

MAKING DECISIONS ABOUT HEPATITIS C TREATMENT

My Normal GP To Prevent Long Term Liver Damage Clinic Times
Side-effects of Treatment Haven't Given Much Thought to Treatment
PCR Test Costs Associated with Treatment A Supportive Partner
Fear of Liver Biopsy Pegylated Interferon Public Hospital Liver Clinic
Specialist Physicians Patient Requests a Referral Impact on Family

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Foreword

This is a timely report. It brings together data from several studies conducted over the past few years. First and foremost of these is the *Challenges to Hepatitis C Treatment Study* which was funded by a grant awarded by the Victorian Department of Human Services to the Australian Research Centre in Sex, Health and Society's (ARCSHS) Director Professor Marian Pitts, Dr Mary O'Brien (then at ARCSHS), Dr Meredith Temple-Smith (now at ARCSHS), Dr William Sievert (Monash Medical Centre) and the Hepatitis C Council of Victoria.

Additional data are drawn from two studies funded by the National Health and Medical Research Council: *Living with Hepatitis C (2000-1)*, awarded to Professor Sandy Gifford (then at Deakin University) and Dr Gabrielle Bammer (Australian National University) and associates; and *Men, Health and Hepatitis C (2002-3)*, awarded to Professor Sandy Gifford, Dr Mary O'Brien (then at ARCSHS) and Associate Professor Anthony Smith (ARCSHS) and associates.

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Executive summary

It is estimated that more than 242,000 Australians have Hepatitis C, and around 16,000 new cases are diagnosed annually. Few with this infection access clinical treatment and even fewer successfully complete a course of Hepatitis C treatment. While some research has been conducted into the quality of life of people with Hepatitis C, virtually no work has examined the broader social contexts of clinical treatment. This report details the range of psychological and social factors associated with decisions to take up treatment, and presents results of a study which used both qualitative and quantitative methods to identify personal, psychological and structural barriers to treatment uptake. This study is unique in that it offers three different perspectives on treatment: those of people with Hepatitis C, General Practitioners (GPs), and Specialist Physicians.

A range of issues impact on the decision to undertake and remain on treatment for Hepatitis C. Factors which were found to be critical in deciding whether to take up treatment included the individual's perception of how the treatment would benefit them, the likely severity of side-effects, and the availability of medical support. The greatest challenges to staying on treatment which were identified by people currently on treatment and those previously in treatment were side-effects associated with treatment and the association of treatment with depression.

People with Hepatitis C

The survey was completed by 224 people with Hepatitis C from throughout Victoria. Demographic analysis of this group showed that:

- 53% were women
- The average age was 43 years (age range 15 to 63 years)
- 81% were born in Australia
- 54% were employed either full or part-time
- 26% were unable to work due to illness
- 36% were rural/regional residents

Average time since diagnosis of Hepatitis C was seven years with 25% of participants receiving a diagnosis ten or more years ago.

The average time since contracting Hepatitis C was 18 years, with 25% of participants contracting Hepatitis C in the past ten years.

Mean year of diagnosis for participants currently on treatment was 1998. Mean year of diagnosis for participants on treatment in the past was 1995. Mean year of diagnosis for participants who have never been on treatment was 1995.

Only 10% of participants recalled receiving pre-test counselling.

48% of respondents were currently seeing a GP for their Hepatitis C. Of these, 34% had seen a GP specifically for their Hepatitis C in the last four weeks.

Current injecting drug users (IDUs) (24%) were significantly less likely than past IDUs (49%) and those who had never injected (60%) to see a GP specifically for Hepatitis C.

Women (54%) were significantly more likely than men (35%) to rate their usual GP as important for managing their Hepatitis C.

Participants with no history of IDU (54%) and past IDUs (46%) were significantly more likely to rate their usual GP as important compared to current IDUs (37%).

69% of people with Hepatitis C had seen a Specialist Physician about their Hepatitis C. Most of these participants (60%) were currently seeing a gastroenterologist or infectious diseases physician on a regular basis.

About half (49%) of the participants had seen a Specialist Physician within six months of receiving their positive Hepatitis C diagnosis.

Participants diagnosed in the past five years (69%) were significantly more likely than those diagnosed more than five years ago (35%) to have seen a Specialist Physician within six months of their diagnosis.

Thirteen per cent of participants were currently seeing a natural therapist about their Hepatitis C.

Currently on Treatment

45 (20%) of the 224 people with Hepatitis C were currently on treatment at the time of the survey.

Men (28%) were more likely than women (13%) to be currently on treatment.

Participants diagnosed in the past five years (31%) were more likely to be currently on treatment compared to those diagnosed more than five years ago (14%).

77% of those participants currently on treatment were on pegylated interferon plus ribavirin, 14% were on standard interferon plus ribavirin and 7% were on pegylated interferon alone.

Those whose last liver biopsy showed moderate (40%) or severe (43%) scarring were more likely to be currently on treatment compared to those with minimal or no scarring (17%).

Participants who had previously been told they had cirrhosis (41%) were more likely to be currently on treatment compared with those who had not (15%).

77% of participants were on pegylated interferon plus ribavirin, 14% were on standard interferon plus ribavirin and 7% were on pegylated interferon alone.

Issues that are important when deciding to take up treatment

- Effectiveness of treatment
- Relationship with doctor/specialist
- Liver status
- Supportive medical services
- Side-effects of treatment
- Having a supportive partner
- Accessibility of liver clinic

Greatest challenges to staying on treatment

- Side-effects associated with treatment
- Association of treatment with depression

Previously on treatment

65 (29%) of participants had previously been on antiviral therapies for Hepatitis C, and 55 (86%) of these had completed the treatment course. On average, participants had completed their previous treatment 2.7 years ago and the treatment was successful in clearing the virus for 24 (45%) of participants.

13% of participants were on pegylated interferon plus ribavirin, 71% were on standard interferon plus ribavirin and 16% were on pegylated interferon alone.

Issues that are important when deciding to take up treatment

- Effectiveness of treatment
- Liver status
- Side-effects of treatment
- Relationship with doctor/specialist
- Supportive medical services
- Other medical problems
- Having a supportive partner
- Accessibility of liver clinic

Greatest challenges to staying on treatment

- Side-effects associated with treatment
- Association of treatment with depression

Never been on treatment

114 (51%) people with Hepatitis C had never undertaken antiviral therapy.
Within this group:

- 26% not given any thought to treatment
- 20% considered treatment but still undecided
- 15% considered treatment and decided to take up treatment
- 39% considered treatment and decided against treatment

Women participants (54%) were significantly more likely than men (47%) to have never been on treatment.

What is important in deciding against treatment?

Side-effects of treatment

Treatment success rate is not good enough

Impact treatment will have on work

Liver status is good at the moment

Impact treatment will have on family/friends

Currently feeling really well

My doctor said that I shouldn't worry about treatment yet

Factors taken into account when considering treatment

Side-effects of treatment

Effectiveness of treatment

Liver status

Other medical problems

Relationship with doctor/specialist

Genotype

Having a supportive partner

Possible negative impact on work

Accessibility of liver clinic

Possible negative impact on family

General Practitioners

- 77% of GPs had diagnosed a patient with Hepatitis C, with 43% often or very often recommending a patient have a test for Hepatitis C
- Most GPs had cared for patients with Hepatitis C for longer than five years
- 75% of GPs had cared for between one and five patients within the past month
- 85% of GPs had less than 5% of their total patient base with Hepatitis C
- 35% had referred ALL patients with Hepatitis C on to a specialist
- 35% had referred less than half of their patients to a specialist

Specialist Physicians

The specialists surveyed had practised on average for 16.5 years (ranging from 1966-2003).

Of those specialists who treated patients with Hepatitis C (n=37)

- 56% managed/treated more than 50 patients with Hepatitis C in the last 12 months
- 84% had worked more than 5 years with Hepatitis C patients
- 57% spent less than 10% of their working time managing patients with Hepatitis C

Chapter 1: Why treat Hepatitis C? The background to this study

Hepatitis C

Hepatitis, or inflammation of the liver, can be caused by a number of very different agents such as viruses, bacteria and exposure to toxic substances. The most common cause of Hepatitis is a virus. Viral Hepatitis sometimes will cause an acute illness over a period of weeks, but rarely causes permanent damage to the liver. Of more concern is when viral Hepatitis persists beyond the initial acute infection to become a chronic illness. This may have serious consequences as a result of the scarring of the liver known as cirrhosis.

