the patient be referred? Does the patient have a pre-existing psychiatric condition that might be exacerbated by treatment? Will the patient have appropriate social support?

The 'Now, Later or Never' study also showed encouraging signs relating to more recent medical practice, whereby participants diagnosed in the past five years (31%) were more likely to have received treatment compared to those diagnosed more than five years ago (14%). A higher proportion of people diagnosed in the past 5 years were referred on within the first 6 months of diagnosis. Improved treatment efficacy was also rated by participants as the most important factor in influencing their decision to begin treatment. Side effects continue to be rated as the biggest challenge to adhering to treatment, while also being rated as the most important consideration for those who decide against treatment.

Access to Treatment and Care For Vietnamese and Cambodian Communities

People from CALD backgrounds often must deal with problems such as communication barriers, isolation and lack of understanding of, and from, the medical system (McNally & Dutertre 2004; MHSS 2007). They face poor access to information in their own language, little knowledge of the Australian healthcare system and poor awareness of their rights.

Equally, people most at risk of hepatitis C also experience a range of social disadvantages. These include unemployment, poor educational opportunities, lack of appropriate housing, the social stigma of injecting drug use, as well as inequalities in relation to access to primary health care and appropriate treatment by health care professionals (McNally et al 2006).

People from CALD backgrounds with hepatitis C may present with more advanced disease than Australian-born people. People with chronic hepatitis C born in a high prevalence country have considerably higher risk of cirrhosis compared with those born in low prevalence countries (Li et al 1997).

Particular ethnic and minority groups may have specific issues concerning treatment uptake. Ethnic and cultural beliefs about blood borne viruses, the meaning of blood and the nature of treatment and illness may have an impact on the decision to pursue treatment (Gifford et al 2003).

While Batey et al's (2002) data shows that 'patients with HCV are coming forward for treatment at similar rates for Australian born and non-Australian born populations', the number of injecting drug users (CALD and non-CALD communities) accessing treatment is very low (Matthews et al 2005).

Concepts of health and well-being for people of Vietnamese and Cambodian backgrounds

Cultural understandings around causes of illness

Buddhism has a central role in the way that people of Vietnamese or Cambodian ethnicity understand health and illness (Downs et al 1997). A person's well-being is linked with their relations with the natural environment, the social world, or the supernatural. Spirits can punish bad behaviour by visiting illness on a family, although illness will hit an innocent family member rather than the guilty person (Steven 2001). Therefore if a person does not respect social norms, they will bring shame and suffering on their family. A possible consequence of this in terms of accessing health care is that if a family feels shame as a result of a member's illness, they may resist publicising this illness through seeking treatment (Dhooper et al 1998).

Events and actions in previous and current lives are often seen as the cause of illness. The theory of karma has a particular influence on people's attitudes to illness and available treatment: if an individual attributes their illness to their karmic heritage, they will show resignation and acceptance of their suffering. In most Asian cultures, suffering is considered an inevitable part of human life. This may result in delay in seeking help (Dhooper et al 1998).

Health is considered a state of equilibrium, the positive result of 'being good' and 'doing good' (Frye 1991). Illness occurs when this equilibrium is disturbed, causing a state of internal 'bad wind'. Contributing to maintaining equilibrium is a delicate balance between 'hot' and 'cold' food or medicine.

The holistic approach to one's well-being described above does not necessarily contradict a more western approach, which looks at bacteria and viruses as the cause of ill-health. People from South-east Asia may believe in all or some of these theories and see them as complementary (Steven 2001).

A direct impact of this ability to marry traditional and western theories of causation can be a pragmatic mixing of traditional medicine and scientific western treatment. Many Vietnamese people, for instance, use traditional remedies in parallel with western-type health care – although they may be reluctant to reveal this to an Australian health care provider (MHSS 2007).

Sociological factors

Most Cambodian and Vietnamese people have come to Australia as refugees. They often carry the trauma of their experience and face many barriers to health care in a new culture with a different language and an unknown health system. Of all the refugees arriving from the former Indochina, Cambodians were possibly the most traumatised by war, starvation, genocide and the loss of family members – all events which have a continuing effect on the population's physical, social and mental health (Downs et al, 1997). In one epidemiological study of refugees in

California, Cambodians were found to be the least educated, sickest and most depressed of all migrant populations across all ages (Meinhardt et al, cited in Frye 1991). Cambodian women have shown high levels of post-traumatic stress disorder (PTSD) which can cause forgetfulness (amongst many other symptoms) and can lead to missed medical appointments or medications.

In her study of Cambodian refugees in Australia (2001), Christine Steven found that causes of illness were separated in pre- and post-migration factors. Pre-migration experiences were seen as the main causes of long-term medical conditions, with many people attributing their current health problems to 'prolonged starvation, untreated illness and injuries sustained during the Pol Pot period or while escaping Cambodia'.

Barriers to health care

While, as explained above, a Buddhist, holistic approach to well-being and a more medical, western-type approach can be complementary, a system of primary health care that reduces medical problems to physical causes without taking into consideration the balance of elements among body, mind and spirit may not be meaningful to people from South-east Asia (Downs et al 1997). Without meaning, they are unlikely to continue seeking such health care.

Barriers to health care include physical barriers (lack of private or public transport), economic barriers (such as difficulty in negotiating time off work without pay to attend appointments), language barriers, and emotional barriers (for instance the anxiety of going to a clinic). Down et al's study (1997) found that women, in particular, may experience a fear of doctors, medical procedures and hospitals.

Another barrier identified was a lack of understanding of western methods of diagnosis. It was found that extensive diagnostic procedures can often be interpreted as part of treatment, and the failure of these procedures to cure can cause a lack of trust in the physician's abilities (Dhooper et al 1998). This is very relevant in the case of hepatitis C treatment, where initial consultations and reviews can take place over several months before treatment is recommended.

Cambodian people have been identified in several studies as the Indochinese refugees at highest risk of stress-related health problems (Frye 1991, Dhooper 1998, D'Avanzo 1994). This high level of depression and the lack of English language are seen as key factors behind the lack of health care access for this community in the US (Frye 1991) and can be a contributor to alcohol and other drug use to calm stress, headaches and pain (D'Avanzo et al 1994).

Gifford et al's (2003) interviews with Cambodian and Laotian women with hepatitis C revealed common experiences of social isolation and depression amongst women from these communities. With low levels of English, many women spent their days at home when their husband was at work and their children at school, and reported lack of support and lack of knowledge about hepatitis C.

Current services

What is in place today to provide information and support about hepatitis C and treatment to these two communities?

Information and support can be obtained from:

- GPs
- Ethno-specific organisations, such as the Vietnamese Community in Australia – Victorian Chapter, the Australian Vietnamese Women’s Welfare Association, and the Cambodian Association of Victoria
- In-language media, such as SBS and 3ZZZ, and the printed press
- Websites – including information in languages other than English
- The hepatitis C Council of Victoria can provide information and advice in English
- The Multicultural Health and Support Service (MHSS) provides information and support for people of CALD backgrounds with BBV and STIs. Among the services provided are the Cambodian and Vietnamese hepatitis C helplines.
- Support agencies for people who inject drugs, such as the South East Alcohol and Drug Services (SEADS), Open Family, HealthWorks, Turning Point Community Health Centres

As for anti-viral treatment, combination therapy is listed as a highly specialised drug under Section 100 of the Pharmaceutical benefits Scheme (PBS). These drugs can only be prescribed by specialist hospital units and dispensed through pharmacies within hospitals that participate in the Highly Specialised Drug Program. Medical practitioners must be formally associated with specialist hospitals to prescribe these drugs as pharmaceutical benefit items.

Practically, this means that only specialist hospitals (and clinics set up by those hospitals) and some GPs involved in shared care programs can prescribe anti-viral treatment for hepatitis C. In order to obtain an appointment with a specialist service, people with hepatitis C must be referred by a GP. The trajectory into treatment therefore involves first a GP referral to a clinic, or to another GP who practices shared care. Another trajectory is that of people diagnosed through the hospital system and are referred to specialised services by the hospital itself.

Research Background

Objective

The objective of this study is to:

- Identify potential and perceived barriers to treatment for South East Asian (specifically Vietnamese and Cambodian) communities in Victoria
- Suggest appropriate hepatitis C treatment models for these communities throughout Victoria (based on the unique example of the Springvale Liver Clinic).

Research Questions

This project explores appropriate hepatitis C treatment models for CALD communities, which incorporate GPs, specialists and mainstream and culturally-specific support services throughout Victoria.

- How can access to anti-viral treatment for Vietnamese and Cambodian people with hepatitis C in Victoria be improved?
- What in the Springvale Liver Clinic model can influence or be used in other clinics with a CALD patient load?

Methodology

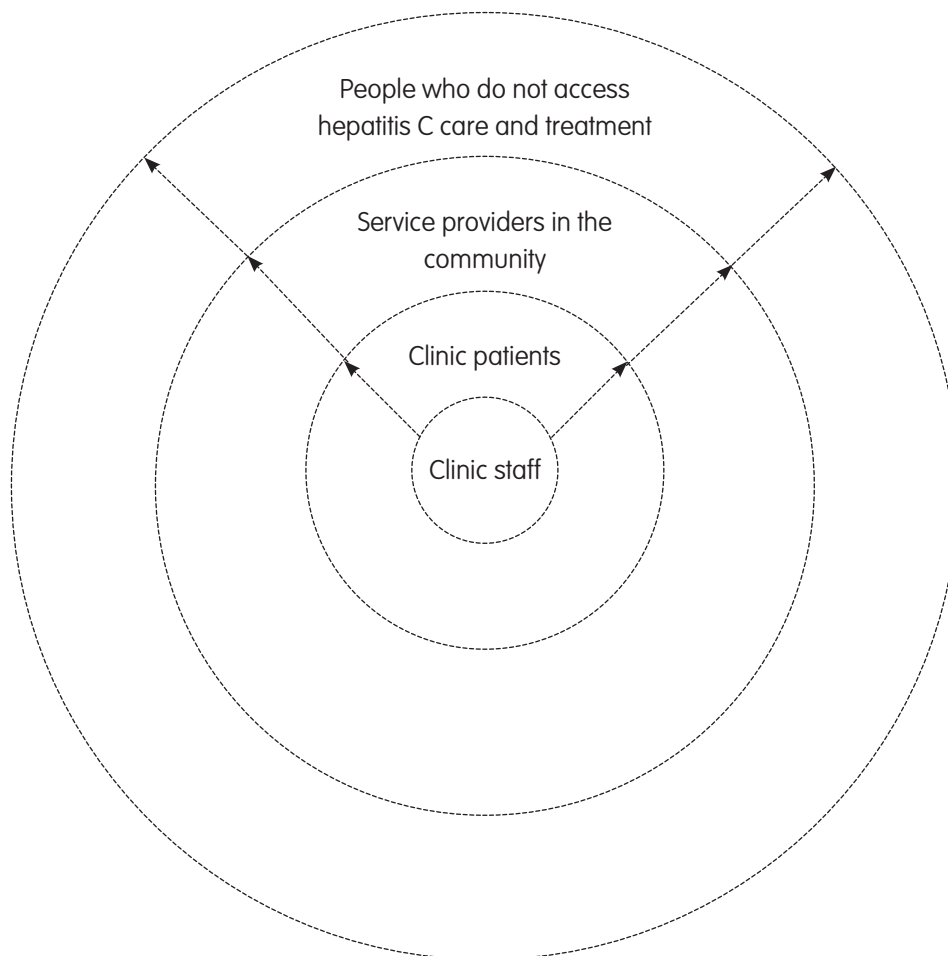
Why the Springvale Liver Clinic?

The Springvale Liver Clinic was selected for its uniqueness in Victoria: a satellite clinic of Monash Medical Centre, it is the only CALD-based liver clinic in the state. Established in 1999 in response to the high number of patients of Vietnamese and Cambodian background coming to Monash Medical Centre, its objective was to try to reach people with liver diseases in the area where they live and work and provide easier access to specialist care and treatment.

With its high CALD patient load (which includes South-East Asian patients, people from the Horn of Africa and the Middle-East), the clinic has become a 'victim of its own success'. Its waiting list is over three months long – similar to waiting lists across Victorian liver clinics. This is itself a sign of success with a population whose disadvantage in terms of accessing mainstream health care is well-known.

This study uses the model of the Springvale Liver Clinic as a starting point. We interviewed patients of the clinic to explore their experience of the clinic and treatment, and the challenges met along the way. We also asked staff at the clinic about issues around hepatitis C care and treatment for this group. In order to understand what may prevent others from going on treatment, we expanded our investigations outside the clinic's premises to local GPs and community workers in the Greater Dandenong area, concluding by interviewing people who do not access hepatitis C care in Dandenong, Springvale and Footscray.

The clinic's model gave us a point of reference to investigate factors of success when working with these two communities. Speaking with people outside the clinic itself allowed us to identify the barriers that may prevent them from accessing treatment and care.



We expand those findings to recommend steps that other liver clinics could follow to reach CALD communities. The suggested treatment models are outlined in the last section of this report.

Research methods

The study uses a qualitative methodological approach. Two groups of people with hepatitis C were interviewed: those receiving treatment and care from the Springvale Liver clinic, and those who have never experienced treatment. Because the decision to start treatment is made in collaboration with general practitioners and specialist physicians, and with the support of other service providers, we also interviewed GPs, staff of the liver clinic and community workers.

Consultations with community organisations, recruitment and interviews for the project occurred between November 2006 and May 2007.

The study involves two stages, one based at the Springvale Liver Clinic and one outside the clinic:

Stage 1 – Total of 32 interviews

- Semi-structured interviews with staff of the Springvale Liver Clinic (10) – four specialists, two nurse educators, one receptionist, one pharmacist, two interpreters. Interviews were conducted at Monash Medical Centre and at the

Springvale Liver Clinic. Information about the project was disseminated at the Springvale Liver Clinic through posters and cards, and with the support of the clinic's staff.

- Semi-structured interviews with Vietnamese and Cambodian patients of the clinic (17) – 8 Vietnamese + 9 Cambodian / 7 women + 10 men, aged 30 to 73 years old. Interviews were conducted at the Springvale Liver Clinic and in people's homes.
- Semi-structured interviews with referring GPs from the Springvale area (5). Interviews were conducted at their practice.

Stage 2 – Total of 22 interviews

- Semi-structured interviews with ethno-specific (Vietnamese and Cambodian) community workers & other service providers working with Vietnamese and Cambodian people with hepatitis C (6):
 - One Cambodian community worker specialising in BBV information
 - One Cambodian female community worker
 - Drug treatment therapy-prescribing GP involved in shared-care pilot program
 - Vietnamese D&A community worker (Footscray)
 - Vietnamese D&A community worker (Dandenong)
 - Antenatal & Sexual Health nurse working in Springvale and Dandenong

Interviews were conducted in interviewees' places of work.

- Semi-structured interviews with people with hepatitis C of Vietnamese and Cambodian background not receiving hepatitis C-specific health care in Springvale, Dandenong and Footscray (16). For recruitment outside the clinic, community workers and other service providers were contacted to disseminate information to Cambodian and Vietnamese service users.

Despite approaching ethno-specific workers and community organisations, we were unable to access people outside the Liver Clinic who did not identify as current or past drug users. Respondents were recruited through NSP and support programs for Injecting Drug Users.

Sixteen interviews were conducted. Thirteen of the people interviewed were Vietnamese, three were Cambodian. There were five women and eleven men. Interviews took place on agencies' premises, in the street and in cafes.

Interviews were conducted face-to-face with an interpreter when requested by the participants, which was in all but three cases for clinic patients. Only two of the injecting drug users interviewed required an interpreter.

Participants were reimbursed \$20 to cover costs they may have incurred by participating in the study. Ethics approval was obtained from La Trobe University Human Ethics Committee and Southern Health Human Research Ethics Committee.

Limitations

People interviewed for this research fall into two specific groups, and do not represent the entirety of people of Vietnamese and Cambodian background with hepatitis C. Therefore there are limitations to the extent to which the research findings can be extended to other people in these communities and to people of CALD background in general.

- People on treatment at the Springvale Liver Clinic have been through a double screening process. From a clinical point of view, they have been deemed psychologically stable enough to commit to treatment despite the risk of side-effects. They have also gone through a process of self-selection: people who are not committed to treatment for a variety of reasons 'drop out', either at the time of referral or around the first few consultations. Those for whom treatment is recommended, and who continue attending, are very motivated and determined to see the treatment through.

This means that we only interviewed people who had support, showed commitment and had faith in the process. We did not interview people with hepatitis C who may have been referred to the clinic but failed to attend appointments and had lost the connection with specialist services.

- Many people with hepatitis C who do not access treatment or specialised care are neither current nor past injecting drug users. It is a limitation of the research that we were only able to recruit through support programs and agencies working with drug users. This sample may not be generalised to the larger Vietnamese and Cambodian community, nor does it capture IDUs of Indochinese background who are not linked to NSPs or support agencies.

PART TWO
FINDINGS

Section 1

The Springvale Liver Clinic And Its Patients

Background On The Clinic

History Of The Clinic

The Springvale Liver Clinic was established in 1999 by Dr Anouk Dev and clinical nurse consultant Sherryne Warner in response to two factors:

- the high number of hepatitis C patients of CALD background attending Monash Medical Centre in Clayton
- the time patients were forced to invest in accessing treatment and care from the hospital

'We wanted something in the community (...) [At Monash] , you often have to wait two hours before you're seen, you have to wait for parking, then you have to queue another hour to get your pharmacy then another hour or half an hour to get your blood... it's half a day! And these people can't afford half a day.'