In 1988, the Hepatitis C virus was identified. This ended the practice that had endured for almost 20 years of identifying as 'non-A, non-B' a viral Hepatitis that was not attributable to either Hepatitis A or Hepatitis B. The diagnostic test to detect antibodies to Hepatitis C became available in Australia in February 1990. Hepatitis C is classified as a Ribonucleic Acid (RNA) virus, in contrast to Hepatitis A, B, D and E, which are made up of the genetically more stable Deoxyribonucleic acid (DNA). As a result, and in contrast to the other forms of viral Hepatitis, Hepatitis C is able to mutate more rapidly, resulting in the evolution of several different Hepatitis C genotypes. This, along with several other features, means that development of a vaccine for Hepatitis C is extremely challenging and is unlikely to be accomplished within the next decade (Thompson and Locarnini, 2001).

Hepatitis C is transmitted by blood to blood contact. Infected blood must enter the body of a person through being injected directly into their bloodstream, or through a rupture or skin opening. Transmission will only be successful if there is sufficient concentration of the virus in the infected blood. In addition to blood, Hepatitis C has been found in other body fluids, but at a concentration which is believed to be too low for transmission to occur.

In Australia, the greatest risk for the transmission of Hepatitis C is from the sharing or re-use of needles, syringes and other drug injecting equipment which have been contaminated by infected blood. Other types of behaviours which may involve blood-to-blood contact include tattooing, body piercing, needlestick injuries and vertical transmission from a mother with Hepatitis C to her baby. While not classified as a sexually transmissible infection, sexual transmission of Hepatitis C is possible if the sexual activity includes blood-to-blood contact.

Hepatitis C in Australia

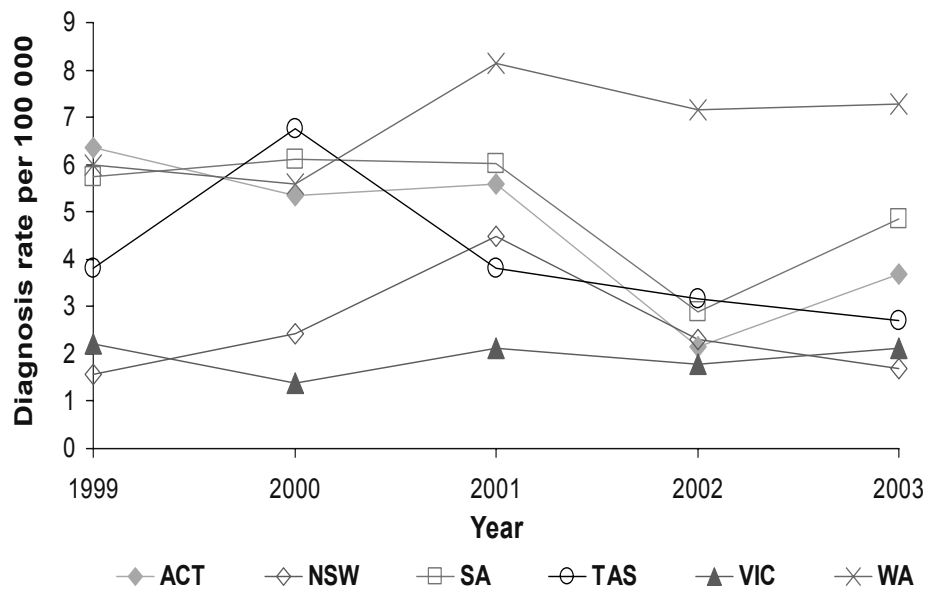
Hepatitis C is now an infectious disease of great public health significance in Australia. It is not randomly distributed among the Australian population and some groups who experience a range of social and economic disadvantages, both in terms of exposure to risks and in relation to access to optimal care, support and treatment, are more affected compared to other more advantaged groups (Crofts et al, 1999). In Australia more than 90% of newly diagnosed cases of Hepatitis C are related to injecting drug use and this further complicates the social picture of risk, support and care (Robotin et al, 2004). Chronic infections of many years standing are sometimes found among communities who migrated to Australia in the 1950s and 1960s. Hepatitis C is highly stigmatised, which impacts on prevention, care, support and treatment (Anti-Discrimination Board of NSW, 2001). Effective public health responses to prevention, support, treatment and care need to address not only individual knowledge, attitudes and behaviours but also acknowledge the changes needed in the wider social contexts that support and promote health (Emmons, 2000).

In 2003, the estimated prevalence of Hepatitis C in Australia was 242,000 cases (NCHECR, 2004). Of those infected with Hepatitis C, up to 25% will spontaneously clear the virus within the first six months following initial infection. Although spontaneous viral clearance has occurred up to two years after initial infection, this is extremely rare. Those whose initial infection was associated with an acute Hepatitis illness appear to be more likely than others to clear the virus spontaneously (Dore, 2004). Of the remaining 75% who develop chronic infection, between 10% and 20% will develop cirrhosis. Hepatitis C-induced cirrhosis is now the most common indication for liver transplants in many countries, including Australia. Based on such figures, NCHECR estimated that in 2003:

- 242,000 people living in Australia had been exposed to the virus
 - 61,000 had cleared their infection
 - 143,000 had chronic Hepatitis C infection with early liver disease
 - 31,000 had chronic Hepatitis C infection and moderate liver disease
 - 7,500 were living with Hepatitis C–related cirrhosis
- (NCHECR 2004)

Figure 1.1 shows the rate of new diagnoses of Hepatitis C on a state and territory basis. Although data are unavailable from Northern Territory and Queensland, it can be seen that Western Australia has consistently recorded the most new infections over the last three years. However, the prevalence of Hepatitis C is greatest in the eastern states, where the population is larger.

Figure 1.1: Newly acquired Hepatitis C infection by year and state/territory¹

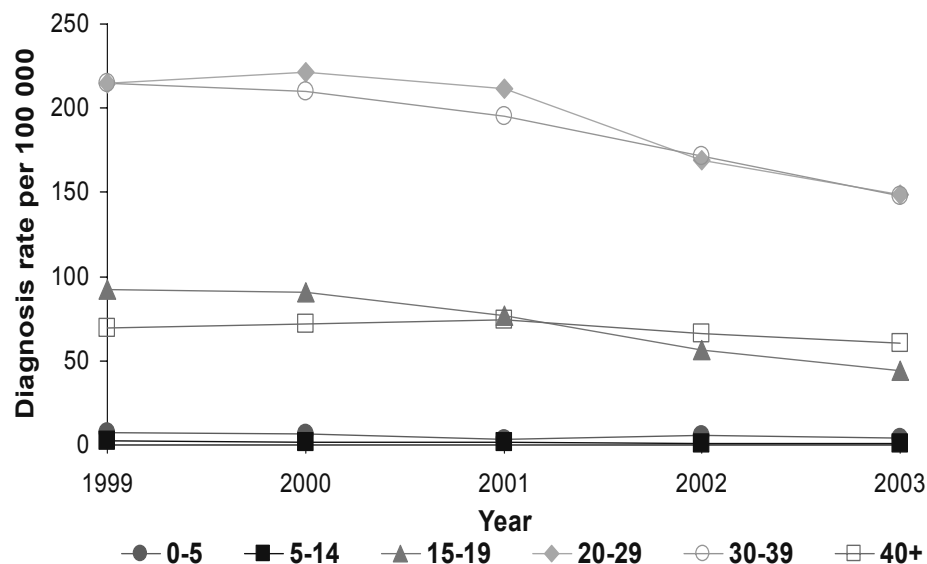


¹ Data not available from NT and QLD

Source: National Notifiable Diseases Surveillance System

Hepatitis C is transmitted at the highest rate amongst young adults, aged under 30 years of age, primarily amongst those who have a history of injecting drug use.

Figure 1.2: Hepatitis C infection by year and age group



Source: National Notifiable Diseases Surveillance System
2004

A number of studies have described the variation of Hepatitis C genotypes within the Australian population. Genotype 1 is the most prevalent (50-55%), followed by genotype 3 (35-40%), genotype 2 (8%), genotype 4 (3%) and other genotypes 6,7,8,9 (1%) (Dev et al, 2002). Some genotypes are associated with a particular demographic: those of younger age and who have acquired Hepatitis C recently more commonly have genotype 3, those with Hepatitis C who were Egyptian-born are often genotype 4, and genotype 6 is associated with being of South-East Asian origin (Baker et al, 1996; Chen et al, 1997; Mison et al, 1997; McCaw et al, 1997; Kaba et al, 1998).

Living with Hepatitis C

The symptoms of Hepatitis C have been well-described. Tiredness and lethargy, often to the point of exhaustion after a normal day at work, are common symptoms of Hepatitis C. Other symptoms include abdominal discomfort, nausea, anorexia, abdominal swelling, headaches and signs of coagulation disorder. Hepatitis C can also cause a number of symptoms which might initially appear unrelated to liver disease, such as skin eruptions. It is a feature of Hepatitis C that the severity of symptoms is not a good indication of the amount of virus in the blood or the presence of liver damage. The tiredness and lethargy experienced by those with Hepatitis C, can be quite marked in people with very little or no evidence of liver damage (Batey, 2003). Conversely, those with quite abnormal liver function tests and quite severe fibrosis may be completely asymptomatic (Dore, 2001a).

Chronic Hepatitis is staged at liver biopsy according to the extent of fibrosis of the liver:

- Stage 0 = no fibrosis (normal)
- Stage 1 = expansion of portal tracts
- Stage 2 = early fibrotic septa
- Stage 3 = linked fibrotic septa with early regenerative change
- Stage 4 = cirrhosis (definite or probable)

(Batey, 2003)

In the same way as the severity of cirrhosis is not always reflected in the degree of Hepatitis C symptoms experienced, neither an individual's liver damage nor the extent of their symptoms can be used as an accurate guide to the psychosocial impact of Hepatitis C. The level of illness perceived by an individual is affected by a wide variety of factors, including their sensitivity to the stigma unfortunately so often associated with Hepatitis C.

Treatment for Hepatitis C

Pathways to treatment

Typically, a person with Hepatitis C is most likely to be diagnosed by a GP. Testing for Hepatitis C by Polymerase Chain Reaction (PCR), which is the only way to detect the presence of active virus in serum, attracts a Medicare

rebate (Kidd, 2003). However, not all people with Hepatitis C will see a GP. Some will be diagnosed within the Alcohol and Drug sector, and this could be as part of hospital-based or home-based withdrawal, or simply as a result of contact with the health system in relation to injecting issues. In some of these cases, other health or welfare issues may be more pressing and Hepatitis C may be of minor concern to both client and practitioner. In this situation, a referral to a liver clinic or specialist is unlikely, and the availability of treatment may barely be mentioned by the practitioner or absorbed by the client.

One of the key issues which should be discussed during post-test counselling is treatment. A referral to a specialist is necessary in order to determine eligibility for, and commencement of, treatment. Specialist referral is therefore a key factor in the treatment pathway.

There is limited guidance, however, for GPs in relation to when to refer a patient with Hepatitis C to specialist care. Some specialists would like to see patients shortly after diagnosis; others prefer to receive referrals for particular reasons (see discussion in Chapter 5). Information offered to GPs in three very accessible guides to Hepatitis C is compared in Table 1.1, and shows the variety of recommendations which are made. It also suggests why many GPs are unaware of exactly when they should refer a patient to a specialist, especially as 'not every person with a positive anti-HCV test result will require specialist referral' (Kidd et al, 2003).

Table 1.1 – Recommendations for GP referral of patients with Hepatitis C

ANCAHRD* 2003 , page 21	People with Hepatitis C 'should be encouraged to attend a liver clinic or specialist on at least one occasion'
Kidd et al, 2003, page 26 The Hepatitis C Update Australian Family Physician	• An indeterminate diagnosis of Hepatitis C • People who 'appear suitable for treatment' and who would be prepared to undertake it • People with signs of liver disease • People with suspected liver cancer or who may be suitable for a liver transplant • Anyone who requests a referral
Harley et al, 2003 The Hepatitis C Update Australian Family Physician	A patient with clinical evidence of liver disease or persistently abnormal ALT levels (levels of enzymes production in the liver, the most commonly monitored enzyme is the alanine aminotransferase, ALT) should be referred to a specialist after screening for other causes of chronic liver disease has been conducted.

* Australian National Council on AIDS, HIV and Related Diseases

Aim of treatment for Hepatitis C

The aim of treatment is to prevent progression of the infection and thereby 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 is severely affected. For some, treatment prevents the advance 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 them anxiety about transmission to others, 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. However, 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).

Many patients with Hepatitis C favour natural or herbal remedies. Few herbal medicines have been evaluated in clinical trials; indeed, as most natural therapies focus on the whole person rather than the treatment itself, it can be argued that clinical trials are an invalid way of testing natural therapies of any kind (Arachne, 2001). The kinds of complementary therapies most commonly used by people with Hepatitis C include liver cleansing diets, naturopathic diets, and herbal or homeopathic treatments.

Eligibility for treatment

Unfortunately, not everyone with Hepatitis C is eligible or suitable for treatment with antiviral therapy. The Pharmaceutical Benefits Scheme has established a list of criteria which must all be satisfied for antiviral therapy to be funded by Medicare:

- Moderate to severe liver inflammation evident on liver biopsy
- Abnormal serum ALT levels in conjunction with chronic Hepatitis C infection (determined by blood-test)
- Not pregnant or breast feeding, and both male and female patients *and their partners* to undertake adequate contraception.

The course of treatment is limited by the patient's genotype and the extent of liver damage. Patients who are eligible for a full course of treatment may have this withdrawn after the first 12 weeks if their body's response to treatment does not result in a specific decrease in viral load (Hepatitis C Council of Victoria, 2003).

Antiviral therapy for Hepatitis C

Antiviral therapy for Hepatitis C uses interferon, a synthetically manufactured protein which mimics the interferon naturally produced by the body in response to any viral infection. It is given in much higher doses than the body would normally produce, thereby boosting the body's immune response and

inhibiting viral replication. The first report of the use of interferon to treat non-A, non-B Hepatitis (subsequently renamed as Hepatitis C) was in 1986 (Hoofnagle et al, 1986). For many years, interferon was used alone as a treatment for Hepatitis C. This is known as monotherapy, and is generally given as a thrice weekly subcutaneous injection for a period of up to 12 months. In 1998, studies showed that a more sustained virological response was achieved when treatment with interferon was combined with ribavirin (Poynard et al, 1998; McHutchison et al, 1998). Ribavirin is not effective alone in treating Hepatitis C, but when used in conjunction with interferon, reduces the likelihood of a relapse after treatment is completed. The precise mechanism by which this occurs is unknown (Sievert, 2003).

Recent randomised trials have shown that treatment with pegylated interferon is more effective than treatment with interferon and ribavirin (Manns et al, 2001; Fried et al, 2002). Pegylation refers to the addition of large molecules of polyethylene glycol to standard interferon which delays its excretion by the kidneys. Conventional interferon therapy requires three injections a week, but a single injection of pegylated interferon can ensure the level of interferon is sufficiently sustained to reduce the chance of the Hepatitis C virus multiplying between doses (Cheng, 2003).

The current international gold standard for Hepatitis C treatment is a combination of pegylated interferon, 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. Treatment generally lasts for 6 or 12 months. Viral load levels are monitored closely during treatment. The decision to persist with 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.

While there appears to be no association between genotype and the progression of disease; this is not the case for the association between genotype and 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 is most successful with those with genotypes 2 and 3. About 30% of patients with genotype 1 compared with approximately 65% of patients with genotypes 2 and 3 have a sustained virologic response. Better treatment response is associated with being female, younger (below 40), and with shorter duration of infection. There is also a more positive outcome for those of Caucasian or Asian ethnicity, the absence of stage 3 or 4 fibrosis, low viral load and for those who abstain from alcohol (Dore, 2001b).

Australian researchers have recently been funded to examine the feasibility and efficacy of the use of pegylated interferon for people with acute or newly diagnosed Hepatitis C. The Australian Trial of Acute Hepatitis C is multi-centred, and will follow the progression of illness in 240 people, half who are treated and half who are not, for 3 years (Dore, 2004).

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 (Dore, 2004). In fact, even after a liver transplant, it is likely that Hepatitis C will reappear in the new liver.

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 current 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, thrombocytopaenia
- **Induction of autoimmunity**
Overactive thyroid, psoriasis or worsening of these
- **Cardiac**
Arrhythmia, congestive failure
- **Susceptibility to infection**

Ribavirin causes four major types of side-effects:

- **Haematological**
Haemolytic anaemia
- **Respiratory**
Cough, breathlessness, pharyngitis, sinusitis
- **Rash**
- **Embryonic development**
Possible birth defects

(National Hepatitis C Resource Manual, 2001)

How many people in Australia have received antiviral therapy?

Despite advances in antiviral therapy for Hepatitis C in recent years, treatment rates in Australia remain low. Annual estimates of the number of Australians who have received antiviral therapy are:

- 2001 1650 prescriptions for Hepatitis C treatment; primarily interferon and ribavirin combination therapy (NCHECR 2002).
- 2002 1640 prescriptions for interferon and ribavirin combination therapy (NCHECR 2003).
- 2003 1285 prescriptions for interferon and ribavirin combination therapy (NCHECR 2004).