(Clinic Director)

The Springvale Liver Clinic is one of two satellite clinics of Monash Medical Centre³. Its premises are unique in Victoria: based in a Community Health Centre, the clinic caters for all ethnic groups in Springvale affected by a liver-related issue: hepatitis C, hepatitis B and other liver conditions: *'I don't know of any other community clinic at the moment that is mainly geared towards two ethnic groups.'* (Clinic Director)

The clinic is open from 2pm to 5pm every Wednesday afternoon. Patients are referred to Monash Medical Centre by their general practitioner, and the Medical Centre then makes an appointment in Springvale for those who live or work in the area. The clinic works by appointment only and is not a drop-in centre.

This satellite clinic receives very little funding from Monash Medical Centre and is solely funded by trials and bulk-billing: *'We see 350 patients a month outside the general clinic (...). We employ four nurses, two secretaries, lab staff...the hospital pays for three quarters of one nurse's salary.'* (Clinic Director)

This lack of resources was apparent throughout this research and was often referred to by staff as having a direct impact on the clinic's ability to take on more patients.

The patient has the choice to access treatment through the Section 100 funded path or by enrolling in a clinical trial. If a patient meets a range of specific criteria (which differ for each clinical trial), he/she is offered the option of going on therapy. Should they choose to participate in a clinical trial, they are then referred back to Monash Medical Centre's main liver clinic for treatment.

Staff

The clinic is run by Dr Anouk Dev, Deputy Director of the Department of Gastroenterology at Monash Medical Centre.

The clinic's staff comprises Dr Dev, four medical specialists and five registrars who work on a roster system. Three medical specialists are present during every clinic. The operations of the clinic are run by a secretary who works at all Monash Medical Centre clinics (Springvale, Cranbourne and Clayton). Pathology is conducted on site, and a pharmacy opened in October 2006 – sparing patients the need to go to Clayton to obtain their medication.

Due to the high number of patients whose preferred language is Vietnamese or Cambodian, two interpreters are on site for the full duration of the clinic.

Roles

Nurses: the key role of the nurses is to provide information at various stages of the patients' trajectory through the clinic (which may involve treatment and always involves monitoring of the illness). This information is provided through a holistic approach that includes *'looking at the social side of things, looking at psychological areas as well as the medical condition'*. As much as possible, all interactions between patients and nurses are conducted with an interpreter.

Within this information provision role, the nurses' intervention is articulated around three stages:

- Prior to the decision to go on treatment (pre-screening session)
- Immediately prior to treatment commencement (start-up session)
- During treatment (monitoring of side effects).

Pre-screenings sessions allow the nurses to discuss treatment options with patients, and to explain the option of accessing treatment through a clinical trial. It is also the opportunity to identify any issues that may make treatment difficult. These sessions also are a way to *'develop a rapport with people before they actually look at treatment, they get a sense of understanding of you as well as what they're going to be doing.'* (Nurse)

The nurse's role complements that of the specialist and *'frees up a bit of consultant time': 'It's very valuable to have that [pre-treatment] session because we allocate more time than the doctor can allow and really look at the social issues as well as employment and physical issues.'* (Nurse)

A start-up session takes place once the patient has agreed to treatment and involves supervising the first injection of pegylated interferon and answering patients' questions about possible side-effects. While, ideally, start-up sessions should be held at the Springvale clinic, in reality, due to staffing and financial constraints, they are held at Monash Medical Centre. In order to be held at Springvale, nurses would need to bring interpreters with them (the two on-site interpreters are too busy with clinic patients).

For the nurses themselves, their main intervention takes place around helping patients stay on treatment through side-effects management: *'We're very involved in that part. We try to encourage [patients] to stay on treatment but ultimately if they want to stop, it's their decision.'* (Nurse)

Specialist physicians: the specialists are the first medical staff that patients see at the clinic and will follow up on patients through every stage of their trajectory of treatment and care.

Initial consultations, before a decision is made about treatment, can involve up to 4 meetings between the specialist and a patient, from *'trying to build a picture of their illness and risk factors'*, through to ordering more tests, going through results and, in some cases, requesting a liver biopsy. The final of these initial consultations will involve a discussion about treatment options.

Subsequent consultations are arranged either to monitor treatment if treatment has commenced or to monitor liver function if the patient is not undertaking treatment.

Pharmacist: since October 2006, the Springvale Liver Clinic has been able to dispense medication on site, sparing patients the need to collect medication at Monash Medical Centre. The role of the pharmacist, however, is broader than the dispensation of medication. It includes discussing side-effects: *'It's in our interest and that of the patients' that we double check, because sometimes they may have concerns that they are not prepared to ask a doctor'*; and encouraging compliance: *'They may not be feeling well after taking the medicine and good reassurance would help them comply with medication'*.

Interpreters: the same Vietnamese and Cambodian interpreters are present at the clinic every week. They are available to support specialists and the secretary with any interpreting needs. Both have knowledge of medical terminology (one is a former medical student) and keep themselves up-to-date with liver conditions and treatment developments through websites and written information distributed at the clinic. The Vietnamese interpreter is a full-time staff of Monash Medical Centre, while the Cambodian interpreter works independently.

Both interpreters are very conscious of the limitations of their role and are cautious not to be seen as information providers themselves – a real risk due to their knowledge of hepatitis C and treatment, familiarity with the Liver Clinic, and ability to speak the patients' language. Patients sometimes will ask them questions following a consultation, such as: 'Do you see a lot of people with this problem?', or 'Do you think I will be the lucky one?'. Interpreters will refer questions to the relevant clinic staff.

Secretary: the secretary's role is central to the running of the clinic. She is the 'face' of the clinic and is in charge of the administration of appointments. As will be shown further in this study, this role is key to reducing drop-out rates. The secretary coordinates all liver clinics at Clayton, Cranbourne and Springvale and manages patients' records and appointments.

Patients

While most of the patients attending the Springvale Liver Clinic come from Springvale itself, some live in other suburbs of the Greater Dandenong area, mainly Keysborough and Noble Park. A small number come from Narre Warren (City of Casey).

The City of Greater Dandenong, in the south-east of Melbourne, is the most multicultural area in Victoria; according to the 2001 Census, 54.4% of its population was born overseas. Of those, 28.9% were born in South East Asia

(Vietnam, Cambodia or Laos). One in two people living in Greater Dandenong spoke a language other than English at home, and of those, 18.4% spoke Vietnamese.

While the 2006 census figures have not been fully analysed yet, early statistical releases show that more than 13,000 people speak Vietnamese at home in this area – by far the largest CALD community in the City of Greater Dandenong. Another 4,561 (2001 census) speak Cambodian – given that the whole Cambodian community in Melbourne in 2001 is only 9,000 people strong, this means that more than half the community lives in Greater Dandenong.

This high representation is reflected among the Springvale Liver Clinic patients: more than half are of Vietnamese or Cambodian background. Other community groups represented include Eastern Europeans, Pacific Islanders and Sudanese.

Patients of the liver clinic are aged 18 to 75 years old, split evenly between men and women.

Every Wednesday, an average of 30 patients are booked for an appointment, all ethnic backgrounds and health conditions combined. Some are at the beginning of the process, and come for initial consultations where tests are conducted to assess their need for anti-viral treatment. Others are on treatment and come for 'reviews'. Others who have completed treatment or for whom treatment was not recommended, come for monitoring of their condition.

A brief analysis of patient data from two clinics in July 2007 revealed that out of 59 patients:

- 34% came for Hepatitis C treatment or monitoring
- Less than 10% were initial consultations
- 65% were of Vietnamese or Cambodian ethnicity (others identified as Chinese, Australian, Sudanese, Italian, Chilean, Filipino and Austrian)
- 53% were men
- Patients were aged between 23 and 76 years old, with 78% aged 30 to 50.
- 20% of patients failed to attend their appointments, and another 12% cancelled
- 41% of patients requested an interpreter (55% of Vietnamese and Cambodian patients)

There are around 150 patients on anti-viral treatment for hepatitis C across all Monash Medical Centre Liver Clinics and across all ethnic groups (about 35 of those are Springvale Liver Clinic's patients of Vietnamese or Cambodian backgrounds). Another 200 are on treatment for hepatitis B. This does not include patients on drug trials.

See Appendix for map of trajectories into the Springvale Liver Clinic

Perceptions And Experiences Of The Liver Clinic

Staff

Semi-structured interviews were conducted with ten staff members of the Springvale Liver Clinic: the clinic director, three medical specialists, two nurse educators, the secretary, pharmacist and two interpreters. Interviews were conducted at Monash Medical Centre and at the Springvale Liver Clinic.

Questions focused on the following themes:

- What makes (or doesn't make) the clinic different from other services
- Challenges of working at the clinic
- Reflections on patients pre-, during and post-treatment
- Perceived barriers to treatment and care for people of Vietnamese and Cambodian backgrounds

Reflections on the clinic

When the clinic originally started, Dr Dev's vision was to set up a specialist centre that was approachable and non-threatening.

'I thought it would be a good thing to provide the same services in their community, where it's accessible, where they can go shopping (...), plus they wouldn't have to worry about the hassles of parking, pharmacy, blood, and the hassles of all of that, we would provide that service. (...) I wanted it to be a multi-disciplinary clinic where they'd feel comfortable, and would see the same faces all the time (...) that they could see that this is what we do, we're out there every week (...) if they need anything extra we can plug them back into the hospital, there's a variety of medical options...'

Some were concerned that the idea of placing a clinic in the heart of a community would not work, as patients may prefer the anonymity of 'coming out of the area, that small town philosophy or being able to go away so people don't know' (Nurse). This has proven not to be the case and from a slow start in 1999, the clinic 'has just got to a point where it is so full that trying to get somebody in there that's new, it's hard.' (Nurse)

All staff interviewed agreed that the clinic offered a good model and was 'working really well'. Some of the reasons mentioned were:

- The 'one-stop shop' model, where all necessary services (specialist, interpreters, pathology, pharmacy) are offered on site.
- The fact that it is located where the communities live, in an area familiar to them, with easy access.
- Non-medical factors that enhance the clinic's accessibility: *'Car park, things like that which are important to them. It's one clinic, there's one counter, and they don't have to worry about getting lost or getting somebody to bring them in because of the language barrier'* (Pharmacist). This somehow pragmatic approach did not surprise one of the specialists: *'I don't know whether the patients see a big difference other than the convenience. I'd be surprised if it made any difference to their perception of care.'*

- It is well accepted in the Vietnamese and Cambodian communities.
- The flexibility of the appointment format, as patients are allowed to transfer between different liver clinics of Monash Medical Centre if they are unable to come on certain days.
- The availability of interpreting services at the clinic was seen as a key element of the clinic's success.

Current challenges

1. Working with people of CALD backgrounds: the Clinic Director believes that *'this is a difficult population because you are totally reliant on interpreters.'*

While this is challenging, there was a perception among clinic staff that the provision of interpreters at the clinic was a sufficient measure to address this issue. The specialists in particular felt that a key feature of the clinic was that the quality of service was not compromised by the fact that patients were of a different cultural background:

'Having worked in different hospitals, I think the treatment of hepatitis C is pretty much standard across all the hospitals, we know that the patients who come to the Springvale Liver Clinic are Vietnamese and Cambodian, so we have interpreting services available at that clinic (...) So in that sense it doesn't matter where they go, because they'll get the same services.' (Medical staff)

'All of the patients are the same. I treat them according to my experience.'

Another important feature of the clinic identified by the Clinic Director as important to the cultural sensitivity of the practice was the fact that all four specialists were of CALD background themselves: Indian, Sri Lankan, Singaporean, and Cambodian. They will soon be joined by a Vietnamese gastroenterologist. *'Having some staff that has some ethnic similarities to the community I think helps. I think that's helped us a lot.'* (Clinic Director)

Cross-cultural training will be provided to registrars in 2008, discussing cultural diversity and how it impacts on the work at the clinic.

2. Waiting list: all agreed that the main challenge at the clinic was the increasing number of referrals from local GPs. While the referrals are welcome, the waiting list for appointments keeps growing. Recent changes in treatment criteria were seen as the main reason for this increase. *'The numbers have just gone through the roof, and to accommodate all these patients with the same three doctors, that is a huge challenge for us. The waiting list is blowing out.'* (Clinic Director)

3. Lack of resources was identified by several members of staff as a *'huge problem'*. The lack of secretaries to administer the clinics in particular was seen as an issue – currently, one secretary organises the five clinics of Monash Medical Centre.

'We have five clinics, and two secretaries to do that.' (Clinic Director)

The lack of time that medical staff could give to each consultation is a source of frustration: *'We do tend to overbook and we do have to rush but that's because we're limited with space, we're limited with numbers and the numbers just keep growing!'* (Clinic Director)

This was echoed by nurses and specialists alike:

'Patients may feel that they are being rushed through and sometimes they are.'
(Nurse)

Patients

Overall patients of the Springvale Liver Clinic did not have strong opinions about the service provided. There were few criticisms and more of a matter-of-fact acceptance that the service was available.

A practical option

The following quote summarises the feedback from patients about the clinic. Asked why he preferred the Springvale Liver Clinic to the clinic at Monash Medical Centre, this patient replied:

'There are three reasons: not having to wait is the first reason; the second reason is because it's close to home; and the third reason is that doctors are the same everywhere.'

Most patients preferred the clinic to hospital appointments for reasons of convenience: ease of parking, closeness to their home or workplace, and short waiting time.

'First it is close to home and secondly I don't have problems parking my car'

'Coming here is better than going to the hospital. 'It's close to home and there are no long queues.'

'It's convenient, and it's good for me. [It's] about 20 minute walk from my house to here, so it's good exercise.'

The general agreement about the hospital was that parking was rare, waiting time too long (*'two or three hours'*) and that it was difficult to find one's way around without good English.

It could be said that patients were not reflective about the clinic, their feedback being essentially pragmatic. These factors however do impact on patients' ability to attend appointments and should not be dismissed. They define the purpose of outreach services, and have a role to play in access to treatment and care. A case study conducted with Cambodian women (Downs et al, 1997) found that physical barriers such as having no car or no access to public transport and economic barriers, for instance, the inability of getting time off work without loss of pay, were key obstacles to accessing medical treatment of any kind for this group.

At the same time as appreciating the practicality of having the clinic within their community, patients did not feel that they had to compromise on the quality of care. They were confident that the quality of service received at the Springvale Liver Clinic was similar to that provided by the hospital.

'I think the service is the same (as at Monash Medical Centre) but it's close to my home, so I can come by myself. I don't need to ask a friend to take me or drive me.'

'The services provided by the hospital and here are almost the same. For me it's an issue of convenience'.

Some patients came to the Community Health Centre for other services, such as dental care, but for most, the only connection with the centre was their visit to the Liver Clinic. Their positive experience of the clinic was therefore not due to a familiarity with the setting, or the convenience of being able to 'group' several appointments in one visit.

Suggestions for improvement

It is important to be reminded that patients may have been reluctant to express dissatisfaction about the clinic despite assurances that the interviews would remain confidential. The absence of a 'culture of complaint' in these communities has also been demonstrated⁴. A community worker to the Springvale Community Health Centre reported receiving some negative comments about the lack of privacy at the clinic and sometimes feeling treated abruptly, but patients themselves did not report this to the researchers.

There were similarities between the few criticisms from patients and the challenges identified by the clinic staff: lack of time with specialists, language issues, and the need for longer opening hours.

The feedback on doctors was generally positive (*'It feels good when I see a doctor, doctors here work efficiently'*) although patients sometimes criticised the short duration of consultations:

'Some [doctors] check me quite carefully and do blood tests, some just look at me and say 'Fine!''

'Some doctors (...) are good but not very clear, they just tell you not to worry, but sometimes there are little problems you want to ask. I think they don't have time (...), lots of people waiting.'

Having the same interpreter every week was seen by some as an added convenience, while others did not mind one way or another. Patients generally trusted interpreters to respect their confidentiality.

'At the beginning I worry because they know my story, they know my disease, but later, I think there's no need to worry about that.'

There were few suggestions for improvement. A small number of respondents had concerns around confidentiality, suggesting that the waiting room be in a separate area and that staff did not mention their name in earshot of other patients. For these respondents, the hospital seemed a better option than a small clinic as they felt more anonymous there.

One patient mentioned that an evening service would be more suitable for those who work during the day. Many people in the Cambodian and Vietnamese communities work in casual, unskilled employment where they are not in a strong position to negotiate leave during work hours. This was mentioned by several patients as an issue.

Referring GPs

Five local GPs were interviewed for this study. All refer their patients with hepatitis C to the Springvale Liver Clinic.

Their relationship with the clinic and its medical staff was overall positive. The A5 referral form was simple to use, and the referral system (through faxing) was easy. All GPs felt that the follow-up from the clinic in regards to informing them of patients' attendance and progress was good (*'better than with most publicly operated clinics'*).

Suggestions for improvement focused on two areas:

1. An increase in the number of clinical updates 'with special input on the latest trends, general review of the current Hep C scene.'

'As GPs we need to be well-informed of the availability of new treatment, so we can in return inform our patients.'