Recent estimates project a four-fold increase in the number of people with Hepatitis C-related cirrhosis in Australia over the next twenty years (NCHECR, 2002; Law et al, 2003), making Hepatitis C a significant public health problem. While the decision to pursue medical treatment for Hepatitis C must remain 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. As treatments continue to improve, and better control of side-effects is achieved, it is likely that demand for treatment will increase.

Complementary therapy

Recent years have seen an increase in the use of natural therapies by people in many Western countries. Australia is no exception to this. A survey of 1000 Australians found that almost half had consulted an alternative practitioner (Pickworth and Lai, 2000, cited in Arachne, 2001). The contribution that natural therapies can make has also been acknowledged by the medical profession. In a study of almost 500 Victorian GPs, over 80% had referred patients on to complementary therapy, such as hypnosis, acupuncture or meditation (Pirodda et al, 2000).

Natural therapies have arisen as a result of a wide variety of philosophies, some of which are ancient, while others are relatively new. The assumptions which underlie different natural therapies can differ dramatically, making it inappropriate to consider them all as a single modality. Similarly the practitioners of these therapies may differ in their depth of training, and so assessing the benefit of such therapies can be challenging. Some of the complementary therapies commonly used in Hepatitis C treatment are:

- Traditional Chinese medicine
- Western herbal medicine
- Herbal medications such as St. Mary's Thistle, licorice root and dandelion
- Acupuncture
- Naturopathy

- Massage
- Meditation
- Vitamin and dietary supplements

(National Hepatitis C Resource Manual, 2001, page 128)

In some states and territories in Australia, complementary practitioners are unregulated. It is therefore advisable for people with Hepatitis C seeking alternative therapy to select a complementary practitioner with care, and to ensure they have qualifications in the field and are members of an appropriate professional body. Practitioner knowledge of Hepatitis C is also important, as some herbs can be toxic to the liver.

Costs of treatment

There are a number of costs associated with treatment for Hepatitis C.

Costs of tests to determine the genotype and viral load, and liver biopsies are refunded by Medicare for patients who are being evaluated for treatment by liver clinic staff. Although the full cost of antiviral treatment is funded by Medicare, hospital pharmacies generally charge (\$23.10 or \$3.70 for Health Card holders) for dispensing each monthly script. Antiviral therapy can be purchased on prescription through a doctor or a specialist, but is a very expensive option as unsubsidised costs of combination therapy have been estimated at \$25,000 per year (Australian Hepatitis Council, 2004).

Associated costs of treatment for Hepatitis C include time lost from work, travel and costs associated with attending for treatment and cost of medications required to keep side-effects under control.

Complementary therapies can be extremely expensive. While these therapies do not receive a rebate under Medicare, some therapies are covered under private health insurance.

Australian social research on Hepatitis C antiviral therapy

While there is good understanding of clinical factors that may enhance successful treatment; there is very little information currently available about the social and psychological factors that influence the success of treatment. Given that treatment lasts between 6 and 12 months, it has the potential to have an enormous impact on the personal and the professional lives of those undertaking treatment. For some people the combination of physical and psychological side-effects of treatment is compounded by their efforts to maintain their usual lifestyle. This can be so overwhelming that they feel forced to withdraw from treatment. For others, anxiety about the level of difficulty of the treatment process prevents them from taking up this option. What are the social and health needs of people undergoing treatment? What assists people to take up and remain on treatment?

In comparison to clinical research, there has been little Australian research conducted on the social and health needs of people with Hepatitis C in general. Much of this research has been carried out by team members of the Hepatitis Social Research Program, a collaboration initially between La Trobe and Deakin Universities and community organisations. Deakin team members have recently relocated to La Trobe University, and the Research Program will continue under the auspices of the Australian Research Centre in Sex, Health and Society. The Program undertook two large scale studies, one of women (*Living with Hepatitis C* in 2000-1) and one of men (*Men, Health and Hep C* in 2002-3). The participants in these studies were recruited somewhat differently from those in the treatment study (2003-2004) which forms the basis of this report. These results help to provide a broader picture of those with Hepatitis C. Some details about these studies and the 3D study by NCSHR are provided in Appendix 1.

Previous research on Hepatitis C

Symptoms

In the *Living with Hepatitis C* study, a largely non-clinical sample of 462 women with Hepatitis C in Victoria and ACT, those symptoms most frequently recorded were tiredness (78%), nausea (44%) and psychological and emotional problems (25%) (Gifford et al, 2003). Amongst the 308 Victorian men in the *Men, Health and Hep C* study (2002-3), tiredness (61%), nausea (30%) and liver pain and swelling (22%) were most commonly reported (Gifford et al, 2004).

Many of these men (35%) and women (48%) with Hepatitis C rated their health as poor to fair in comparison to only 18% of men and 17% of women as assessed by the Australian National Health Survey (Gifford et al, 2003; 2004).

Health care use

Most (75%) participants in the 3D Project were diagnosed with Hepatitis C by a doctor, although information on where the diagnosis took place was not collected. Questions on diagnostic setting were included in the *Living with Hepatitis C* and *Men, Health and Hep C* studies, and showed that most were diagnosed in the general practice setting (63% men, 64% women) (Gifford et al, 2003; Gifford et al, 2004). Other places of diagnosis included hospitals (men 12%, women 13%), prison/detention centres (men 11%, women 2%), alcohol and drug clinics (men 8%, women 8%) and sexual health services (3% men, 7% women), and the Blood Bank (men 4%, women 6%).

Results from the men's and women's studies suggested that men and women with Hepatitis C do not seek and use health care in the same way. These differences were independent of time since infection and diagnosis, and self-reported health status. Men tended not to seek medical support for their Hepatitis C unless they had symptoms which required medical intervention. In contrast, physically healthy women with no symptoms were likely to see a

doctor for Hepatitis C, but interestingly more often perceived discrimination from health professionals. Current IDUs used medical services least frequently (Temple-Smith et al, 2003).

Patterns of referral to a specialist were consistent for both men and women in the *Living with Hepatitis C* (2000-2001) and *Men, Health and Hep C* (2002-2003) studies. At the time of diagnosis, 39% of women were referred on to a liver clinic and since being diagnosed 52% of women had been referred. Women who had never injected (73%) were more likely to have been referred to a liver clinic than past IDUs (66%) or current IDUs (32%) (Gifford et al, 2003).

Referrals for men were less frequent. Thirty percent of men were referred to a specialist on diagnosis, and since being diagnosed, 37% had been referred to a liver clinic. Men who had never injected (72%) were more likely to have been referred to a liver clinic than past IDUs (62%) or current IDUs (18%) (Gifford et al, 2004).

Treatment

In the *Living with Hepatitis C* study, only 17% (7% interferon alone, 10% combination therapy) of women had received treatment, and this was associated with the length of time since infection. Women who had previously injected drugs were less likely to have received treatment. Of the women who had never received treatment, the main reasons offered were that they had never heard of treatment (27%), they were not eligible (16%) or that they had decided against it because of the side-effects (17%). One third of women had tried alternative therapies in the last 12 months (Gifford et al, 2003).

Twenty percent of men in *Men, Health and Hep C* study reported receiving treatment for their Hepatitis C; 6% had received interferon alone, and 14% reported having had combination therapy. Similarly to the women's study, men who had been infected for longer were more likely to have received treatment, and those who had previously injected drugs were less likely to have been treated. Of the 80% of men who had never received treatment, an alarming 42% had never heard of treatment, 34% stated they did not need it as they were currently healthy, and 26% were concerned about side-effects. One third of the men had tried alternative therapies in the last 12 months (Gifford et al, 2004).

Around 10% -11% of approximately 500 participants of the 3D study conducted in NSW had received treatment; these people were more likely to be older and have had their infection for more than a decade. In keeping with this, participants who were referred to a specialist were significantly more likely to be over 45 years of age. Ex and current injecting drug users were less likely to have received treatment than those who had never injected (Hopwood and Treloar, 2003).

A Needs Assessment conducted by the Australian Hepatitis Council found that reasons for deciding against treatment centred around the perceived

difficulties of managing the more challenging side-effects, such as depression, as well as an inability to be able to modify daily life to accommodate the difficulties that being on treatment might create. Some people had not considered treatment because they knew nothing of it, while others knew of it, but were ineligible either because their liver function was normal or because they had too much liver damage to tolerate treatment.

For those who had undergone treatment, side-effects were the most challenging aspect. Support from others was paramount – not only from family and friends, but also from health professionals. Higher retention in treatment was evident when people were adequately prepared and well supported by an appropriate health service. The Needs Assessment found that people with Hepatitis C from priority population groups did have difficulty in accessing treatment. These included Indigenous Australians, those of culturally and linguistically diverse communities, rural residents and prisoners.

This report highlighted the fact that while liver clinics are being accessed by a wide range of people with Hepatitis C, the numbers undergoing treatment are still lower than could be expected. One explanation for this is that many people referred to the liver clinics by general practitioners are in fact ineligible for treatment (Australian Hepatitis Council, 2003).

Decisions about treatment

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.

Minimal research has been undertaken into examining the routes into treatment for Hepatitis C and decisions about the uptake of treatment from the perspective of the potential patients and prescribing physicians. From the existing Australian research it is evident that there are a range of factors influencing decisions to commence treatment and to adhere to treatment including economic factors, concerns of side-effects, concerns about the impact of compliance requirements on family and work commitments, and perceptions of discrimination by treatment staff. 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).

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 (O'Brien and Gifford, 2001).

Decisions not to begin treatment at any given time may also have psychological consequences. Conversely, a non-successful outcome of a

long course of therapy can also be detrimental to a person's health physically, psychologically and socially. The picture is further complicated by the fact that sustained response rates to a second course of treatment are extremely low. A review of 13 studies estimated the response rate to be between 1% and 3% (Alberti et al, 1997).

Conclusion

Decisions to take up treatment are not straightforward. Treatment involves a heavy time and possibly heavy financial commitment, involving weekly visits to a hospital or prescribing place for between six and twelve months. There are also the possible side-effects described above. The fact that symptoms of Hepatitis C are sometimes not as significant for an individual as the side-effects of treatment makes the decision to begin treatment particularly difficult for some. Uncertainty associated with the success of outcome may also limit willingness to begin and maintain treatment. Finally, there are potentially serious life changes required e.g. abstinence for alcohol, from drugs, and pregnancy (as one treatment drug is teratogenic). For those with an unsupported or unstable way of life, the required changes in lifestyle may be particularly difficult to achieve and sustain.

There are also a number of decisions to be made on the part of the medical practitioner managing a patient with Hepatitis C. When should the patient be referred to a specialist? Does the patient have a pre-existing psychiatric condition that might be exacerbated by the treatment? Are there risks of re-infection? Will the patient have appropriate social support from their family or wider social network?

This project aims to provide a fuller understanding of the issues that are relevant to the uptake and maintenance of treatment for Hepatitis C. The study which forms the basis of this monograph is unique because it examines treatment issues from three different perspectives – that of people with Hepatitis C, the General Practitioner and the Specialist Physician. In addition, the views of people with Hepatitis C who have considered but rejected treatment, as well as those who have previously been on treatment, and those who are currently on treatment were sought. This has provided a wealth of data which can be used to improve Hepatitis C treatment uptake and adherence to treatment.

Chapter 2: The study: Now, later or never? Challenges of Hepatitis C treatment

The ARCSHS Treatment Study aimed to develop a fuller understanding of the barriers to uptake of treatment for Hepatitis C. The study was particularly concerned with social and psychological concomitants of treatment uptake and with those factors that enhanced or impeded treatment adherence. The aims of the research were:

- To identify social and psychological barriers to the decisions to begin treatment for Hepatitis C
- To understand further the variables that influence successful adherence to treatment

Both qualitative and quantitative research methods were used in the study.

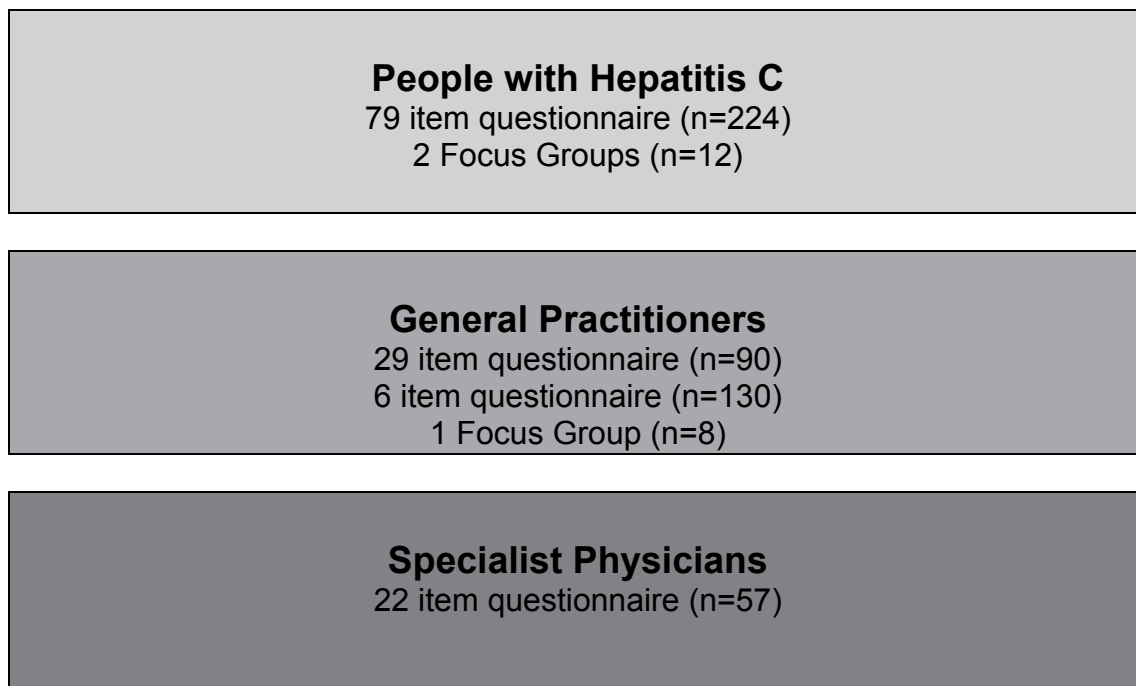
Three population groups were of interest in this research:

- People with Hepatitis C
- General Practitioners
- Specialist Physicians

People with Hepatitis C were asked to provide information on facilitators and barriers to treatment. Antiviral therapy treatment for Hepatitis C is managed by a Specialist Physician, to whom a patient is referred by a GP. To ascertain whether any structural barriers existed for patients who wished to access Specialist Physicians, information on Hepatitis C, including Hepatitis C caseload, was sought from both GPs and Specialist Physicians.

The study was conducted in 2003-2004. Questionnaires for people with Hepatitis C, GPs and Specialist Physicians were administered during the period from August 2003 until April 2004. Focus groups were conducted with people with Hepatitis C and GPs, and these were completed by May 2004. The sampling framework is shown in Figure 2.1.

Figure 2.1 Sampling Framework



People with Hepatitis C

Questionnaire for people with Hepatitis C

Community and professional consultation informed the development of the research instrument. Consisting of 79 items, the self-administered questionnaire covered issues such as diagnosis with Hepatitis C, pre- and post-test counselling, health and medical care received for Hepatitis C, current health and well-being, reasons for starting, stopping or deciding against treatment for Hepatitis C and challenges associated with staying on treatment.

Given that so little is known of treatment issues from the perspective of the person with Hepatitis C, no attempt was made to recruit participants randomly. The study aimed to collect information from as many eligible participants as possible within the financial confines of the study. It was also the intention to recruit people who had never experienced treatment, who were currently on treatment, and people who had completed treatment. Participants were recruited from a range of sites in Victoria including liver clinics at major hospitals (Monash Medical Centre, Alfred, Box Hill, Maroondah and Ballarat Hospitals), needle and syringe exchanges, and community health centres. The project was widely advertised using posters, pamphlets, community radio 3CR (*Hep Chat* program), the *Good Liver* (Newsletter of the Victorian Hepatitis C Council), and other community newsletters. Invitations to participate were also sent to men and women who had been involved in the *Living with Hepatitis C* and *Men, Health and Hep C* studies, and who had

completed a form saying they would be happy to be contacted about future studies. All interested persons were encouraged to participate. Both urban and rural participants were sought. A total of 800 questionnaires were distributed.

Focus groups for people with Hepatitis C

Two focus groups were held with 12 participants (5 men, 7 women) to investigate particular issues in more depth. The focus groups were guided by a theme list derived from the findings of the survey component of the study. The discussions were audio recorded and the transcripts thematically analysed.

General Practitioners

Questionnaire for GPs

A 29 item questionnaire was administered with the assistance of the Northern Division of General Practice (Melbourne). The catchment of the Northern Division comprises the City of Whittlesea, the northern portion of the City of Darebin, and the City of Moreland east of Sydney Road in Melbourne. A one page brief about the project was placed in the Northern Division's bimonthly news bulletin, *Division News*. The study was also advertised in the Division's weekly *Friday Fax*. A total of 455 questionnaires were posted to all GPs who were registered as members with the Northern Division of GPs.