This would help GPs respond to patients' questions that arise from their appointments with specialists at the liver clinic: *'My only complaint is that we don't get anything from the people we refer to, apart from the correspondence, so and so has come for review today, ALT is normal, etc. When they talk [to the patients] about this study, or this new drug, we don't know... And the patients come to us asking 'Do you know anything about this new drug?' and we don't!'*

At the same time as expressing a desire for more clinical information, some GPs admitted that they could *'hardly cope with the workload already'*, so their ability to attend clinical updates is likely to be limited.

2. Another area where improvement was suggested was in the administration of the clinic and the management of appointments. Two GPs expressed 'disappointment' with communication from the clinic and felt that phone calls from patients and from themselves were not returned.

'People are saying to me when they try to ring up there's always an answering machine and no one gets back to them. These are people who try to phone on their own (...).There's no one there to talk to patients when they ring up for queries.'

'There's a waiting list of three months, there's nothing we can do about that. But there should be someone ringing them back.'

All agreed that the waiting list was an issue: *'If the waiting list was a bit shorter that would be nice.'*

3. Another GP complained that having to re-refer patients when they failed to attend their clinic was extraneous.

'The problem with the clinic is that once they fall out you have to do a new referral, and each time you've got to fax it in, and it takes a bit of time for them to contact the patient sometimes.'

Patients' privacy at the Liver Clinic

How much do patients worry about indirectly disclosing their status by attending the clinic?

The waiting area is shared with the Community Health Centre, although on Wednesday afternoons it is mainly used by patients of the Liver Clinic. Those patients report to a separate counter, under a large 'Liver Clinic' sign translated in Cambodian and Vietnamese. For each patient, doctors take a file behind this counter and call the relevant person. The waiting area is visible from the street.

Staff members were divided on this issue, with a nurse noting that *'In the waiting room it's very clear who's on treatment and who's not, they come in with bags, the bags are labelled with basically what they're taking (...) So confidentiality in that sense tends not to – it's not really there even though they'd like it to be there.'*

A community worker based at the Springvale Community Health Centre reported that some patients had complained to her about what they perceived as a lack of privacy. *'I think in the future the liver clinic should have their own place, rather than be here. Sometimes people feel a bit shameful to sit in the front here. (...) we don't need to put a big sign, like 'This is a liver clinic', something like that.'*

Another clinic staff member saw the 'openness' of the waiting area as a bonus: *'You've got to understand, they're all having the same problem (...) It's like a fellow sufferer sharing their suffering (...) In fact they compare notes: 'Are you being treated this way? What are you given?''*

When raised with patients, the issue of privacy (or lack of it) at the clinic, and more specifically of the waiting area, revealed surprising findings. The visibility of the waiting area led the researchers to suspect that some patients may feel nervous about the lack of privacy of their appointments. Presence in the waiting area on Wednesday afternoon is a tacit admission of having *'liver disease'*. And indeed, some patients were nervous about this, saying that if they saw someone they knew, they would *'hide'*, or reporting that they generally waited in the street until the time of their appointment in order to minimise their time inside the waiting area. Others recounted incidents of acquaintances being embarrassed by an inadvertent encounter.

'The other day I ran into a member of my wife's family in the clinic, so I know what that person was there for (...) Then they say: 'No no, I didn't go here for hepatitis, I just go for general check-up..''

'I have a friend who comes here, and when he sees me, he doesn't want to talk to me, or he wants to get away from me (...) Probably he doesn't want me to know he has this disease.'

Overall however, most patients' responses to questions about the clinic's privacy refuted any notion that this may be an issue.

'I don't care because anyone who comes here, they have a problem.'

'Initially yes I worry that someone will walk past and they may know that I have hepatitis, but later I feel that's fine, don't worry.'

'If they ask me why I'm here I will tell them I've got hepatitis C, it's nothing to hide, it's not a sin!'

Some even used their time in the waiting area to make connections and discuss their illness, thereby re-defining the waiting room as a safe space to discuss this sensitive issue.

'When I come here to see the doctor I meet some other friends (we meet here and we become friends here) and we share information about this disease (...) I think it's good because I can find out what side effects they have and we share information about this.'

'It makes me happy if I see a fellow Cambodian who comes here, in the same situation. We socialise, we tell one another about this disease.'

Several patients used their time in the waiting area to look at posters and flyers in their language.

People With Hepatitis C Who Access Treatment and Care – The Example of Patients of the Springvale Liver Clinic

Who Comes To The Springvale Liver Clinic?

This information was collected through interviews with the Liver Clinic staff.

The majority of patients with hepatitis C come to the clinic referred by their GP, although some have been diagnosed and referred through the hospital system.

Amongst the patients groups at the Springvale Liver Clinic, people of Vietnamese and Cambodian background are *'the oldest ones, like 30 – 40 plus.'*

Few are injecting drug users: *'For a lot of the [older age group], it has to do with mass vaccination programs and that's why we're seeing the 50 year olds. But we still do see injecting drug users. A lot of the time they're not on-going users but they've used in the past. (...) Of the younger ones, quite a proportion [of infection] would be from intravenous drug use'* (Specialist).

The few young injecting drug users who come to the clinic are *'20–25 years old, sometimes in couple'*.

Injecting drug users were identified by the Clinic Director as the main group that is being missed by the clinic: *'I think their lives are so erratic, treatment is the last thing on their minds (...) I think these guys are just trying to make do and coming to a clinic (...) I don't think they want to do it.'*

That many patients were not injecting drug users has presented a particular challenge for the nurses: they found that much of the translated written material available was focused on injecting drug use practices, and therefore not relevant to the older patient group. As a result, they wrote their own material, which they see as more *'culturally correct'*.

Asked if they had noticed any cultural differences between the Vietnamese and Cambodian communities, the clinic staff mentioned differences in levels of literacy

and the importance placed on confidentiality. Vietnamese patients are likely to have been settled in Australia for a longer period of time, and to have a higher level of English literacy. They are also better networked, and have access to GPs from their language background (which in turn helps their access to information, medical assistance and treatment).

Cambodian people are more recently arrived, may be less fluent in English, and due to the history of political persecution in Cambodia – where most educated people were killed by the Pol Pot regime – have little education even in the Cambodian language. One staff member noted that Cambodian people are more secretive and more isolated, and concerned about ‘gossip’⁵: *‘They don’t really want people to know. Vietnamese people tend to be a little bit more open about what’s happening.’*

‘With the Cambodians, trust is a major, major problem.’ (Clinic director)

Some discussions are more culturally-sensitive than others, as observed by the Clinic Director during consultations: *‘I find the time where I have to spend most time on cultural issues is when I am trying to get a liver biopsy out of a person, because I know the reasons for them not having one are different from a Caucasian (...) and the other thing is when they’re starting on treatment you need to spend a little bit more time talking about things like the heat, and the liver...’* (Clinic Director)

Interviews With Patients

Seventeen hepatitis C patients of the Springvale Liver Clinic were interviewed for this study. Below is a break down of patients’ characteristics:

- 10 men and 7 women
- 9 Cambodian and 8 Vietnamese
- Aged between 30 and 72 years old
- In Australia for a period ranging from 4 to 29 years (10 had been in Australian for more than ten years)
- Living in suburbs between Clayton and Dandenong, including Keysborough, Noble Park, and Springvale
- Family Situation: 14 lived with spouse and children, two with spouse only, and one on his own
- 9 were not working; the remaining 8 worked, mainly in factory work and tailoring

Interviews were conducted at the clinic or in people’s homes. Only two people did not require an interpreter for the interview.

Diagnosis

None of the patients interviewed knew how they became infected.

‘When I was tested and my results said I had hepatitis, I asked myself: ‘Why?’. I am unsure how I got it.’

‘I don’t know how I catch this disease.’

Most suspected that infection occurred through mass immunisation campaigns in their country of birth – a suggestion often first made by GPs and medical staff at the clinic that made sense to them.

⁵ This was also a finding of Gifford et al 2003

'I know that I am infected with this disease because under Pol Pot they have very few needles and they use the same needle again and again'

'Use the same needle, sterilise it with water and inject from one to another.'

For two patients, the diagnosis was particularly confusing as a medical check-up on arrival in Australia did not reveal the virus. The positive result came a few years later.

The link between alcohol or food hygiene and hepatitis C was unclear, and a few patients thought they may have become infected through drinking (*'When I was in the army I was drinking too much'*) or unhygienic eating practices under the Pol Pot dictatorship: *'I don't know for sure, because people like me, during the communist regime, we had to go to the countryside, there was nothing to eat, we ate things from the forest, so maybe I got the virus from there.'*

This is in accordance with previous findings that knowledge of risk factors is directly related to ethnicity: a person of South East Asian background is less likely to identify practices that could expose them to HCV than a Caucasian person (Dev et al 2004). In Dev et al's study, South East Asian patients stated ingestion of contaminated food, contact with infected household members and poor hygiene as possible causes of transmission.

GPs were the most common source of diagnosis: people would feel unwell and their family doctor would order blood tests, including hepatitis B and C. A few had been diagnosed through the hospital system when admitted for surgical operations.

Patients' reactions varied widely on learning they had hepatitis C, from extreme concern to a more relaxed attitude.

The first reaction was often 'worry':

'I worry about it because if hepatitis C stays in my body for quite a long time it makes me have cancer.'

'I worry about it because it is a concern to my health and it will affect the lives of some people who are in contact with me.'

'Some people have hep C, even liver cancer, and they still drink, they don't care. But I worry about myself because I want to be healthy.'

'Also I feel quite sad, because I don't want to die soon.'

However, on understanding more about the disease, some felt less concerned: 'In Cambodia I asked the doctor and he told me that this is just a normal disease, to just keep an eye on watching your food, don't drink alcohol, it will be fine because it doesn't kill you they said.'

Others were not concerned, either because of a fatalistic attitude to life or because of a conscious decision to be positive:

'I believe in God so I don't worry. That's my life, that's my destiny.'

'You know, if death comes to someone, it's destiny, you cannot change it.'

'Worrying too much is not good! The people I know who get sick it's because they worry too much.'

'The first reason [why I don't worry] is that I am in Australia and I know that I can go to the doctor, either at Monash or my family doctor, who can provide me with good treatment; the second reason is that it won't make me any better to be worried. I believe that if I cannot be treated here in Australia I cannot be treated anywhere in the world.'

Patients all reported feeling unwell due to their hepatitis C: *'It makes me tired almost every time, every day'; 'Having the disease makes me tired all the time'; 'I feel exhausted and very heavy in the forehead.'*

Disclosure

All patients had told at least their immediate family, mainly out of a desire to protect them from possible contamination:

'I can't hide it from them, I want them to be cautious.'

'I did tell people, but not everyone. I told my family, and some people close to me, I tell them to be careful if I'm bleeding or whatever because I don't want to make trouble for other people.'

Telling people outside the close family circle was more complex, and few were open about their infection: *'There is no need to tell friends, it is not a custom in Asian communities to share personal information.'*

A few patients had no qualms telling others - although they were the exception rather than the rule: *'Of course I told my brothers and sisters and my husband. And some friends, they saw me at the clinic and I tell them.'*

The overwhelming majority of patients were nervous about others knowing because they feared negative reactions: *'English friends, they don't care. I tell them, they say 'Never mind'. But for the Chinese or Vietnamese, if they hear that you are sick, they're scared. And they are not very friendly, you know.'*

Reflections on Treatment

Staff Perspectives

Treatment is the principal reason why patients come to the clinic, even though it will not always be the outcome of the referral. Regardless of how the referral was presented to them by their GP, patients do not attend the clinic expecting monitoring of their condition, but with the belief that they will be able to access treatment.

'[GPs] don't really tell patients one way or another, they just kind of say 'It's for management of your hepatitis.' (Specialist)

'Most of the time I see patients either who have been diagnosed with hepatitis C and they want to start treatment, or they want to discuss treatment options with a specialist.' (Medical Staff)

The people who attend the clinic are generally highly motivated in regards to treatment:

'One thing with this population is they want treatment and they want it now.'
(Clinic Director)

'Once they know about the rate of cirrhosis and liver cancer, they often want to just get on: "How do I get started?"' (Specialist)

Recommending treatment

Treatment today is more accessible than ever, with the removal in 2006 of criteria that linked treatment access to serological markers: *'Now it's very much a matter of: 'If they've got hepatitis C, they are all potentially eligible for treatment'* (Specialist). For the medical staff, it becomes a matter of assessing social and psychological factors, more than clinical factors: *'Alcohol, drugs, psychiatric issues and what kind of supports they have, and also whether they're likely to be able to cope with the treatment and whether they have the support – you know, whether they live in stable accommodation and are they based in Melbourne or half the time they're flitting between the country [of origin] and here and stuff.'* (Specialist)

While treatment is available, it is not always recommended, and it is one of the nurses' roles to assess the patient's suitability. This is not a unilateral assessment, but a discussion with the patient: *'I encourage the choice, so you give them options, it's not an easy decision to make and it's something they need to consider at the time (...). There are people that you sometimes think you'd like to talk them out of treatment because maybe it is not the right time for them at the moment. But ultimately it's their choice as individuals – it's their decision to make.'* (Nurse)

This decision-making process is influenced by the negative impression patients often have about treatment, based on word-of-mouth in their community (*'They're put off by their friends' experience and tend not to access treatment'*). To address this, staff provide information and education, in the patients' language, that will allow them to make an informed decision: *'Most people, once you actually start talking to them about the benefits of being on treatment or you talk about the positive aspects of it, they tend to have a better understanding, but it's very easy to take the negative side.'* (Nurse)

Section 100 or trial?

Patients are offered the possibility to go on a clinical trial instead of S100 treatment. Trials present the advantage of not having a waiting period (the recruitment periods are often short, and trials are managed by staff at the Clayton Monash Medical Centre). Some trials are shorter than the 6 or 12 month course of anti-viral drugs prescribed under the Pharmaceutical Benefit Scheme. However, patients' willingness to go on trial varies: *'The concept of a trial means so many different things to different people. For some people, they're being used as guinea pigs. For other people it's a chance to access treatment that may be better than the standard treatment, and certainly for people who are genotype 1 where the treatment rates aren't so high, especially with the newer things that we have in trial that we know are better, they may want them'* (Clinic Director)

The medical staff at the clinic strongly recommend trial:

'Our primary goal is to get patients into trials. We're an academic unit.'
(Clinic Director)

'Why not? Because then we learn more about the disease.' (Specialist)

'I always mention to them that on trial they will be helping the future generation, and of course the people, and maybe even themselves.' (Specialist)

Role of GPs

By all accounts, the role of referring GPs was seen by the clinic staff as crucial to treatment access. *'GPs that work in those communities have a high level of vigilance to check for hepatitis C in patients that come through the door'*. The relationship between local GPs and the clinic extends beyond the point of referral, as the nursing staff is available to answer GP queries about their patients: *'We do get GPs that ring us to ask about side-effects or if they have a patient that has been considering treatment (...). So we have a lot of phone calls from our GPs.'*

Due to their central role, on-going GP education was seen as essential by all the specialists. One of them commented that it was *'the only way to increase treatment'*. The objective of such a program would be to *'inform them about the services available and raise their awareness to think about hepatitis C in every Asian patient that walks through the door.'*

'The GPs are aware of us, but sometimes they are not aware of the new developments, such as the removal of liver biopsy as a pre-requisite for treatment.(...) Sometimes GPs equate normal liver function test to no cirrhosis (...). That's not right, because people can have cirrhosis and yet have a normal liver function test.' (Specialist)

Another specialist thought that *'educating GPs more so that they can target their patients more is very important. Patients are likely to rely on their GP to tell them when is a good time [for treatment].'*

It was acknowledged however that any education program needed to take into account GPs' availability: *'Unfortunately, GPs in the Springvale area are mainly mono GPs (...) or they're a husband and wife team. And they are so flat out.'*

Staff's perception of patients' knowledge

'I would have hoped to have said they would know a fair bit but generally speaking, no they don't. They know very little.' (Nurse)

It was generally believed by the clinic staff that patient arrived at the clinic with little understanding of hepatitis C and a great deal of confusion around the difference between hepatitis C and B. They know that it is a disease of the liver, and know *'hepatitis is a sort of swelling of the liver.'* (Interpreter)

The medical staff at the clinic believed that patients are very clear that hepatitis C is not related to HIV: *'There doesn't seem to be an association with HIV, it's probably more with hep B (...), there's a very definite confusion between the two.'* (Nurse)

As for treatment, even though they have been referred by a GP who already provided some information, the level of knowledge is low: *'Some of them say they didn't know that there is treatment. Some of them do know through their relatives and friends. So it's 50/50 maybe: 50 know there is treatment, 50 don't know.'* (Specialist)

Knowledge of side effects

Side-effects feature high on the list of information that is known to patients, as it seems the main information passed on by the community word-of-mouth (see *'Barriers'*). *'The GP and specialist might tell patients one thing but they've listened to people in their community speak about this particular virus so they have a different perception.'*

Whether patients know about side-effects before they attend the clinic, or enquire once treatment has been mentioned to them as an option, is unclear. They are also informed about side-effects through the written pamphlets and fact sheets provided by the clinic and through face-to-face discussion with specialists and nurses.

Managing side-effects is a task shared by nurses and specialists physicians. Patients concerns can be articulated around two themes: the impact of side-effects on their ability to work, and the impact on their physical appearance.