In addition to demographic information, the 29 item survey included questions on sources of Hepatitis C knowledge, involvement with Hepatitis C patients, reasons for testing for Hepatitis C, referral practices, shared care, and difficulties in managing patients with Hepatitis C.

A follow-up one page questionnaire containing 6 items from the original questionnaire was sent to all GPs in the Northern Division area. GPs were asked to fax the one page questionnaire back only if they had not already returned the full 29 item questionnaire. The aim of the one page, faxed return, questionnaire was to determine the number of GPs who were not treating patients with Hepatitis C, and to increase the sample size around the issue of Hepatitis C caseloads.

Focus group for GPs

A focus group was held with eight GPs (3 men and 5 women) at the Northern Division of GPs. The aim of the focus group was to further elucidate particular aspects of the study. The group was facilitated by a GP with extensive experience in managing patients with Hepatitis C. The discussion was audio recorded and fully transcribed.

Specialist Physicians

Questionnaire for Specialist Physicians

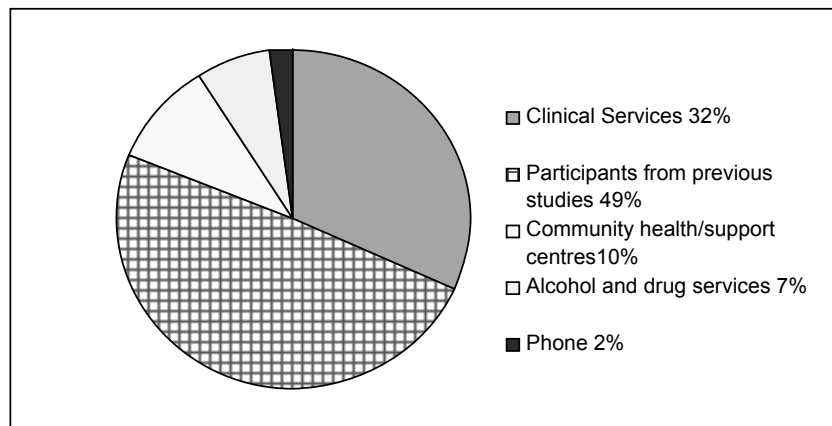
Specialist Physicians were invited to complete a 22 item self-administered questionnaire. The questionnaire was mailed to 113 specialist physicians working in the area of Hepatitis C throughout Victoria using the mailing list provided by Gastroenterological Society of Australia (GESA).

The questionnaire covered a range of topics, ranging from sources of Hepatitis C knowledge, involvement with Hepatitis C patients, referral preferences, shared care, reasons for and barriers to adherence to Hepatitis C treatment.

Chapter 3: People with Hepatitis C

A total of 224 people with Hepatitis C completed the survey for the study. Participants were recruited from a variety of settings, including clinical services, drug and alcohol services and community networks. As can be seen from Figure 3.1, approximately half of the participants were accessed through their involvement in the studies *Living with Hepatitis C* and *Men, Health and Hep C*. Men and women in these studies were themselves recruited from a number of sources. Given that the vast majority of those with Hepatitis C in Australia acquired the infection through injecting drug use, particular effort was made in these studies to recruit current injecting drug users through outreach organisations, to ensure that the experiences of those who may have less access to health services were not overlooked.

Figure 3.1 Recruitment of people with Hepatitis C



In this chapter, the responses from people with Hepatitis C are presented in four sections:

- 1. Results from the total sample of people with Hepatitis C**
- 2. Those currently undergoing treatment**
- 3. Those who had previously received treatment**
- 4. Those who have never received treatment**

The last group (Those who have never received treatment) was further divided into four groups, covering those who:

- Had not thought about treatment
- Were considering treatment
- Had decided to commence treatment
- Had decided against treatment

For ease of reading, where appropriate, results are presented in tabular or list format. Headings which have been **bolded** and underlined consist of the actual question used in the survey.

Demographics of total sample:

- Over half the sample were women (53%)
- Average age = 43 years (SD 9.4)
- Age range 15 to 63 years
- 81% born in Australia
- 49% had completed high school; an additional 23% had completed a tertiary degree
- 54% employed either full or part-time
- 26% unable to work due to illness
- 35% earned less than \$250 per week
- 50% owned or were paying off their own house or flat; 13% were living in public/community housing
- Only one person (0.5%) identified as an Aboriginal or Torres Strait Islander
- 36% were rural/regional residents

In what year were you diagnosed with Hepatitis C? (n=213)

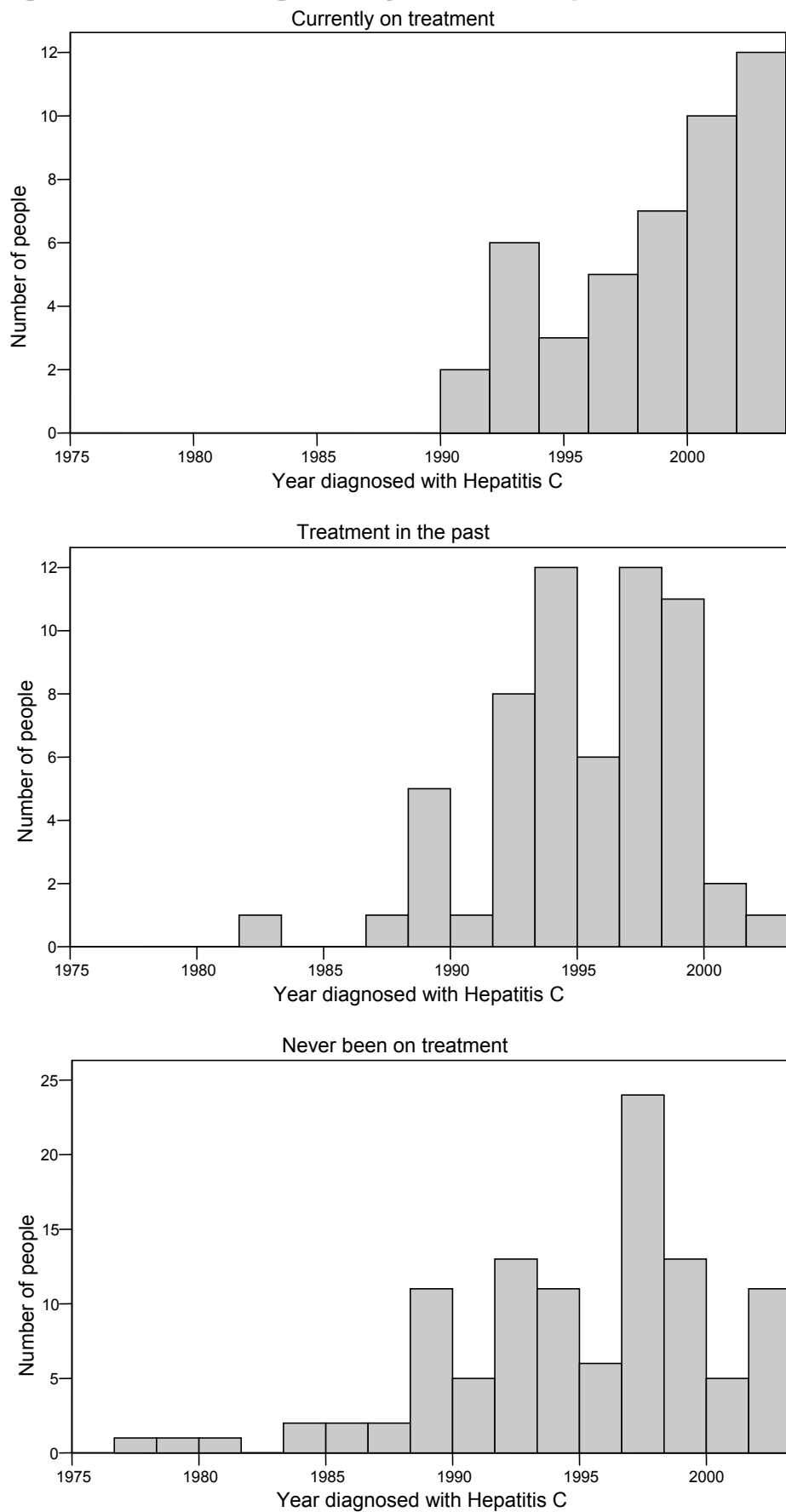
- The average time since diagnosis of Hepatitis C was 7 years, (SD = 4.8) ranging from 1997-2003, with 25% of participants diagnosed ten or more years ago.
- The average time since contracting Hepatitis C was 18 years, (SD = 9.7) ranging from 1950-2003, with 25% of participants contracting Hepatitis C in the past ten years.

The mean year of diagnosis for participants currently on treatment was 1998. The mean year of diagnosis for participants on treatment in the past was 1995.

The mean year of diagnosis for participants who had never been on treatment was 1995.

These were significant differences; ($F(2,210) = 8.076, p < 0.001$).

Figure 3.2 Year of diagnosis by treatment experience



How do you think you got Hepatitis C? (n=209)

Mode of infection	%
Injecting drug use	62
Blood transfusion	14
Tattooing	3
Unsafe/unsterilised equipment	2
Body piercing	1
Don't know	13

In general, would you say your health is... (n=220)

Health	%
Poor to fair	47
Good	35
Very good to excellent	18

Have you ever in the past experienced any symptoms which you believe are related to Hepatitis C? (n=216)

180 people (83%) had experienced symptoms which they believe were related to Hepatitis C. The most common symptoms experienced by this group were:

Hepatitis C related symptoms	%
Fatigue/lethargy	96
Lack of energy	92
Aches and pains	73
Liver pain	63
Poor concentration	61
Joint pain	59

Are you currently experiencing any symptoms which you believe are related to Hepatitis C? (n=212)

134 respondents (63%) were currently experiencing symptoms; 19% were not currently experiencing symptoms and 18% were not sure if they were experiencing symptoms connected to Hepatitis C.

Of the 134 respondents who were experiencing symptoms, at least half were experiencing one of the following symptoms:

Symptoms	%
Fatigue/lethargy	87
Lack of energy	81
Aches and pains	61
Poor concentration	52
Joint pain	50
Liver pain	49

Have you ever had a Hepatitis C test? (n=213)

This question included the following explanation: “This is also called an anti-HCV or Hepatitis C antibody test. It looks to see if your body has produced antibodies to fight the Hepatitis C virus, but does not look for the virus itself.” The initial screening test for Hepatitis C is an antibody test. After infection it can take up to 6 months before antibodies can be detected. A Hepatitis C polymerase chain reaction (PCR) test can be performed to detect the active presence of the virus, the viral load and the genotype of the virus. One hundred and fifty one (71%) of respondents stated that they have had a Hepatitis C test, a further 25% (n=53) were unsure whether they had had such a test, the remaining 4% stated that they had not had such a test.

Of the total sample, 151 (71%) reported having had a Hepatitis C test.

How did you first come to be tested for Hepatitis C? (n=216)

The most common reasons for being tested were:

Reason	%
My doctor suggested it	31
I asked for a test	24
Routine screening (e.g. part of antenatal tests, prior to surgery, for becoming a blood donor, a health exam for a new job/superannuation/entering prison/entering treatment)	20

Who ordered this test? (n=159)

Who ordered test	%
General Practitioner (GP)	51
Doctor in a hospital clinic	28
Doctor in a community health centre	5
Doctor at a drug & alcohol service	5
Doctor in a jail/detention centre	2
Doctor in a sexual health clinic	1
Other	11
<i>(Missing: n=65)</i>	

Hepatitis C tests were most commonly ordered by General Practitioners.

Have you ever had a PCR test to confirm that you have had the Hepatitis C virus? (The PCR test is used to detect small amounts of the virus in your blood.) (n=217)

Sixty-nine percent of participants had had a confirmatory PCR test, 23% were not sure whether they had had such a test.

Who ordered this test? (n=147)

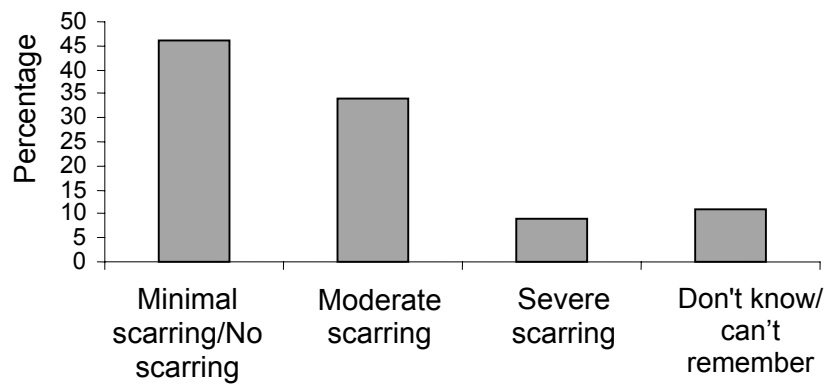
Who ordered test	%
Doctor in a hospital clinic	48
General Practitioner (GP)	31
Doctor in a community health centre	4
Doctor at a drug & alcohol service	1
Doctor in a jail/detention centre	1
Other	15
<i>(Missing: n=77)</i>	

PCR tests were most commonly ordered by a doctor in a hospital.

Have you ever had a liver biopsy?

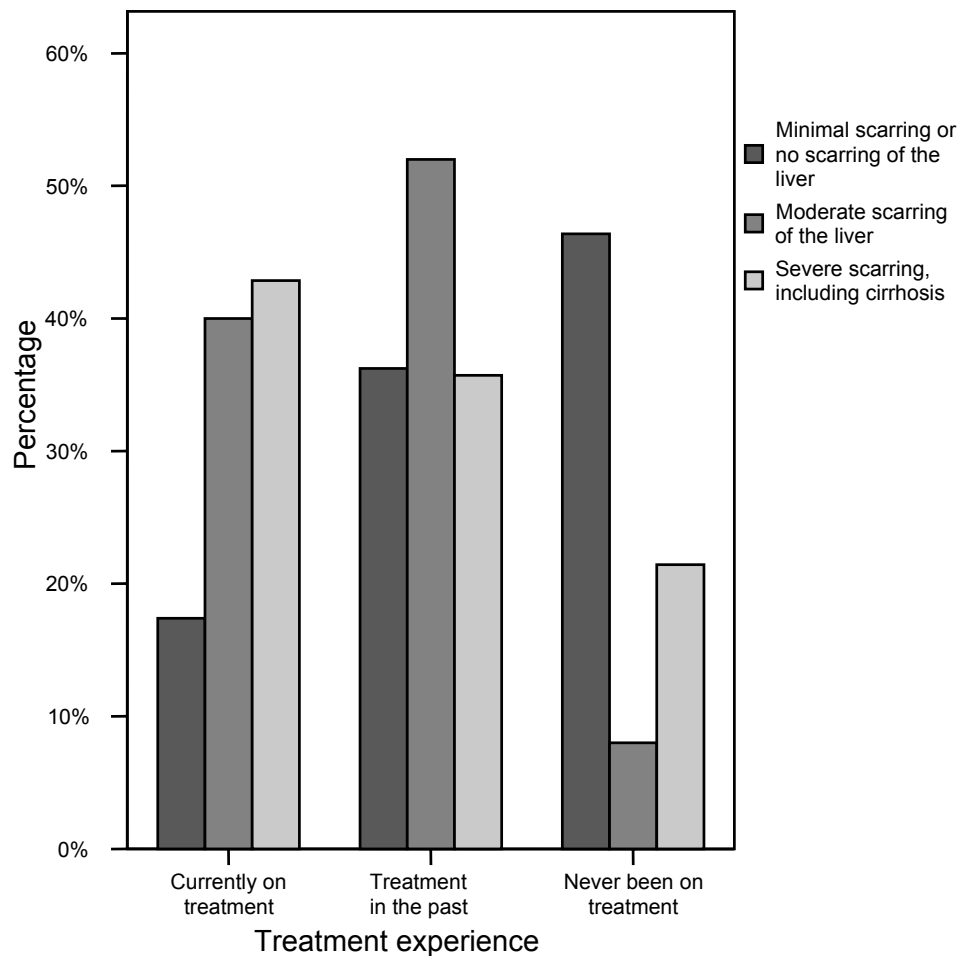
Most participants in the sample had had a liver biopsy (68%). Of these participants who had had a liver biopsy almost half had minimal scarring.

Figure 3.3 Liver scarring reported from most recent biopsy (n=223)



- 46% reported that their most recent biopsy showed minimal scarring
- 34% moderate scarring
- 9% severe scarring, including cirrhosis
- 11% don't know/can't remember

Figure 3.4 Liver scarring by treatment experience



Remarks from focus group

Some participants expressed frustration at being unable to access treatment under the Pharmaceutical Benefits Scheme, because their level of liver damage was not sufficiently severe to be eligible for reimbursed treatment.