'If they're looking at treatment they're mainly looking at whether or not they can work (...). Most people that we tend to see, work may not always be consistent so it's very important to them.' (Nurse)

'I think employment is a big issue. A lot of them are in very low paid jobs, they're working you know, from dawn till late in the evenings and for them to come to clinic, it's quite a hassle, you know. I don't know if their employers are always that understanding.' (Specialist)

This is of particular importance for a population that is often living close to the poverty line: *'A lot of them are just surviving on the slimmest of budgets (...) some of them are earning four dollars an hour.'* (Clinic Director)

Other concerns regard the physical aspect of treatment, such as weight loss, fatigue or hair loss; *'Certainly for the Cambodian community, they care very much if they don't look right (...) The one that seems to worry them mainly is the hair falling out.'* (Nurse)

Specialists are reluctant to *'dose-adjust'* as *'you pay the price with lower response rates'*, but they will always discuss side-effects with their patients: *'Sometimes it's just a matter of reassuring them and trying to get them through without any extra medication or dose adjusting.'* (Specialist)

Treatment 'compliance'

Staff at the clinic had different interpretations on the level of patient compliance to doctor's instructions and to treatment.

Some found that patients from these particular cultural groups showed a high level of compliance, from the first referral (*'they just turn up at the clinic because they've been told to'*) to the way they followed treatment: *'They tend to follow instructions extremely well (...) they tend to complain less about symptoms.'* (Specialist)

The language barriers and process of using interpreters contributed to this lack of questioning. A specialist suggested that they may find *'Asking questions just too hard, [they think] I'll just say Yes or No and just get on with it.'*

What for some appeared as a high level of compliance was seen by others as a way *'not to argue or want to change things. They're more wanting to please rather than ask questions'* (Nurse); or as a reaction to the amount of information they need to absorb: *'I always say do you understand that, do you have any questions? But they're so stunned, they don't have any questions.'*(Clinic Director)

Another aspect of this *'compliance'* regarding symptoms and side effects was explained by a staff member as a fear of being taken off treatment: *'They seem to have less [side effects] because they don't report them (...) Because this is an expensive program (...) they are always worried about what if they can't make it? Like the doctor may decide 'You've got too many issues'. But these people have got a certain condition and they want to cure it or fix it.'* (Pharmacist)

Patient compliance was also related to the fact that the treatment has a *'timeframe'* *'They are ready to trade off 12 months of their life for a better quality of life.'* (Pharmacist)

Case Study 1 – ‘Waiting For Death’

Tran has been in Australia for ten years and ill for most of that time. He spends many hours a day wrapped in a blanket in his lounge room, watching cable on a large plasma TV, unable to work and too exhausted to leave his house.

Tran was told he had hepatitis C at the same time as being diagnosed with liver cancer. His GP at the time referred him to hospital for tests on his swollen liver: *‘When I first went and got the X-ray and ultrasound, they found the four lumps. The first one was very big’.*

This was almost ten years ago. Tran remembers that at the time, the specialist from a large city hospital told him to *‘go home and wait for death’* – which he did: *‘Because I could not find any treatments or any cure for that, so of course I listened to them, I came home and waited for death.’*

But information he heard on the radio changed his life: *‘Then one day I listened to SBS Radio in Vietnamese, which mentions a man who helped his wife to get over the cancer through yoga and also through diet. Then I telephoned that man and that man sends me a book, you know, explaining things that he took part in. I took on exercise and yoga and diet for three years. Then when I got an ultrasound again, the three small lumps seem to become unimportant. So that’s why they propose operation to remove the big one, then they did remove it.’*

Tran lifts his track suit top and shows the large scar along the right side of his abdomen, explaining that he is now missing about a third of his liver.

By this time, Tran had transferred to Monash Medical Centre, where the operation was conducted. *‘And then that doctor proposed treatment to get the hepatitis C virus to become dormant.’*

Tran undertook a 12 month course of anti-viral treatment, which was successful. The side-effects created mood swings that are lingering on despite the end of the treatment. *‘The other day I went out on the streets and see two people have a fight, but I stand there crying even though it was none of my business. It causes emotional change. I can’t control myself.’*

Tran speaks highly of Monash Medical Centre and the Springvale Liver Clinic, who gave him hope when he thought there was none. *‘I feel really honoured – it is great to be treated that way, and receive the treatment. So that’s – what I’ve received is very very treasured already.’*

Ever since he started receiving care through the clinic, Tran feels he has been able to ask any question that was on his mind. His main query, though, is one that remains unanswered: *‘The only question I want an answer from them is how long I can survive.’*

Patients' Perspectives About Treatment

Of the seventeen patients interviewed, 14 had been or were currently on treatment (including 4 who had completed treatment and one who had stopped), 3 were not on treatment, either because they did not want to be or because treatment had not been recommended at this stage.

Obtaining information about treatment

There were several preferred sources of information about hepatitis C and treatment options:

- Patients often referred to GPs as the preferred source of information, as talking to a GP allowed for face-to-face interaction, often in the patients' language. This is particularly true of Vietnamese patients as they have access to GPs who speak Vietnamese, whereas Cambodian GPs are rare.
- *'I want the doctor to answer me face-to-face and explain to me clearly. A friend can (...) provide information to me, that's okay, but I prefer to have explanation from the doctor.'*
- Written information (in their language) was favoured by some due to its privacy. *'I like written information, so that I can read and think about it and how that disease affects [the] individual'.*
- *'Every time the [clinic] gives me anything I go home and read it carefully.'*
- Written information was not everyone's choice: *'Too much written information, I can't remember it all.'*
- Radio was liked by some and distrusted by others: *'Sometimes news and radio is not appropriate, because it is a specific area. I think the doctor is better.'* A female patient of Vietnamese background disagreed with this: *'When [the radio] talks about this problem, I sit and just listen. They talk about it on SBS.'*
- One Cambodian woman mentioned the playgroup she attended with her child as the best source of information for her. This was a Cambodian playgroup run from the Springvale Community Health Centre.

Some of the patients interviewed did not see the Liver Clinic as a place to get information. One patient commented that the clinic was *'just for checking'* – if he had a question, he would ask his GP. Another patient explained: *'When I come to the specialist doctor I want to know the results, how the results are going.'*

For others however, the information provided by the clinic about treatment and side effects was the first – and only – information they ever obtained related to hepatitis C.

'I couldn't get information from anywhere until they referred me to the clinic.'

'I got all the questions, all the queries answered because it's a good thing to be here, I mean compare Australia [to] Vietnam, here, whenever I got any queries, the questions are answered or explained.'

The role of community word-of-mouth

Dev's study of South East Asian people with hepatitis C (2004) found that in ethnic minorities information is often circulated by word of mouth. Information provided by liver clinics and GPs is then circulated into the wider community, 'including relatives and friends both in the local community and abroad'.

None of the patients interviewed at the Springvale Liver Clinic mentioned friends and word-of-mouth in direct response to open questions about sources of information. However, it was obvious through other responses that they obtained and trusted information circulated at the community level:

'I have a friend who has hepatitis C and they die because of [it], because it becomes cancer. And also I have a friend who has hepatitis C, but they have injection, and they can control the disease.'

'I have a friend, I discussed with him whether to have treatment. He says he doesn't want to have treatment because of side effects. (...) But another friend said that with the treatment, it cures the disease. So I wanted to cure my disease.'

'I want to tell people [about having hepatitis C] in case they know something about the medicine and they can help me.'

The 'community grapevine' can be a deterrent to treatment access, but can also be used as a way to disseminate positive information about treatment and success rate, as shown in the following example, from a patient who has successfully completed treatment: *'I told many Cambodian people that if you got hepatitis C you have to take medicine. If someone come and ask me, I tell it like that.'* Talking to an elderly Cambodian woman at the swimming pool, he reports saying: *'You must go, you see me, before I'm skinny, now you see, I'm strong'.*

More than half the patients interviewed felt that they had enough information to make a decision about treatment. A small number felt that they did not have enough information and did not know where to access information in their own language.

Making a decision about treatment

All patients interviewed felt that they had made a considered decision about treatment. The factors that influenced their decision differed from person to person. The reason most commonly cited was wanting to make the most of treatment availability in Australia – as opposed to country of origin:

'When you live here, you must let them treat you because it is lucky. I came to this country and I can have treatment'

'In Australia, they can access western medication or the doctor (...) My husband told me that in Australia doctors are very good.'

'My feeling is that the majority of people from my community want to get treatment, because in our homeland they don't have such a service.'

Other reasons cited included:

- A sense of responsibility about one's own well-being: *'Because I have a disease I have to go to a doctor, it's my responsibility to seek treatment. Whatever one has to do, he or she has to do it the best way possible.'*

- Trust in medical advice: *'They are specialists and if they tell me to do something I must cooperate'*
- Feeling that their health required it: *'[My] ALT kept rising and I told the GP I was exhausted (...). That's why I asked the GP to write the letter to request treatment.'*
'If I did not decide to have treatment it may become cancer'

Some patients reported that the decision to go on treatment was difficult:

'Nothing is perfect, it's 50/50, so I went over it in my head and then I decided myself. The 50% to make me do it were: I have a chance to be healthy, if I don't try it I'll never get anything and if I get scared I can stop anytime. And I don't need to pay anything. So I decide to do it.'

'Making a decision is very hard. I can tell you it is as hard as the disease itself.'

While for others, there was no hesitation:

'I said; OK, I sign. And the doctor said: Why don't you discuss with your wife. I said: It's my life, not my wife's.'

The decision was generally made after receiving information from the clinic, and consulting with family and sometimes friends: *'I ask the doctor at the liver clinic: 'Which way is better?' and then I asked the same thing to my family doctor. Then I go home and talk to my wife, and I decide to go on treatment'*

All the patients remembered being told about side-effects before starting treatment.

Experience of treatment

The patients interviewed at the Springvale Liver Clinic experienced a range of side-effects, from mild to severe, including: fatigue, loss of appetite, loss of weight, hair loss, mood swings, irritability and depression.

'I lose weight, 10 kilos.'

'Before treatment I knew that there would be side effects, but after I been on treatment for four weeks and I feel that I have difficulty and especially I feel depressed sometimes because I can't do anything.'

'The tablet [gives me] a bad taste in mouth, especially when I drink water I don't taste the taste of the water.'

'Being on treatment makes me shy, more shy. And sometimes I feel too shy to go out and be in a crowd.'

'When I was on treatment it made me lose my hair.'

'I had a lot of trouble. I get fever every week, when I have the injection I get fever. And I'm hurting, and I drink a lot of water and then I don't have room for my food, and I get skinnier and skinnier.'

Despite these side effects, patients expressed no regret about being on treatment. Hearing about her side effects, a clinic's specialist asked this woman if she wanted to remain on treatment: *'I said, 'Yes, I want to have it all' (...) because I want to cure it so I want to continue on that medication.'*

This determination was echoed by others:

'I'm happy because I have medication for the treatment. I want to have a cure – I want to be cured.'

'No one can be happy to be on treatment, but we have to, no choice.'

'In March, if my condition doesn't improve, then I must stop. I think, then what happens? What happens to my liver?'

In cases where treatment had not been recommended yet, this could be a source of great frustration: *'I want it more than anything else on earth (...) And I'm just thinking why do you wait until the last day? I think the earlier it is, the better. I want to get treatment as early as possible.'*

Patients put their faith in anti-viral treatment over traditional medicine

Many patients with hepatitis C favour natural or herbal remedies (McNally et al 2004). The kinds of complementary therapies most commonly used by people with hepatitis C include liver-cleansing diets, naturopathic diets, and herbal or homeopathic treatments.

Dev's research with GPs working with CALD patients with hepatitis C (2002) found that *'In treating patients from non-English speaking background frustration was expressed that many patients preferred alternative therapies and would not see a specialist in western medicine'*. This was also a finding of the Gifford et al's (2003) interviews with Cambodian and Laotian women with hepatitis C. The study found that around half of the Cambodian women interviewed had used Chinese medicine, particularly before being diagnosed with hepatitis C, when they felt unwell without knowing the cause. Some were receiving the herbs directly from Cambodia. All had stopped taking them, either because they weren't working or because they feared it may interfere with western medications they were taking.

Ethno-specific community workers thought that many people in their community used traditional medicine, which they imported from Cambodia and Vietnam, or bought there and brought back. They will try traditional medicine before turning to western medicine.

'[Cambodian] people in Australia, they think that western medicine is good for them, but sometimes they think it is expensive (...). That's why they decide to go to their own country, to find some traditional healer who can help them. Traditional medicine is especially popular for people coming from rural areas, from generation to generation.' (Cambodian worker)

Asked about this, 14 out of 17 of the patients interviewed denied using traditional medicine for the liver or for any other illness: *'I don't know anything about traditional medicine, I only know about medication provided by a script.'*

Responses varied from a simple explanation to adamant denial. For some, not taking Chinese remedies was based on practical considerations: *'If I stayed in my country I would use traditional medicine, like herbs. But not in here, because here I can't find the herbs I need. [Also], western medication is quicker.'*

Some patients were particularly worried about the risks associated with combining traditional medicine and western medication: *'Because when you mix treatments you don't know which is complementary, which are contradictory, that's why we don't know, you know, it may become dangerous. My older sister, and my father also get [liver] cancer. Because my sister lives in Vietnam now, she's quite wealthy, she got money, so she go through treatments, use Interferon and also mix it up with Chinese old traditional methods – I mean everything, you know, to survive – to live, but actually she died already. She just died.'*

'I wouldn't dare. I would be scared because taking different types of medication would cause some impact or something.'

This was echoed by medical staff at the clinic: *'I've got nothing against it, except when they are taking our medication, I advise them not to take them because of the risk of interaction'.*

Three of the patients interviewed admitted to having used Chinese herbal medicine in the past: one who did not want anti-viral treatment because he felt well, another because he had finished the treatment and wanted to maintain his good health: *'I told the doctor after all I wasn't on any treatment at all, so could I try the Chinese medicine and the doctor agrees because it doesn't hurt to try new things.'*

The third, a Cambodian woman used traditional medicine while in Cambodia before going on treatment. *'A friend told me that Chinese medicine was good for hepatitis C' (...)* *I wanted Chinese medicine to kill all the virus'.* As soon as she had the opportunity to access anti-viral treatment in Australia she stopped taking the traditional remedies.

It is possible that patients who come to the clinic for western-type treatment and are committed to the process are those who have placed their faith in western medicine over traditional therapies. The clinic's pharmacist commented that *'most probably culturally they are seeking traditional medicines, so it's a big step for them to move to a western medicine modern treatment'*. Another explanation is that, as reported by the Multicultural Health and Support Service in Melbourne (2007), *'many use traditional remedies in parallel with biomedical care, but may be reluctant to reveal this to a health care provider.'* This was indeed the impression of the medical staff at the Springvale Liver Clinic, who suspected that patients may use herbal medication but were reluctant to admit it: *'Often I get a sense that they're on it but they don't tell us.'*

Indeed, it was suggested by some patients that using traditional therapies was a sign of lack of education (therefore an embarrassing admission) or that they feared it could be interpreted as a sign of non-compliance to western treatment.

Barriers to Treatment and Care Identified by Clinic Staff and People on Treatment

Barriers Identified by Staff

- Until recently, *'the biggest barrier was liver biopsies'* (Nurse). The removal of the mandatory biopsy *'has made a huge difference for people looking at treatment.'*
- **Family influence:** *"I have had instances where the family decided no, they didn't want their mother to go through treatment (...). They're frightened that they're going to put their parents through all the side effects (...) They may not be able to look after the grandchildren like they do, so part of their work will be affected.'* (Nurse)
- **Age:** *'There is a percentage with hepatitis C who are quite elderly and just can't be bothered and don't want the side effects'* (Nurse)

'Most of the time they think: "I am up to the age where everyday is a bonus, so why bother? If they are side effects, why should I go through that?''
(Interpreter)

'The only other group [outside IDUs] that I find difficult to treat are ... there are some who are 55+, 60+ who are not interested in treatment. They don't understand that the disease does take off after a certain age and sometimes you need to treat them and they are very resistant to being on treatment. (...) and they don't understand the concept of disease progression.' (Clinic Director)

- **Community feedback** about treatment is essentially negative, and mainly focuses on side effects and the duration of treatment. The 'community grapevine' is currently a barrier to considering treatment, as patients can be *'put off by their friends' experience and tend not to access treatment'* (Nurse).

Positive feedback from people who have had a good result does not seem to be circulated. *'The GP and specialist may tell patients one thing but 'they've listened to people in their community speak about this particular virus so they have a different perception'* (Nurse)

- **Lack of resources** that would allow better follow-up is a huge barrier: *'Should we ring people a day before [their appointment] – that takes money, it takes a lot of manpower. We don't have that manpower, we don't have the money'* (Specialist). This lack of resources has an impact at many stages of the treatment process: more resources would mean more doctors, able to see more patients, and therefore a shorter waiting list; an extra secretary would allow more follow-up, and therefore a smaller drop-out rate; having more time would allow the medical staff and nurses to do more community and GP education. The lack of resources was also identified by GPs as an issue as it impacts on the clinic's administrative support and their ability to follow up patient queries and confirm appointment times.
- The **lack of nursing support** is directly linked to the resource issue. Currently, nurses are based at Clayton and are rarely available to come to Springvale. This is a staffing issue that could be addressed with more funding. The clinic director

identified the need for a nurse to dedicate her time to the satellite clinics (with relevant interpreter) as a priority for funding.

- The *need for psychiatric support* was considered essential to increasing treatment uptake: if pre-treatment assessments, and/or on-going support, are made conditions to treatment, patients would have to pay for the gap (if they find a bulk-billing psychiatrist) and the interpreter cost. *'I think the main service that we have a lot of difficulty accessing through the hospital system is psych, that's a very big problem. We do have quite a few private psychiatrists that we do see and our patients see (...) Some of our psychiatrists bulk bill but mostly it's between the psychiatrist and the patient, depending on their means as to whether or not they'll bulk bill them or not.'* (Nurse)
- Some staff felt that the *language barrier* was being addressed by the provision of on-site interpreters, whereas other staff members noted that the use of interpreters shortened dramatically the time doctors spent talking to patients and the amount of information provided to help patients make an informed decision. It was noted that the provision of printed information in their language was not suitable for the older population who may not be literate

Dealing with patients' failure to attend and patients who drop out

While the clinic has a three months waiting list prior to a first appointment, it also has a substantial number of people who miss appointments. Every Wednesday, between 15 and 20% of patients booked in do not present, which can be frustrating for the doctors rostered on the day: *'A lot of people, they don't turn up – and they don't call us that they're not coming (...) so we are sitting there and sometimes we don't see patients because these people didn't turn up.'*

The clinic staff identified the following reasons why patients miss appointments:

- The length of the waiting list: *'Because of that long gap, what happens is that people move on. People forget. Whereas if you receive a referral from a GP two weeks ago and have an appointment within four weeks, it's still fresh in their mind.'* (Specialist)

This was also the analysis offered by one of the interpreters: The appointments are *'such a long time away. So it's not that they want to drop-out, they just don't remember to turn up'*.

- Maintaining contact with this patient group can be difficult: *'With phone contacts they often change their number or they're at work and you can't get them during the day or those at home can't speak English – the first point of contact is difficult.'* (Nurse)

Another issue is the fact that information such as appointment letters is written in English, and *'making sure it gets to the right address'* (Nurse). This is also a resourcing issue.

A failure to attend an appointment does not equate to a 'drop out' (some who no longer attends the clinic), although it can indicate one. 'Dropping-out' may occur at any time of the patient's relationship with the clinic, although there are some key steps in the process that stand out as 'drop-out points' (see *Mind Map in Appendix*). This includes the few months between the GP referral and the first

clinic appointment, the period around the first few consultations, and further consultations for patients who have not been prescribed treatment. *'I think the problem is the first timers. The majority of people that don't come are the initial consultation. And a lot of them are IV drug users.'* (Specialist)

Once patients are on treatment, they tend to be committed to the process and it is very rare for people to drop-out during treatment: a specialist estimated that over 90% of the clinic's patients complete treatment. *'I think once they engage in the clinic and they start, they've shown a pattern of coming and starting to know the doctors and understand their illness and have had some education...'*

Why do people drop out of the treatment and care process? Two hypotheses were offered by clinic staff:

- The lack of understanding of the need for monitoring of the liver as an alternative to anti-viral treatment: *'It's an education thing. When they come in after their first visit, we tell them: 'Well, your liver may or may not be damaged' and then they kind of go 'Oh well, maybe my liver is not so bad', and they just don't think it's so important and don't come back.'* (Specialist)
'Some of them were seen five, ten years ago, they thought we are not giving them treatment, and they just stop coming and do nothing. And then five, ten years down the line they got cancer.' (Specialist)
- Failing to attend a first appointment could also be a way for patients who may not have wanted to contradict their doctor's advice by expressing their lack of interest in treatment: *'If they don't want treatment they'll say yes but they don't turn up'* (Nurse)

Suggestions to improve access

- **'More manpower'** (Specialist): *'I'd love to be able to increase it, we could have more clinics there. Unfortunately everything comes back to funding and the politics of things and resources and space and everything else.'* (Nurse)
- **Shared care:** *'Let's say that instead of coming to see us every four weeks they see us every eight weeks, and every four weeks see their GP. And if the GP has any concern, they ring us.'*(Medical Staff)
- **A drop-in service**, where people can come at a time convenient for them and do not get 'bumped out' if they have missed an appointment: *'That would be just brilliant to be able to do that.'* (Nurse)
- **More community education**, through group sessions providing information about hepatitis C and treatment.
- **Increased communication with GPs.** A model that was tried out when the clinic started allowing nurses to speak to the patients' GP before the patient started treatment. To *'actually talk to the GP about what was happening with the patient'* meant that GPs were more involved and aware of the possible challenges awaiting their patient. *'And that was really good'* (Nurse). It could not be continued however due to the amount of staff and funding required.

Barriers Identified by People on Treatment

Sixteen of the seventeen patients interviewed either were on, had completed or were awaiting treatment. People who have agreed to treatment may not be in the best position to articulate barriers; they have either overcome them, or may not have experienced them. However, those who reported initial hesitations about taking up treatment helped identify possible barriers. Others had heard people in their community express their hesitation or fears about going on treatment and made these comments.

The main barrier identified was related to not being able to meet one's responsibility, be it work, financial commitments or family.

'If I got treatment and this interferes with my work, it will be another major issue for me.'

'For example, I have a friend who's got hepatitis B, but the friend's problem was that he had a mortgage. Then if he underwent treatment he did not have money to service the mortgage. So that is the dilemma (...) Because he knows of side-effects of treatment, if they've got side-effects, they cannot work.'

'At the beginning I have hesitation because my children were still young and I did not know what side effects I would have after the injection. But when my parents came I decided to have the injection.'

Other barriers identified included:

- Fear of side effects: *'People rely heavily on rumour. If there is someone in the community who receives treatment and it doesn't run out very well, or that particular person has quite bad side effects, then some people in the community will know, and it will add up to make the story more scary.'*
- The length of treatment may dissuade potential patients: *'People are probably too busy in their lives to seek treatment, because treatment is not one day, it can take up to a year.'*
- Believing that being sick is part of one's destiny and cannot be interfered with: *'Different people have got different reasons. Some of them, maybe they think it is their destiny, that death calls you so you have to go, you cannot resist it, just your destiny.'*
- Feeling well: *'Some people may think they're okay, or the doctor says 'You got strong antibodies so you can survive for 30 or 40 years or more.'*

'The symptoms are not too bad; they still run a normal life.'

From someone who decided not to go on treatment: *'I never have (...) concern about this disease at all, because my health is normal.'*

- Fear of liver biopsy: *'They keep sending me a letter want me to have a biopsy, and I just didn't want to have it. I waited – not waited, but I delay it until a year later, I have biopsy and then I come to this clinic.'*
- Lack of information: *'The reason why they don't want to go ahead with the treatment is because they are not sure about the result, they don't know much about medication, they don't know much about treatment. I'm not sure if that's because they don't have much information before making a decision about treatment, or if they just don't want to know about it'*

Suggestions to improve access

Addressing the community's reliance on word-of-mouth for information, and the negative reporting about treatment, was seen as an effective way to encourage treatment access by several patients.

'The community relies on each other for information. So no matter how much information GPs or researchers give to let them know about treatment, they don't care, [they] still rely on information from the community (...) So the most effective way is for someone in the community who has hep C to know the right information and try to convince others. If we have a condition, we have a disease, the treatment is available, we have to find a way to take it.'

Several patients declared that they already did, or would be willing to, share information about treatment in their community by informally talking to others about their experience.

'Myself, if I get some good results I would be prepared to tell everyone who thinks about treatment.'

'Some of my friends, they have hep C like me, and they come and ask me about treatment and about the new medications, and I tell them whatever I know. They ask me why I take it, and I say 'If I don't try I'll never get anything'. I try to encourage them to go forward.'

'I think more people know about treatment now, more than before, because a lot of people have hepatitis C, Aussie people too. I try to explain to them, don't be scared, now they have found good medicine, don't be scared.'

'I just say don't worry about your hair, or about losing weight, don't worry, after the treatment, you will be the same as before.'

'How can you be scared about treatment, because it makes you better, it gives you long life.'

Case Study 2 – ‘They Keep Putting Up Walls’

For Anthony, trying to access treatment has been a source of great frustration. He has been interested in treatment for several years, has been referred to a liver clinic by his GP on two occasions, but never met the criteria.

‘The first time, the doctor at the clinic said that because I was still using drugs and that, he can’t put me on the program. So I got off the drugs and I went back and he said that because I’m on the psych medication, I can’t... So I thought, too many obstacles ... I can’t get off that! I can’t tell the doctor not to give [the anti-psych medication] to me.’

Anthony has a good relationship with his family GP, who referred him to the clinic in the first place. He turned to his GP again when he wanted a second referral. ‘I went back to the doctor for something else and he told me: *‘What happened when you went to [the liver clinic]? I explained to him and so he gave me another referral and he said, ‘try it again’. But they still didn’t put me on the program.’*

At the clinic, it was explained to him that *‘the medication on that treatment program might clash with what I’m already on. I told him, I’ll sign in!’*

Jail was where Anthony learnt of his status, and where he obtained most of his information about the virus. *‘I was in a drug unit, and they talk about prevention, and what to do if you’re already on it (sic), the scarring of the liver, not to share and all that.’*

Having access to this education helped him deal with his feelings about having hepatitis C.

‘I felt a bit scared at first because I didn’t know much about it. The more you learnt about it ... because you have to take care of yourself, you know? I didn’t even know there were programs where you could go and get treatment for it.’

Being ‘knocked back’ twice has made him angry with a system that he feels is excluding him from treatment: *‘They keep putting up walls’*. Although the clinic’s specialist recommended that he made further appointments to monitor his liver condition, Anthony cannot see the point. *‘I said’ Forget it!’ I can get it checked any time. If he’s not going to put me on it I’m not coming back to get it checked every six months...’*

While he has stopped using heroin, Anthony uses alcohol, although he knows the effect it has on his liver. *‘I drink a lot now, even though they told me not to.’* But knowing that he cannot access treatment means he has no motivation to stop drinking, or to keep in touch with the liver clinic. *‘What if it gets really bad, I’m not going to get on it anyway... I can’t be bothered.’*

Section 2

Referring GPs

Five general practitioners were interviewed for this research. Four practiced in Springvale, one in Clayton. All had referred to the Springvale Liver Clinic in the past 12 months.

Questions focused on the following themes:

- Patient profiles
- Trigger points for testing
- Referral practices
- Relationship with specialist services, in particular with the Springvale Liver clinic

Two of the GPs were drug-replacement therapy prescribers with a high patient load of injecting drug users, while the other three cared mainly for the Vietnamese and Cambodian communities. Three GPs were of Vietnamese background, none of Cambodian background.

Vietnamese and/or Cambodian patients represent between 40% and 90% of these GPs' total patient numbers.

GPs reported between 1% and 20% of patients with hepatitis C, with the highest numbers being reported by drug-replacement therapy prescribers – one commented that around 80% of his Vietnamese or Cambodian patients on drug-replacement therapy have hepatitis C. Another one estimated that about 10% of his Cambodian patients had hepatitis C.

Research conducted in 2001 with 241 GPs working with large CALD communities (Dev and Sievert, 2002) found that a third of the GPs surveyed did not feel well-informed about hepatitis C. The survey aimed to better understand the management of chronic hepatitis C infection in general practices and to define GPs' knowledge base regarding risk factors for hepatitis C acquisition, particularly for people of CALD background. The majority of GPs interviewed were not aware of cultural practices associated with hepatitis C transmission, such as cosmetic tattooing.

The survey clearly identified a need for improved access to information about hepatitis C, due to the uncertainty expressed by GPs themselves about treatment advances, modes of transmission in high-risk ethnic groups, and possible complications. GPs expressed their frustration in accessing reliable information about current treatment outcomes, and linguistically and culturally appropriate information for their patients. Medical journals were seen as the most useful source of information about hepatitis C.

GPs as Point of Access to Treatment and Care

Diagnosing Patients

GPs diagnosed most of their patients with hepatitis C, with the exception of some injecting drugs users who had been previously diagnosed.

The main prompts for testing were injecting drug use (even if only occasional) and being born in South East Asia: *'If they are new immigrants or they have arrived in Australia without being tested, I systematically look for it.'*

Different GPs had different 'alarm bells', with some testing Vietnam- or Cambodia-born patients systematically *'as a baseline thing'* and others only testing those with a history of drug use.

'A lot of [patients from South East Asia] have a high incidence of hepatitis in their community so when they first come to see me I screen them for hepatitis B and C'

'If someone is not a drug user, I would very rarely [test for hepatitis C], unless they specifically request it.'

Other prompts included: tattoos, pregnancy, blood transfusion and recent trips back to Vietnam. None of the GPs interviewed had screened children, or young people born in Australia who were not using drugs.

They had rarely experienced a patient refusing to be tested, reporting that most patients *'feel very lucky to have the opportunity to get screened'*. The rare examples they could recall where a patient did not want to be tested were because patients *'were just not ready to have a look into their health system (...). They say: 'I don't think there's anything wrong with me', or because the blood taking was too painful due to collapsed veins.*

Simultaneously, news from the community can also act as an impetus to act and approach their community GP for information on treatment.

'If someone has just died of Hep C or Hep B liver cancer, they just pour in and request blood tests! But if the population is quiet they drift away.'

Referring to Specialist Services

When and why to refer a patient to a specialist service varied markedly between GPs. While they referred most of their patients with hepatitis C, they reacted to different prompts:

'I want to monitor them first. If there is something that I'm concerned that's beyond my ability to treat I will refer them on. But a lot of them are stable, asymptomatic...'

'If the liver function is normal, the ALT is normal there is no reason to refer.'

'I refer them all.'

'If the PCR is negative then I don't refer them. If a PCR is positive then I do refer systematically.'

Three of the GPs interviewed (including the two drug-replacement therapy prescribers) reported referring to treatment more freely since the protocol changed in 2006.

'Certainly we push it quite a lot; we always have, but increasingly with the more open treatment since the beginning of last year. Whereas previously it was really a waste of time to send them to the Liver Clinic, now it's not, so it is much broader in scale.'

'I used to refer them only when their ALT was high, but now I don't wait for the ALT to rise.'

With the recent changes, GPs could not think why they may not refer a patient to specialist services. *'I have yet to think of a reason why I would do such a thing'*. They refer patients with mental health issues, trusting the clinic to assess patients' suitability for treatment.

In 90% of cases, patients are either happy to be referred or simply agree to it. *'They are a few who say they're not interested in treatment' but 99% of my patients are very keen to be referred.'*

'Most of them go the first time because they want to know what's going on and get some help.'

Barriers to Treatment and Care Identified by GPs

GPs are involved at different points of the treatment and care continuum. Their knowledge of patients and of the context of their lives provides opportunities to identify patients' concerns – opportunities that may not be available to specialists.

Through their on-going relationship with patients, they are in the unique position of hearing why a patient may be reluctant to be referred to a liver clinic, or why they may stop attending clinic appointments.

Patients Who Refuse Referral to a Liver Clinic

As explained above, GPs estimate that more than nine in ten patients welcome a referral to specialist services. The few patients who refuse to be referred provide valuable information about the barriers to treatment and care in those communities.

The reasons provided to GPs include: fear of liver biopsy, of treatment side effects; 'people who have had hep C for a long time; and people whose life is typically chaotic.'

Those 'fears' are based on community word-of-mouth, which is known to be a key source of information for these communities (McNally & Dutertre, 2004): *'They fear having something invasive done to them, for example a liver biopsy, they dread that because they've heard of somebody having that. Or they fear the treatment – they've heard of the side-effects.'*

For some patients, the only information they have ever accessed about hepatitis C or treatment (before discussing it with their GP) has been through people in their community.

'Some of them actually don't know [about treatment], and they have heard that hep C is incurable. They have a bit of a sad outlook about hep C, some patients.'

'Usually they come to me and ask; there's no treatment about hep C, is that correct? That's what the feeling is in the community.'

Another common assumption is that the treatment will fail: *'I will only experience side effects and I won't be cured anyway, so why go through it?'*

Patients Who Drop Out

Another group of patients does not openly refuse to be referred, but drops out in the early stages of visiting the clinic: *'Some of them they just go once or twice and then they fall out, and then I get a letter from the liver clinic to say that they haven't continued.'*

GPs have the opportunity to ask patients their motivation for failing to attend their clinic appointment as they are likely to see those same patients again in their surgery.

There is a great array of reasons why patients may miss appointments, from pragmatic ones (such as misunderstanding the time of the next appointment) to reasons that have to do with their understanding of the natural history of hepatitis C. According to GPs, the most frequently cited reasons are:

- being in full-time work and finding it difficult to attend appointments during work hours
- unreliability associated with frequent drug use
- long periods of absence from Australia or frequent change of address: *'Their family is [in the country or origin], or they go to get married (...) They leave without telling us, and they stop going to the clinic'*

A key reason cited by GPs is the patient's frustration at being monitored but not accessing treatment.

'The people who drop out tend to say things like: "They don't do anything you know, we just go there and each time it's blood test every three months or every six months, and every time I come they do that and they say "It's fine", so if I'm fine why should I go back, it's just time consuming.'

I forget!' or 'I get sick of it!'; 'You told me that I would get treatment but they don't give me anything!'

'They say there's nothing wrong with me and I didn't have to go back again. But I think they're making an excuse maybe because they themselves have decided that they don't want to go back because they feel nothing's been done, but they don't understand the concept of monitoring.'

'They're sick of being followed up, of being told that they are normal. That's why we have some unfortunate cases that they refused to be followed up and they end up with nasty things.'

If a patient has failed to attend an appointment, their GP receives a letter to this effect. The GP then needs to discuss this with the patient and if agreed, to re-refer. Few GPs have the time to contact patients to follow this up (*'If I had the time I'd do it but I don't'*), but will raise it with the patient when they see him/her next.

'Those ones when I see them again I get them to go back. So more or less I try to get them to keep going with the program.'

Suggestions to Improve Access

The five GPs interviewed reported trying to pre-empt the drop-out rate at the referral stage by making sure they don't refer specifically for treatment: *'I will explain the program to them and tell them that's what we need to do, and if it becomes necessary they have treatment, as most of them would... It's not a big problem with me that the specialist decides to wait and see. It happens, but to the minority.'*

The GPs see themselves as being in a privileged position to increase patients' understanding of the need for monitoring of the disease: *'I think that they need education from their GP, and it is very important for the GP to address the issue that this year it is normal, but we don't know about it in the future. The patient needs to have good education about the natural history of hep C, and then to have education about new medications (...). For all those things I think the GP has a very important role in talking to the patient.'*

SECTION 3

COMMUNITY-BASED SERVICE PROVIDERS

Six service providers working in Springvale, Dandenong and Footscray were interviewed about their experiences working with people of Vietnamese or Cambodian backgrounds who have hepatitis C. Four were community workers of Vietnamese or Cambodian backgrounds, one a sexual health nurse, one a local GP⁶. Two of the service providers worked exclusively with injecting drug users, the remaining four worked in the broader community.

The objective of our interviews with these workers was to collect information about people in the Vietnamese and Cambodian communities who had hepatitis C but did not access care or treatment. We were interested to know if the service providers came across many people in this situation. Why did they think these people did not attend a liver clinic? What was the workers' role in supporting people with hepatitis C?

Although we were interested in people from the broader Vietnamese and Cambodian communities, the service providers interviewed believed that people who inject drugs are the main group of concern in terms of high hepatitis C incidence and low access to hepatitis C-related care.

Vietnamese and Cambodian Communities

A Point Of Contact

Community workers and other health service providers confirmed Dev and Sievert's (2002) findings that GPs were often the first port of call for queries about hepatitis C. The study found that people of Vietnamese and Cambodian backgrounds turned to GPs over community workers: they placed their trust in medical professionals when they needed medical advice. They may approach a community worker afterward to obtain clarification on the information provided by the GP, such as: whether they should use western medicine or traditional medicine; side effects; or for help talking to their family about the side effects of treatment.

Vietnamese patients mostly go to a Vietnamese GP, but because there are few Cambodian GPs, Cambodian patients often choose a GP from another ethnic group (including Anglo-Saxon) for privacy reasons. *'With people who don't speak English they go to Cambodian GPs. If people speak English and they don't want to be identified they would rather go to a GP who speaks English or a GP who is not of Cambodian background.'* (Cambodian worker)

'In that context it is probably really important who their GP is because some GPs are better at that kind of work than others. And the Cambodians' access to GP is not nearly as good as the Vietnamese because there's only a couple of Cambodian-speaking GPs – whereas there's lots of Vietnamese-speaking GPs around Springvale.' (Sexual Health Nurse)

⁶ This GP, despite being based in Springvale and having many patients with hepatitis C, does not refer to the Springvale Liver Clinic, as he is part of a shared-care pilot program linked to another hospital.

If approached by someone from their community with questions about hepatitis C, how much information was provided depended on the workers' level of knowledge and their profession. One worker would recommend that her clients call the AIDSline service in their language to obtain more information: *'It is very accurate and clear, rather than you ask me and I have no time to explain. And also, if you go to a GP and ask, GP is time and costs money. They can't sit and explain to you because their time is money.'*

Some of the service providers interviewed encourage their clients to access treatment, while others prefer to remain neutral. A Vietnamese worker, for instance, felt that discussion about treatment needed to be conducted by a medical professional: *'What I can do is just encourage them to see a doctor for testing and prevention (...) and if he recommends treatment, have the treatment as well (...) I think it's the job of a doctor much more than me.'* (Vietnamese worker)

Treatment is not recommended when women are diagnosed during pregnancy, but they are informed that they should contact the Liver Clinic after the birth of their child. The onus is on them to do this and there is no systematic follow up from a health professional: *'I would say that there is treatment, I wouldn't concentrate on that very much because they're pregnant.'* (Sexual Health Nurse)

Information

Community-based workers were critical of the amount of information available in their language, and of their format.

'The majority of Cambodian people who were born before the Pol Pot regime are illiterate so they can't read the language. We lack a lot of resource in hep C information to people in the community, not just in Cambodian language but other languages as well.' (Cambodian worker)

'I think we should find another strategy to produce resources (...) You need to do tape recording, short stories ... Listening rather than reading.' (Vietnamese worker)

A Vietnamese worker mentioned that there is a lack of translated information about how to maintain a healthy diet.

Knowledge

Service providers reported that knowledge about hepatitis C in both the Cambodian and Vietnamese communities is low. People do not differentiate between hepatitis A, B and C, which they all see as 'liver disease'.

'They are confused between hepatitis C and hepatitis B. They don't know much. They say "Well, I have got a liver disease" and when I ask them "What kind of liver disease?" they have no idea.' (Cambodian worker)

'A lot of people, I remember when we ran a stall at the local plaza, they don't know the difference between A,B,C. (...) They don't know much about it, they don't know how you can get hepatitis C.' (Vietnamese worker)

People know that hepatitis C can cause liver cancer – particularly as many know someone who has died of liver cancer.

An area where knowledge is low is that of mode of transmission. Many people with hepatitis C believe that they became infected through sharing a meal or drink with someone who was carrying the virus. They also believe that they can infect others through the same means: *'They worry about the usual contact, like sharing the cutlery, eating and (...) they may transmit to the family. And even though they know their doctor says it is not transmitted that way but still they're worried.'* (Vietnamese worker)

A small survey conducted by AIDSLINE (Yip 2006) with 15 Cambodian people found that 80% of respondents thought hepatitis C was transmitted through sharing food and drinks.

According to community workers, people do not confuse hepatitis C with HIV: *'Actually there is no mix up with hepatitis C and HIV (...) HIV is like yes, it is so serious and ... it's all a big stigma much more than hepatitis.'* (Vietnamese worker)

Service providers also believed that in these CALD communities, people did not make a direct link between hepatitis C and injecting drug use: *'They don't think that only injecting drug users can get hepatitis C, anyone can have it.'* (Cambodian worker)

Injecting Drug Users

Community-based workers found injecting drug users generally well-informed about hepatitis, thanks to regular contact with Needle and Syringe Program (NSP) workers, Drug and Alcohol (D&A) counsellors, information provided by friends, or time spent in jail where they received information about blood borne viruses.

'Most of the people who come here have access to a D&A counsellor, and they often have contact with NSP programs who do provide them with a lot of information. Also often they've heard about it from their friends. So I think they are reasonably well-informed.' (GP)

For this drug-replacement therapy prescriber, his patients' level of information includes knowledge of their hepatitis C status: *'I would say about 50-60% of my patients who have hep C already know.'*

A worker reported finding drug users more interested in how to live with hepatitis C than in prevention or modes of infection-related information.

'It's like [they want to know] a lot about how to live with hep C, the way to eat, and things like which food is good for people living with hep C.'

Discussing hepatitis C is very sensitive and it can take a long time for this worker to feel that the issue can be raised: *'Hep C is definitely a sensitive topic unless you know someone well, and they trust you. That's why we spend a lot of time doing outreach (...) before you go into the medical background (...). You talk about who they're using with, and how they're using, make the client aware of harm minimisation and all that, before you touch on that topic, because it's quite a sensitive topic.'* (Vietnamese worker)

There are several points in the relationship of a service provider with injecting drug users where hepatitis C testing can be discussed: when clients present for an intake assessment before going into detox, or in a clinical setting, screening new patients on their first appointment.

Barriers to Treatment Access For People of Vietnamese or Cambodian Backgrounds Who Inject Drugs

Barriers

Service providers working with injecting drug users all agreed that being an injecting drug user in itself was not an obstacle to treatment. What mattered was the frequency of use and ability to decrease their addiction.

- Frequent drug use: for heavy drug users, health was not a priority as they had more pressing needs.

'They seem not concerned about their health' (Cambodian worker)

'It's quite low down on their list of priorities. It is an unfortunate thing that their health in general is not a concern for them, their immediate concerns are housing, finance, or the law, and so on.' (GP)

'It's just not a priority at the moment. Or they may intend, or they're interested, but it just doesn't happen because of the lifestyle, too many other things going on.' (Sexual Health Nurse)

- Length of treatment and commitment required: *'If they actually get to the point where they're a bit more settled and they're looking at a more stable life it's still not a priority because they haven't been stable long enough to take on something like a six-month or twelve-month treatment, which is big.'* (Sexual Health nurse)
- Negative impression of treatment based on word-of-mouth about side-effects *'Their impression is generally negative, they think it will make them feel really really sick, whereas from experience in the handful of patients we referred to treatment I don't think we've had serious side effects.'* (GP)

In a survey of people with hepatitis C in Victoria, McNally et al (2006) found that the effectiveness of treatment was the most important factor in influencing their decision to begin treatment. While this barrier was reported by GPs and clinic staff, in this study it was not mentioned by people with hepatitis C themselves. On the contrary, a community worker working with IDUs stated: *'I've never had anyone say to me: I'm not going to do it because it doesn't work all the time.'*

Suggestions to Improve Access

Service providers concurred that where there is a desire for change, and when this change translates into less frequent drug use, an environment is created where hepatitis C treatment can be discussed. The group most likely to be interested in treatment is therefore IDUs who are on drug-substitute programs, have stopped (or dramatically decreased) their heroin use and are working.

'Let say they'd been using two or three times a day in the past, but now with [drug-substitution] treatment they're using once or twice a week, and they go back to school or are working, I think that's enough stability for them to be on [hepatitis C] treatment (...). For most patients I would recommend it.' (GP)

'If they want to change then they will seek treatment.'(Vietnamese worker)

'[If] they go through treatment and go through detox, counselling and support, then they become more aware of themselves and their health... but when they're still using, I don't think they're concerned much about their health.'

(Vietnamese worker)

The GP reported a rate of anti-viral treatment uptake of 30 – 40% of his patients on a drug-substitute program, with little difference between ethnic groups.

'Caucasian and South East Asian clients have similar uptake to treatment, it's reasonably low.' (GP)

The possibility of making treatment options more attractive to people who inject drugs is supported by the result of a small survey conducted by a Dandenong-based NSP with their service users (of all ethnicities). Asked about what area they wanted to learn most about, respondents placed hepatitis C treatment on top of the list. This prompted a worker to suggest that drug users were not against treatment per se, but that the current regimen is the problem: *'If somebody said 'you can take a week's course' they'd be there!'*

Case Study 3 – ‘You Only Get One Chance’

Lee was 19 when she started using, and 20 when she was diagnosed with hepatitis C – ten years ago. Like many drug users, she was diagnosed through the correctional system. She kept using heavily for another seven years. Today, she is married, has a child, and uses only sporadically. She has also successfully completed anti-viral treatment.

‘At the time, when I was diagnosed, I wasn’t worried, because I knew that you can’t die in the near future. By then I knew it could affect you 20 years later, but then people tell me 20 years later you could be dying from something else besides hep C, so I wasn’t worried.’

So what changed? *‘I had my first child, and I was starting to worry about passing it on to the child (...). I really wanted to do this [treatment] so that in the future I wouldn’t have to worry about having another child.’*

Another reason why Lee was keen to clear the virus was thinking *‘it would be great not to have to tell the doctors that I had hep C.’*

‘I really dread going to doctors to have blood tests because I’m scared I’m going to have to tell them, they might judge you as a drug user (...) I had that experience, every time I go

to a hospital or GP, if something is serious I’ve got to tell them about my history, it seems like they frown upon you.’ Treatment was a difficult experience, with severe mood swings and side-effects.

‘A month or two into the treatment I couldn’t have a conversation with people without crying, every little thing upset me ... I was just so pissed off and angry!’

Lee also lost hair, and didn’t menstruate for more than a year. She has also had problems with her thyroid glands.

Despite this, she thinks of treatment as a positive experience, because it worked. *‘I’m really glad that all that effort was worth it’.*

During her 12 months on anti-viral medication, Lee was still injecting, albeit occasionally. Her life was relatively stable, with a job and a family, and she doesn’t feel that her drug use interfered with her ability to follow the anti-viral treatment. *‘They told us they don’t expect us to stay abstinent but if we really want to use, just to use safely.’*

Today, Lee is proud of her achievement and keen to encourage other drug users to consider treatment themselves. *‘I talk to other users about it and I say to them ‘You’ve got to do it when you’re stable because you only get one chance at it.’*

While she still uses occasionally, sharing is not an option: the price to pay is too high. *‘Even if I go out with my friends and we’re using, I really make sure everything is clean and new. I tell them: ‘Look, I’ve been through a year of this, I finally came out of it OK, I don’t want to go through it again. And knowing that you only get one chance, that really scares me too.’*

Section 4

People Not Accessing Treatment or Care – Interviews With People Who Inject Drugs

All interviewees were current or recent drug-users, although this was not set out as a recruitment criteria (the criteria was 'people not receiving treatment or care for hepatitis C'). They were recruited through community-based service providers, including Needle and Syringe Programs, health care programs, and the longitudinal research project run by the Burnet Institute in Footscray. Some recruitment took place in the street, in areas where people of Vietnamese and Cambodian backgrounds who inject drugs are known to congregate.

Sixteen people were interviewed: thirteen were Vietnamese, three Cambodian, five were women and eleven were men. Interviews took place on agencies' premises, in the street and in cafes.

All interviews but two were conducted in English without an interpreter.

Questions focused on the following themes:

- Circumstances of diagnoses
- Knowledge of hepatitis C and treatment
- Relationships with health care services
- Disclosure and stigma
- Reasons for not accessing treatment

It should not be assumed that drug users have no interest in treatment. There was a great variety of scenarios, levels of knowledge, intensity of drug use, and reasons why people would/would not consider treatment. Despite the fact that all people interviewed were drug users (current or recent) and of Vietnamese or Cambodian background, they were far from a homogenous group. The following findings attempt to reflect the diversity of their opinions and experiences.

Living With Hepatitis C

About a quarter of the people interviewed were diagnosed in jail. It is well known that the prevalence of hepatitis C is high among prison entrants and that other prisoners are at risk of contracting HCV while incarcerated (Hellard et al 2001; Levy M 2007).⁷ Furthermore, in a study of risk-behaviour of young Indo-Chinese IDUs, Maher et al (2001) found that incarceration has an impact on risk-behaviour (such as lifetime sharing of needles and syringes) and was a major risk factor for the transmission of blood-borne viruses among IDUs.

Others were diagnosed through a drug-replacement therapy prescriber, at the local Needle Syringe Program, through hospital visits for other ailments or as they were about to enter a period of detox. *'Sometimes I go to the Western Hospital and I do detox for one week, so they do tests for me.'*

⁷ According to Australian Doctor (July 2007), the level of infection among men in prison in Australia is about 40%, and 66% among women (who are more likely to be jailed for drug offences).

When diagnosed with hepatitis C, the responses from injecting drug users were not different to responses from other people in their community:

'I do worry more than before, because even though you might not be sick or might long term, then there's a small minority who do become very sick, so I worry about that.'

'I know that in the long run it's going to affect me and my liver, so that's not a good feeling.'

For some, injecting drug use clearly takes priority and there is no space for concern about what is a likely to be a long term issue:

'The reason why I didn't really worry at that time was I was, you know, using and dealing on the street so you don't... it's not a primary thing to worry about. The main thing is to deal, and get money, and pick up drugs and support your habit ... that was the main thing.'

Several respondents mentioned a desire to have children as a reason for being concerned about having hepatitis C: *'I feel a bit worried, just in case I have a family or something like that.'*

Knowledge about hepatitis C

The level of knowledge about hepatitis C varied widely from one person to another. Those linked to longitudinal research projects such as those run by the Burnet Institute in Footscray, and particularly people who had received peer educator training, were more knowledgeable than others. Generally, knowledge about symptoms and the impact of the virus was limited. About half the people interviewed were unclear about the effect of hepatitis C on their health, and did not know that hepatitis C affects the liver.

'Last week, a friend of mine, he went to the hospital, and he tested for hepatitis C and HIV and the doctor told him that where he injected in the groin, the virus goes to the heart and the lungs and stays there, and soon he dies from cancer.'

Almost all respondents reported that they would prefer written information in English (most did not read Vietnamese).

Sources of information about hepatitis C included: NSP, local health care agencies, GPs, the internet, and friends. One respondent reported getting all his information from friends, and *'no-one ever talks about it'*. He was amongst a handful of respondents who had poor literacy in any language. Educators were frustrated at times at the lack of knowledge amongst their peers: *'Because they are at a point in their life where supporting their habit is the main thing ... we tell them everyday, you know, it just goes in one ear and comes out the other!'*

A young woman who had become infected in the first few months of using, being well informed is part of her frustration and disappointment when told of her status: *'I know all that, but still I ended up having it.'*

Feeling unwell

It was difficult, particularly for frequent drug users, to isolate the reasons why they may be feeling unwell: withdrawal, drug-replacement therapy, feeling generally run

down, all were seen as partly responsible for feelings of ill health. They accepted that hepatitis C may also play a part, but found it hard to recognise its symptoms.

'I do feel unwell but I don't know where it's from, is it because of the gear or what?'

'I'm not sure, because it's pretty hard to recognise the symptoms from using and, I'm having methadone as well, so if you feel unwell you don't know if it's from hep C or from methadone or what.'

'It's Not A Big Deal'

Harm minimisation messages were widely known and understood. Only one person said she wasn't aware of the risk of transmission of hepatitis C through sharing: *'I don't know much. That it's not very contagious, you can't pass it to anyone else by drinking, kissing or anything like that (...). How do I pass it? I don't know, there's no way, you can't pass it.'*

The belief that hepatitis C is 'part and parcel' of being an injecting drug user meant that most people who inject drugs are fatalistic about becoming infected.

'It's a combination of noticing everyone having hep C, who is injecting, and you're being told it's not a big deal, you're not as careful.'

'We think anyone who uses got it.'

'When I got diagnosed, I wasn't really surprised or shocked, because I was hanging around people who said, you know, 'If you inject, you get hep C' so you sort of expect to get it.'

Becoming infected with HIV through sharing was seen as a much higher concern than hepatitis C as 'we know that users all have hep C anyway.'

'At the time [of diagnosis] I didn't know that someone could get hep C by sharing needles, I thought only AIDS.'

'When I know what I got, [I was] a little bit worried but happy I didn't get AIDS.'

While knowledge around modes of transmission was high, it rarely translated into a change in risk-taking behaviour. There were several reasons for this. One was the nature of addiction itself, as explained clearly by this young woman: *'If you're in a situation where you're hanging out, you're sick, you have no money, and someone's offering you a hit, you're going to take it! You're not gonna go 'Hey, do you have hep C? If you do, I'm not gonna use your fit, or give me half I'm gonna take it away'... I don't really think that's going to happen!'*

Fear of HIV can act as a deterrent to sharing. But one young man's response would tend to indicate that drug users make decisions around risk that can contribute to the spread of hepatitis C: in his experience, users sometimes ask each other before sharing equipment if they had 'anything'. When the answer was hepatitis C, the response would be, *"That's OK then" because it wasn't HIV. The fear of HIV is much stronger.'*

Accessing Services

The main sources of information about hepatitis C were friends, peer-educators, research projects that they may be involved in, or time in jail.

Some respondents had a GP and a drug-replacement therapy prescriber, some a drug-replacement therapy prescriber only. It is difficult to generalise on the issue of access to services as each respondent had a different relationship with their health provider. However, the following issues came out strongly from the interviews:

- When feeling ill, all people interviewed reported not seeking medical care. They either *'just go out and hang around'*, or *'stay home and take Panadol.'*
- Most of the respondents had not told their family GP of their hepatitis C status, and in many cases, their GP hadn't asked.

'It's just hard... It doesn't sort of 'mix' together. I'd like to keep it separate.'

'I never do any hepatitis C test or anything there.'

'I told my methadone doctor but not the other ones, there is no reason.'

- Some turned to their drug-replacement therapy prescribers for questions around general health – although they were aware that the doctor had little time for more than drug-prescribing. It was felt that drug-treatment prescribers would be less judgemental about drug use.

'It's much easier. Your methadone doctor would understand more and would not discriminate. If you say you've got hep C and you go to a normal doctor they'll ask, 'How did you get it?'

'I had that experience, every time I go to a hospital or GP, if something is serious I've got to tell them about my history, it seems like they frown upon you.'

Some respondents reported feeling discriminated against by hospitals, but this was not everyone's experience, and others felt that they had been well treated.

All respondents reported a high level of trust in local NSP services. If testing was available from one of those agencies, they would prefer accessing it there than going to a private medical professional.

'I told my methadone doctor [about having hepatitis C] and he said I had to give him blood to test it. But if I want I go to HealthWorks and they do it for me too.'

'I feel that the clinic in Fitzroy or Footscray they'd help you more or they understand more.'

When asked where they would go for information about hepatitis C treatment and care, most respondents felt that their drug-replacement therapy prescribers were the most reliable source. As found through the interviews with community service providers, there is a higher level of confidence in the abilities of medical professionals to provide such information than there is in community-based workers or agencies.

Disclosure

All respondents were unaware of the high prevalence of hepatitis C in their ethnic community. They seemed oblivious to the possibility that some members of their family, or some of their non-drug using friends, may be infected. They saw hepatitis C solely as an injecting drug-related issue, and sharing injecting equipment as the main source of infection.

Most of the respondents had disclosed their status to their family, in order to protect them from possible infection.

'I need to let them know that I might be a risk to them as well.'

'Some people, they need to know, like my parents. They need to know I can't share things (...) cups and spoons. I've got my own cup anyway, my own spoon...'

'My parents, they really worry about me sharing bowls, chopsticks and spoons with them.'

They sometimes disclosed to other users, on the basis that they assumed everyone was infected.

'We just joke about it, just teasing each other and stuff like that.'

'It's just something that comes up when we're drinking. They're my friends; I'm going to tell them!'

They were reluctant to disclose outside these circles, fearing discrimination.

'I don't talk about it with anybody (...) cos' I feel that it's confidential. They don't need to know and I don't need to know about them.'

'If you tell someone who doesn't know they may worry. When they don't know something they feel afraid and feel they don't want to get close to you.'

'I am not sure but I think [people in the Vietnamese community] think people with hep C must have done something bad, they don't know anything about hep C.'

'I just worry maybe [my employer] could be judgemental, he wouldn't want me to work there. I think sometimes people think it's [like] AIDS.'

Stigma

The issue of stigma around hepatitis C in the Vietnamese and Cambodian communities is complex and multi-layered: while it is seen as a common infection, the fear of transmission can result in ostracising people with hepatitis C, and a reluctance to disclose.

On one hand, 'liver disease' is seen as common, and therefore *'not something to be ashamed of or humiliated'*. (Clinic patient)

'A lot of the Cambodian or Vietnamese people, they have so many relatives who have the disease. The older ones, they go: 'Oh, I have this, my uncle, my father, you know, they have this.' (Clinic staff)

'Patients tend to come in with their families and kids, and the fact that they have hepatitis C does not seem to be an embarrassing condition.' (Clinic staff)

On the other hand, a lack of understanding of modes of transmission acted as a deterrent for people with hepatitis C to disclosing their status. A 2004 study of ethnic and cultural determinants of risk assessment for hepatitis C (Dev et al) found that the low level of awareness of modes of acquisition of South East Asian people with hepatitis C affected people's willingness to disclose their status. The main reason why patients chose not to disclose their infection was because they were afraid of not being invited to the house of friends, acquaintances and family; they also feared their own ability to infect others – therefore sharing the community's lack of clarity about modes of transmission.

This was confirmed by the clinic patients' responses to questions about possible community reactions.

'If I tell everyone, they may think the disease may be contagious, and passed on to them (...). They may get away from me.' (Clinic patient)

'I have people saying: 'I'm very scared of hep C; if I know someone with hep C, I don't want to even share the dishes.' And how can I tell them that I am one of them? I feel even more ... you know, like we are the sub-class of society.' (Clinic patient)

'People think that it can be transmitted through sharing food and drink (...) you feel isolated in your community, and also in your own family.' (Cambodian worker)

This was also a concern for injecting drug users. Those who had told their family about their status did so to protect family members from possible infection.

Drug use, hepatitis and HIV

For older people with hepatitis C – such as the patients of the liver clinic – there is clearly no perceived association with injecting drug use.

'For the older people, they don't think "I've got hep C because I am a drug user" or "I did something with drugs". Never thought about it. Never ever. It is "Oh I got liver disease because I share a cup with people in the community.' (Cambodian worker)

'I don't think it is a stereotype that necessarily translates across. (...) Once they realise that a lot of them have acquired it from childhood immunisation there doesn't seem to be much of a taboo'. (Clinic staff)

There is also no perceived association with HIV: *'It's not AIDS! With hepatitis C the people who carry it, it's just bad luck, it's different from sexually transmitted diseases, where it's because of their behaviour, so that's why they should be ashamed of it. Here, it's just bad luck.'* (Clinic patient)

Amongst people who inject drugs, the perception of a link between injecting drug use and hepatitis C risk was almost opposite to that of the rest of their community. Injecting drug users perceived hepatitis C solely as a virus associated with injecting, and had no awareness of the prevalence of infection in their community or of alternative ways of transmission. Because of this, they could be reluctant to reveal their status to their family or outside their injecting circles.

'They wouldn't support me anyway.'

'They don't really speak English so they don't really know that much.'

Even amongst users, carrying the virus can be stigmatising. Vietnamese heroin users commonly start by smoking the drug ('chasing the dragon') before moving to injecting it (Kersall et al, 2001). This is regarded as indicative of greater control over their drug use. Findings from this recent Burnet Institute study show that some respondents cited a preference for smoking for '*general health reasons*' or specific health concerns associated with injecting, including exposure to HIV or hepatitis C.

A Vietnamese woman who was an occasional user explained that injecting heroin is seen as a sign of addiction, whereas smoking it is not. *'If you're Vietnamese and injecting you are considered a junkie, there's no return. So there's a separation, smoking is more acceptable. It's like once you go to the needle, you're gone.'* Being infected with hepatitis C is associated with injecting.

Barriers To Treatment And Care

Barriers

Lack of knowledge about treatment

Like knowledge of the virus itself, knowledge of treatment was limited. Five of the sixteen people interviewed did not know or were unsure that treatment existed (*'I heard there was a cure for Hep C, is there?'*), others had been given some information by their GP or accessed information at an NSP: *'My doctor's talked to me, he wants me to get in this program that lasts for about a year, taking these pills. But I think there's a few side-effects to it, so he's going to give me a brochure or something.'*

Once again, peer educators were better informed than other users, (*'through the peer group education I have learnt things about treatment'*), although this knowledge was at times vague or even inaccurate.

There was a perception that treatment requires a high level of commitment, with weekly appointments and hospital visits that could affect schooling or work: *'The way treatment was sold to me it sounded like you had to go to all these appointments, and get some blood tests... it was just on-going, and pretty much long-term, and (...) I'm just sort of managing so I thought I want to at last finish school and then I can do that.'*

Reasons for not wanting treatment

Some of the reasons given for not wanting to undertake treatment were very similar to those given by patients of the liver clinic: fear of hair loss or weight loss and decline in appearance; fear that treatment would interfere with work/school/family obligations; feeling well.

Many of the people interviewed felt that drug use was an obstacle to treatment. However, current injection drug use has not been an exclusion criterion for access to government-funded treatment for hepatitis C infection since May 2001. Despite the removal of this barrier to treatment access for current injecting drug users, the number of IDUs receiving treatment remains extremely low (Matthews et al, 2005).

In our research, frequency of injecting was key to respondents' interest in treatment. Those who used frequently prioritised their drug use over all other concerns, and felt that their drug use was a barrier to taking up treatment.

'I worry about it, but because I'm addicted I don't have the time to go and find out. I'm just too busy trying to find money.'

'I guess because I use (...) maybe that's what's stopping me from doing things I want to do, like go and get treatment. Because I'm too hung up on the gear and I'm always thinking about my next hit.'

This could mean either that someone felt they had to get off drugs all together ...: *'If [my liver] gets really bad, I have to go on treatment to get better. If I stop using it's better. Stop using is the best, but it's a little bit hard.'*

This could also mean that they had to get their life 'in order' before thinking of treatment:

'[Treatment] is a good thing but I don't feel ready yet. I have family problems still happening; I don't really have the time for treatment with all the troubles happening.'

'I will think about [it] when I reduce my using and I'm on a program.'

It was obvious from talking to people with different degrees of drug use that the more stable their life became – generally thanks to drug-replacement therapy programs – the more they became concerned about their health and the impact of hepatitis C on their future well-being: *'Now that I am at a more stable point in my life, you think 'Oh, how stupid, you know, it was so easy to prevent... it's my fault. You know, 5 seconds, I'm not gonna die if I wait 5 seconds.'*

In this context, the idea of side-effects or of committing to several months of treatment can be seen as a threat to a newly-found, and still fragile, stability.

'There's just too many things going on in my life at the moment, I don't think I could handle school, work and treatment, especially the mood swings and stuff.'

'I'm just getting stabilized now, I don't want to go through that mental depression and then maybe start using and that.'

'I'm trying to do one thing at a time (...). I'm trying to straighten my life up, and I know it takes time and I don't want to do something that makes me lose my focus.'

It is worth noting that none of the people interviewed mentioned the lack of guarantee of treatment success as a barrier to accessing anti-viral treatment. For some, it may be because their knowledge of treatment did not extend that far. But as one of the young women interviewed put it: *'[With treatment], at least you're giving yourself a chance.'*

Suggestions

It was clear during these interviews that drug users of Vietnamese or Cambodian backgrounds were more comfortable discussing health issues with services that knew of their drug use, such as drug replacement therapy prescribers and Needle Syringe Programs. Given the widely documented discrimination experienced by drug users in hospitals and other mainstream services (C-Change report 2001), methadone-prescribing GPs and NSPs provide an alternative, offering an environment that is non-judgemental and can support them with some of the more challenging aspects of treatment.

It is also essential to improve the perceived discrimination from mainstream services. As argued by Day et al (2003), *'if IDUs are to be encouraged into drug treatment it is essential that service providers are perceived to be non-discriminatory.'*

The spectrum of opinions about health and well-being represented in this brief sample raises the question of how blanket assumptions are often made about injecting drug users, such as lack of adherence to treatment, lack of concern about one's health, chaotic lifestyle, etc. It clearly appeared that different levels of addiction and the ability to manage the addiction can create situations where treatment can be considered.

PART THREE
SUMMARY OF FINDINGS AND RECOMMENDATIONS



Summary Of Findings

Challenges to Accessing Hepatitis C Treatment and Care for People of Vietnamese and Cambodian Background

The difficulties that people of CALD background – including Vietnamese and Cambodian – may encounter in accessing health information and care are well reported. They include, amongst others, language barriers, difficulties in understanding the health system, lack of access to transport and lack of information about health options.

In regard to accessing hepatitis C treatment, this research indicates that the people who overcome these barriers and access the Springvale Liver Clinic show a high level of motivation to take up hepatitis C treatment. They come to the clinic expecting to access treatment without delay.

Once patients have started treatment, their level of adherence to treatment is also very high, with a specialist estimating that over 90% of the clinic's patients complete treatment.

Despite this, many obstacles remain for people of Vietnamese and Cambodian backgrounds on the way to anti-viral treatment. Some difficulties occur before treatment is even heard of or considered and discourage them from taking 'the first step'. Others happen when they have already engaged with the process, and make it difficult for them to remain on the treatment and care 'journey'.

Making The First Step

The main barrier to treatment for people with hepatitis C was their knowledge or perception of treatment side-effects. While people's knowledge or even awareness of treatment was sometimes limited, the single aspect of treatment they knew about before any other was its side-effects. This knowledge was often acquired or reinforced by the community word-of-mouth, which is essentially negative when it comes to anti-viral treatment.

Without treatment side-effects, most of the barriers listed below would not exist. When a person with hepatitis C is making a decision about going on treatment, perception of side-effects weighs heavily in the balance, and is often the key element that tips the balance on the side of rejection.

Other barriers identified by the people interviewed were:

- **Feeling well**, and the perception that this feeling of well-being is a reflection of their liver's good health. These act as a barrier on two levels: a person who feels well often does not see the need for treatment, and particularly a treatment that may include side-effects and a temporary decline of well-being.
- **Old age**: older people who feel well may estimate that the risk of developing liver damage in the long term is outweighed by the potential decrease in quality of life due to treatment side-effects. This decision can sometimes be made by the family, who do not want to put their parent through the treatment side-effects. Even if they are feeling unwell, some older people estimate that their life expectancy is such that it is not worth undertaking treatment.

- The *fear that treatment will interfere with other responsibilities*. This is particularly true of people who are employed outside the home and who fear that treatment will interfere with their ability to work. It can also be the case for people who have family responsibilities, be it a mother looking after her children or grand-parents who have housework and babysitting duties.
- *Length of treatment* and the commitment required, be it in terms of clinic appointments (which may be during work hours) or the fear that treatment will make them feel ill for many months.
- *Community word-of-mouth*: the community 'grapevine' is currently a barrier because it often carries negative messages about treatment. As explained by a Springvale Liver Clinic patient, people are likely to trust community information over more 'official' sources such as doctors and health workers. People with hepatitis C are concerned about treatment because they have heard that they may lose their hair, lose weight, feel tired or depressed.... They have not heard stories of treatment success, or positive feedback from people who underwent treatment.
- *Lack of information about treatment*: for many people, the main source of information is friends, family and acquaintances. This information may be out-of-date (e.g. mentioning the need for a liver biopsy), inaccurate or only relate to a particular person.

These barriers were particularly acute for three sub-groups in the Vietnamese and Cambodian communities:

- Older people (60+), who make assessment of their need for treatment partly based on their age and perceived life expectancy
- People who are working in paid employment and fear that treatment will interfere with their ability to maintain this commitment. They may also not be confident in negotiating time off work to attend appointments.
- People who inject drugs.

For *people who inject drugs*, some barriers to treatment are specific to their drug addiction while other barriers are similar to those experienced by the general population. Like others, they fear side-effects that will affect their health and their appearance. Their knowledge about treatment was sometimes limited, as was their understanding of hepatitis C and its impact on their health.

For those who had achieved stability in their life, the fear of jeopardising family commitments, employment or schooling by suffering from debilitating side effects was also strong. Many of the people interviewed who had reached this point in their life expressed their fragility, and their vulnerability to depression. Behind this loomed the fear that the psychological side effects of hepatitis C treatment may weaken their resolve not to use drugs.

Other barriers are more specifically related to the life-style associated with addiction. Many mentioned the need to stabilise their life before they could 'tackle' treatment. The commitment required for treatment often seemed an insurmountable obstacle at a time when their life may have been focused on the day-to-day survival, on obtaining drugs or on resolving other, more pressing issues such as homelessness or child-support.

An obstacle that was unique to people who inject drugs was their negative experience of the hospital system, and, sometimes, of GPs. The prospect of needing to engage with clinics and hospitals in the initial phase of treatment was a significant discouraging element for some.

Stigma and the fear of discrimination have been identified in previous research as central to people's decision-making around hepatitis C treatment and care. This was not a finding of this research. While there was undeniably a fear of discrimination from community members based on a lack of understanding of transmission risk, there did not seem to be 'shame' associated with the fact of being infected itself. Also, the fear of discrimination did not appear to play a part in decisions around accessing treatment.

Staying the Course

For people who have taken the first step, discussed the possibility of treatment with their GP and agreed to be referred to a liver clinic, the journey only begins, and many challenges remain. This is shown in the level of 'failure to attend' (patients who have an appointment but do not present to the clinic) and in the drop-out rate (people who drop-out of the treatment and care process all together). The rate of 10 to 15% of failure to attend ('FTAs') every Wednesday highlights the difficulties patients face in fitting appointments into their lives. These include:

- **Population mobility:** Clinic staff, GPs and community-based providers interviewed for this research reported a high level of mobility in these communities, with people travelling to Vietnam or Cambodia for long periods of time without re-scheduling medical appointments or informing services.
- **Need for reminders/follow-up phone calls:** the number of people missing appointments is low amongst patients on treatment, but high amongst those who only attend the Springvale Liver Clinic for blood tests and monitoring. These 'reviews' take place every three, six months or 12 months. Our findings show that patients forget appointments, and that a reminder close to the date would be helpful. Practitioners claimed that most patients did not intentionally miss their appointments but genuinely forgot. Reminding people of appointments is not currently possible due to resource issues. This difficulty is compounded by the fact that letters or reminder phone calls/messages would need to be translated to be fully understood – therefore causing further interpreting and translating costs.
- **Difficulty in attending appointments during work hours:** demands with employment and the fear of debilitating side-effects have been shown to be an obstacle to treatment. It is also a problem when the clinic is only open during work hours. For many people, attending review appointments means missing work, or disclosing their health status to an employer. This is particularly challenging for a population that typically works in the low paid, unskilled sector, on a casual basis, and has little job security.
- **Drug use:** much was said by medical professionals and drug users alike about people who inject drugs' chaotic, day-to-day lifestyle and their high rate of failure to attend appointments. As patients, they may have agreed to being referred to a liver clinic but may find the reality of long-term appointments difficult to commit to.

The number of patients who 'drop-out', either by never presenting or by stopping to present after a few appointments is more difficult to establish but is, by all accounts, high enough to warrant attention. It is a sign of the challenges faced by the Springvale Liver clinic in trying to keep patients engaged in their 'journey' to better health. The research identified two critical times when a patient's risk of 'drop out' increased:

- between the GP referral and the first liver clinic appointment
- between the initial consultation with a specialist and the time when treatment is recommended (there may be 3 or 4 consultations and several tests before the specialist is able to make a recommendation)

Other developments may also result in a number of patients terminating their relationship with the clinic:

- after these early consultations, if treatment is not recommended
- when treatment (S100 or trial) is terminated due to lack of result
- when treatment (S100 or trial) is completed but deemed unsuccessful

For people who have accessed information and are linked to a specialist service, the barriers to engaging further with treatment and care were identified as:

- ***Lack of understanding of disease history and the need for monitoring its progression:*** while Vietnamese and Cambodian people are very keen to access Western treatment, some show great frustration with the fact that treatment is not always recommended or not recommended during the initial consultations. Some patients come to the clinic for several months for tests and monitoring of their condition before a decision is made. Clinic staff and GPs reported their patients' frustration with this process. They attributed it to a lack of understanding of the natural progression of the disease and of the need for patients to have their liver function monitored even when they have no symptoms and feel well.
- ***Not wanting treatment:*** GPs and liver clinic staff suspected that failing to attend appointments may be a way for patients unwilling to contradict their referring GP to express their reluctance to attend a liver clinic. This apparent 'compliance' can be a cultural norm or it may be that patients are afraid of upsetting their GP by refusing to be referred.

Lessons From the Springvale Liver Clinic

In many ways, the Springvale Liver clinic does not differ from other liver clinics around the state. Staff and patients felt very confident that the level of clinical services provided was equal to that provided at the Monash medical centre, and that patients were not disadvantaged in any way by attending the clinic. This was a point that the clinic's specialists were keen to emphasize, and that many patients made.

What makes the clinic unique is more subtle: as explained by the Clinic Director, Dr Anouk Dev, *'It is unique in its geography; I don't think it's unique in its practice... I think the ideology and the passion for it to start off with is probably unique, but the on-the-ground functioning of it is not.'*

The approach taken by the clinic – to make services more accessible to patients of Vietnamese and Cambodian backgrounds – permeates the patients' journey through the clinic on many levels. It includes pragmatic factors such as location and ease of physical access; a commitment to interpreting services for all; a holistic approach that looks beyond the service provided by clinicians to incorporate all staff involved in the patients' care; and an acknowledgement of the need for culturally-sensitive health provision.

Making it easier for patients to attend the clinic

The Springvale Liver Clinic understands that in order to attract patients to the clinic, it needs to make it as easy as possible for them to fit appointments within their life. This is particularly important for people with hepatitis C because they may feel well and because treatment is complex: for both reasons, they may be tempted to 'put off' attending a liver clinic if it proves too difficult.

Below are some of the characteristics of the Springvale Liver Clinic that promote ease of access:

- It is based in the community it serves, in an environment that is familiar to patients. In the case of the clinic, it is in a Community Health Centre, but it could also be in an ethno-specific agency, or a Needle and Syringe Program. The key factor, as articulated by clinic staff, is to base the clinic in an environment seen by potential patients as non-threatening.
- It is easily accessible: located near shops, with convenient parking nearby.
- Because the health centre is smaller than a hospital, the time spent waiting to be called is much shorter. This makes it easier for people who work or have other obligations to attend appointments.
- It provides all services on-site, so that patients do not have to go to multiple locations to get their care. This includes pharmacy, pathology and nurse education. Ideally, it would also include counselling/psychology.

Promoting a collaborative approach between staff

The Springvale Liver Clinic has created an environment where all staff members are encouraged to share relevant information about patients. This helps build a complete picture of patients' health. What a patient may not wish to reveal to a specialist (such as an adverse reaction to medication), they may feel comfortable

discussing with a nurse or pharmacist. This also contributes to saving consultation time, as staff other than specialist clinicians can deliver information or provide advice on side-effect management.

Weekly team meetings to discuss cases are an essential component of this collaboration.

An important component of this collaborative approach is the fact that all services are on site, physically based in the liver clinic, with the same staff members present every week. Such information-sharing and consultation of colleagues is difficult in a hospital environment where services such as nurse education, pharmacy or pathology may be located on different floors.

Working with CALD groups

Access to health care is heavily influenced by patients' cultural backgrounds, English literacy, past experience with the health care system and history of migration. Below are the measures put in place by the Springvale Liver Clinic in response to the large number of patients of Vietnamese and Cambodian backgrounds who come to the clinic:

- Having interpreters on site (instead of on call): seeing the same interpreter every week contributes to building trust between patients and interpreters (this is particularly important for newly-arrived communities). Patients feel that the interpreter knows and understands their situation. Having interpreters also reflects that the clinic is serious about working with its CALD population, by engaging an interpreter and using English as the exception – a direct reverse of the situation most patients would be used to in health services.
- Doctors of similar cultural and language background to the patient group: when possible, it contributes to making the clinic more approachable for patients. It also saves previous consultation time as clinicians will not need to turn to an interpreter in their communication with patients who speak the same language. *'Having some staff that has some ethnic similarities to the community I think (...) helped us a lot.'* (Springvale Liver Clinic Director)
- Adapting Information & Education material to the needs of the local ethnic communities: Most of the material available in Victoria targets people who inject drugs (who make up the core population of people with hepatitis C). Even if translated, it is based on an English version that is not relevant to the patient group and has not been adapted to their circumstances. People with hepatitis C who have never injected drugs may reject this material as not appropriate to their needs, or as offensive. To address this, the nurse educators at the Monash Medical Centre have written their own material, which is translated in Vietnamese and Cambodian. There is a need for increased funding to allow this material to be regularly updated – to reflect changes in treatment eligibility – and translated in other languages.

Recommendations

These recommendations assume that not one single model of care and treatment will universally increase access to hepatitis C treatment and care. It is not this study's intention to offer a clinical model that will suit all communities – such models do not, and should not, exist. The underlying principle to delivering appropriate care is to acknowledge and understand the workings of culture and context which mean a variety of care models need to be implemented to address this complexity.

It is widely acknowledged that all CALD communities are different, and within each language or ethnic community additional differences exist. A consequence of this heterogeneity is that health services need to be flexible in their models of service delivery. What works in Springvale, with Vietnamese and Cambodian communities, may not work elsewhere

The findings from this study demonstrate that there are policies and practices which can increase access and improve the experience of treatment and care for people from CALD backgrounds.

Based on the experience of the Springvale Liver Clinic, this study has identified a range of factors that can contribute to a liver clinic's success in attracting CALD communities, increasing the number of people on treatment and improving their experience of treatment and care. Some of these 'elements of strength' characterise the experience of the Springvale Liver Clinic, while some are more of a 'wish list' based on gaps identified.

1. Support the development of community-based liver clinics

The findings show that there are significant benefits associated with a community-based Liver Clinic that is not located within a hospital.

The 'small scale' approach allows for all relevant services (i.e. pharmacist and interpreters) to work interactively with specialists. A wide range of factors were acknowledged as important to people attending the community-based liver clinic. While many of these factors may appear simple, such as having available parking next to the building, or the clinic being located in a familiar and inviting Primary Health Care setting, it needs to be stressed that these practices were highly valued by people attending the clinic.

2. Adapt the service to the cultural needs of the patient group

The findings show that running a Liver Clinic which has a significant number of CALD community members requires considerably more administrative support than a mainstream clinic. The uniqueness associated with a clinic that works with CALD communities also requires:

- Interpreters as central to the running of a Liver Clinic
- Cross cultural training of staff
- Recruitment of staff of similar cultural background to client group

- Flexibility in the delivery of care to accommodate patients' difficulties in attending appointments

3. Address the treatment drop out rate and the 'failure to attend' rate

Patients dropping out of care or failing to attend appointments were identified by most staff at the Liver Clinic as a significant barrier to care and treatment. A range of strategies were suggested by the health care workers to reduce the number of 'drop outs' and 'failure to attend'. These include:

- Finding ways to better explain the need for monitoring and the natural history of the disease. It is important for patients to understand that treatment is not the sole aim of a Liver Clinic
- Increasing the role of GPs in keeping patients involved in managing their hepatitis
- Increasing administrative support to provide more patient follow up
- Promoting a collaborative approach between staff to maximise chances that patients concerns and hesitations are noticed, recorded and addressed
- Developing relationship with local D&A services (drop-out is high for IDU) including needle and syringe programs and methadone prescribers
- Supporting a free psychiatric service to increase the number of patients accessing treatment who are considered 'vulnerable' due to mental or emotional health issues
- Acknowledge and support the pivotal role of Clinical Nurse Consultants to provide treatment and care education and support, with the help of interpreters.

4. Develop culturally appropriate information about hepatitis C and hepatitis C treatment. Support sustainable means for this information to reach the broader community.

The study found that there was very little information available about hepatitis C generally, and about hepatitis C treatment, for people from CALD backgrounds. Most in-language material about treatment available to patients attending the clinic was provided by drug companies and most information about hepatitis C has a strong focus on safe injecting drug use, which is not always relevant to CALD communities.

Information needs to be developed specifically for communities with a high prevalence of hepatitis C. In addition:

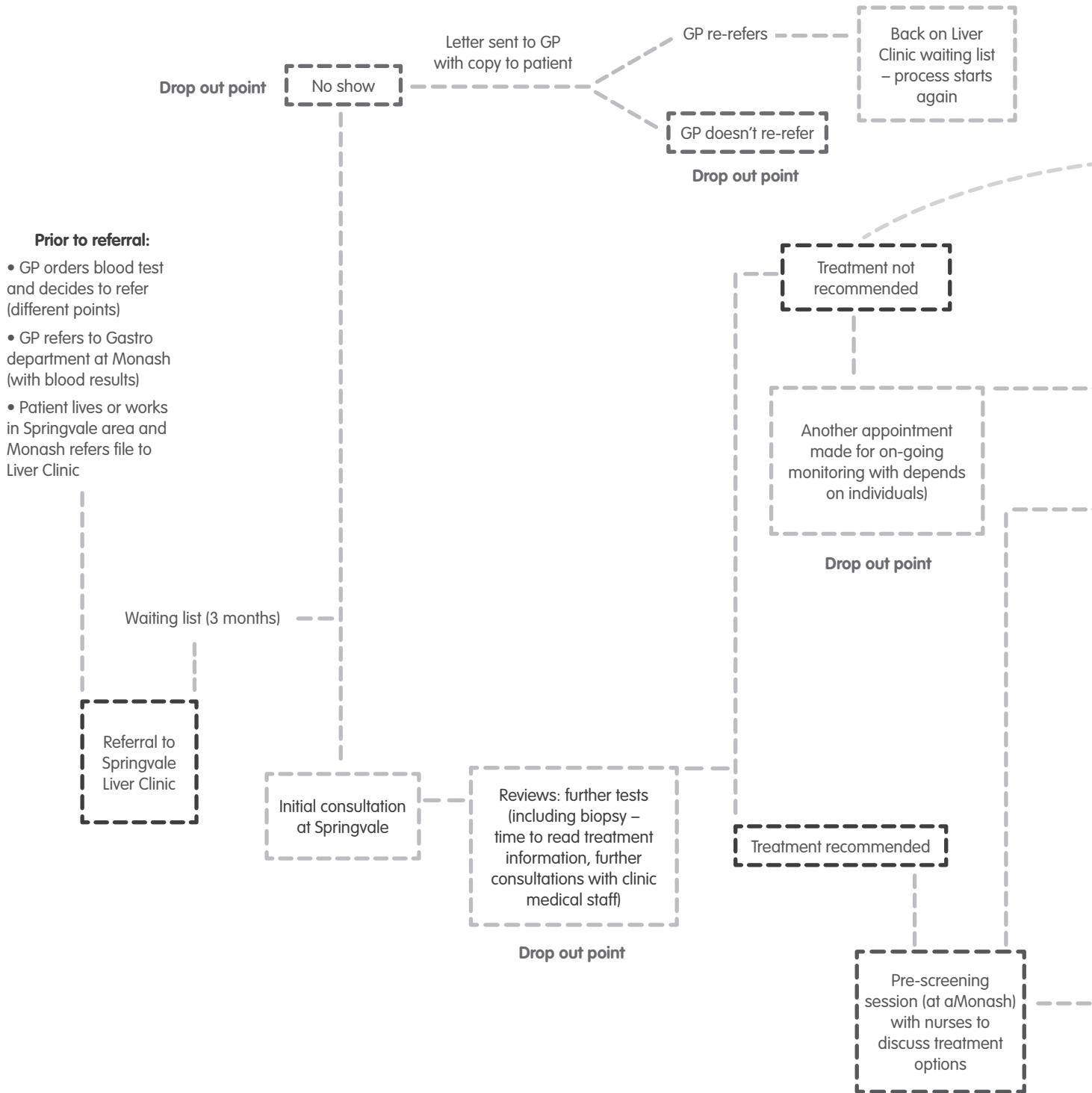
- Sufficient funding needs to be provided for regular updates to mirror constant treatment or treatment access developments
- All relevant information needs to be accessible to GPs
- Audio-visual medium needs to be used to address illiteracy
- Ethnic media need to be used to promote this information

5. Counteract the negative image of treatment in the community

The findings from this study show that people's knowledge about hepatitis C treatment comes from their doctor AND from within their community. Stories that circulate within the community about treatment tend to reflect outdated information and negative experiences of treatment. Treatment success stories need to be promoted throughout the community, including ethnic organisations and workers and ethnic media. Other means to promote up-to-date information to the community may include taking part in community run forums/festivals and utilising the informal and extremely effective 'grapevine' to circulate up-dated and positive information about treatment by supporting patients with positive experiences to become advocates.

It is imperative that GPs are used to circulate positive information about hepatitis C treatment and the role of Liver Clinics in managing the well being of people with hepatitis.

APPENDIX



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