‘...even though the treatment sucks... I wanted to clear this and get on with my life instead of having to be sick. I’m not eligible for treatment. I guess I have to wait and hope that it never gets worse...if some other treatment regime comes up which the PBS will pay for without you having to have, you know, extreme liver damage, then I’ll do it’ (FG 2).

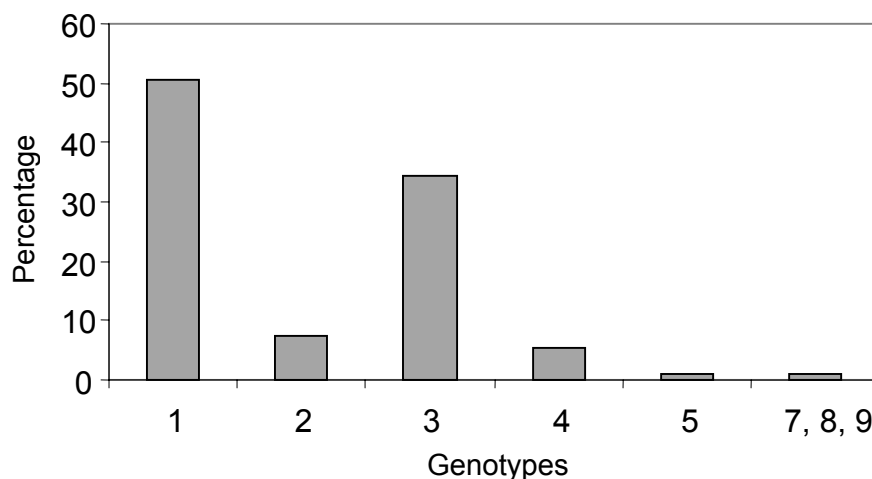
Have you ever been told that you have cirrhosis? (n=215)

14% had been told they had cirrhosis.

Do you know your Hepatitis C genotype? (n=199)

61% of participants had been told their Hepatitis C genotype but only 39% could remember what it was. The most common were genotype 1 (51%) and genotype 3 (34%), with 8% identifying genotype 2 and 5% genotype 4.

Figure 3.5 Hepatitis C genotype



Before you had the Hepatitis C test were you given information or counselling about Hepatitis C? (n=222)

Unlike in the case of HIV pre-test counselling, Hepatitis C pre-test counselling is not mandatory, although it is recommended. Only 10% of participants recalled receiving pre-test counselling.

Since the time you received your test result, have you been given any of the following information by a doctor/nurse/counsellor? (n=211-221)

Since receiving their diagnosis many participants reported receiving information on particular topics.

Information received about:	%
Keeping alcohol intake down	92
How Hepatitis C is transmitted	88
How to reduce transmission to others	85
Liver damage from Hepatitis C	84
How Hepatitis C may affect your health	82
Treatments that are available	80
Possible side-effects of treatments	76
How to access treatments	67

Fewer participants had received information about other issues.

Information received about:	%
Vaccination against Hepatitis B	53
How to understand test results	48
Vaccinations against Hepatitis A	47
The significance of Hepatitis C genotypes	45

Since receiving their diagnosis some participants reported receiving no information about:

Information not received about:	%
A referral to a health care worker	64
Vaccination against Hepatitis A	45
How to understand the test results	43
Significance of genotype, including own genotype	40
Vaccination against Hepatitis B	39
How to access treatment	26

Most participants (81%) had received a referral to a specialist clinic (n= 218). Other referrals for further support were to health care workers (33%), information about Hepatitis C community services (58%) and information about alternative therapies for Hepatitis C (32%).

Please indicate the importance of the following resources in helping you manage your Hepatitis C (n = 207-212)

Participants most commonly rated the following medical practitioners as being important in managing their Hepatitis C:

Medical Practitioner	%
Doctors at a liver clinic	64
Specialist physicians	53
Normal GP	46

Focus group participants expressed the view that support was an important issue in deciding to undergo treatment:

‘I’d like to be able to ring up a specialist or a doctor or someone and say “What do I do if this is happening?” or have those sort of links and I haven’t felt overly confident from the specialist or the GP that that would actually happen if I went on treatment’ (FG 1).

Fewer participants rated the following resources as important in helping to manage their Hepatitis C:

Other resources	%
Natural therapists	40
Hepatitis C support organisations	38
Others with Hepatitis C	32
Counsellors, nurse educators, drug & alcohol workers	32
The internet	22

Focus group comments on Health Practitioners

It was evident that some participants had been frustrated by advice or care given to them by health practitioners.

‘I went from one to three GPs and at least two of them say “oh there is a treatment, but it doesn’t work. It’s not successful”’ (FG 2).

‘I thought the quality of information I got was pretty shocking’ (FG 2).

‘The thing I find really annoying was nowhere to go in the medical system where people would talk about all the bits of your body at once and how they relate to each other...’ (FG 2).

‘I had really huge symptoms and I went to a GP...it took me a year to realise I should go to another doctor who sent me to a specialist straight away’ (FG 2).

‘It took me three GPs to find a good one’ (FG 1).

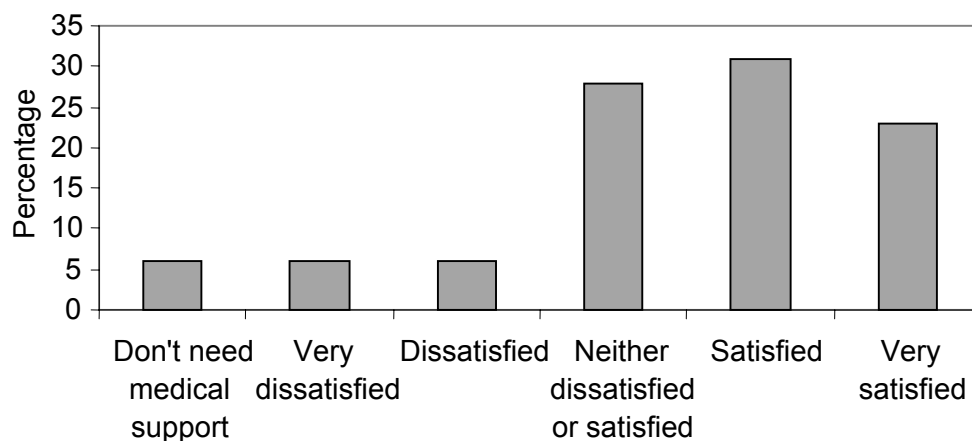
‘It took me a few counsellors before I found one I actually felt safe with’ (FG 1).

Are you currently seeing a GP for your Hepatitis C? (n=220)

Only 48% of respondents were currently seeing a GP for their Hepatitis C. Of these, 34% had seen a GP specifically for their Hepatitis C in the last four weeks. Current IDUs (24%) were significantly less likely than past IDUs (49%) and those who had never injected (60%) to see a GP specifically for Hepatitis C ($\chi^2 = 11.8$, $p = .003$).

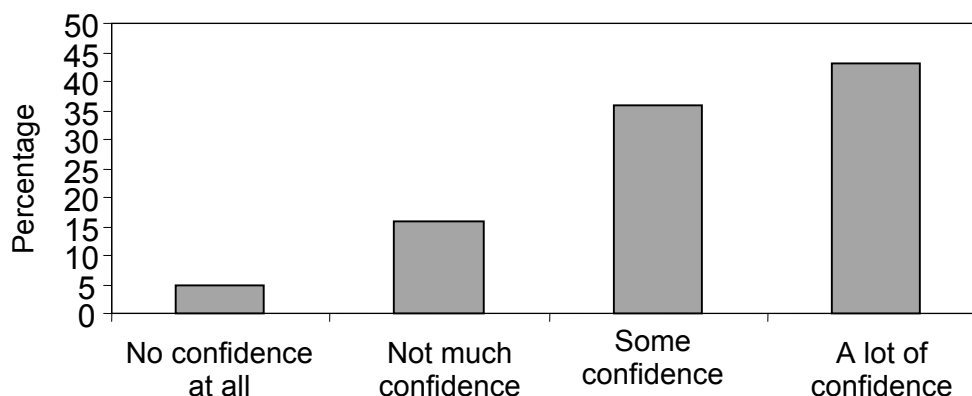
Participants were asked to rate their satisfaction with their current level of care from their GP in relation to their Hepatitis C. As can be seen from Figure 3.6 almost half of the participants who were currently seeing a GP were satisfied or very satisfied.

Figure 3.6 Level of satisfaction with GP in relation to Hepatitis C (n=127)



Most people who were seeing a GP for their Hepatitis C were confident of their doctor's level of knowledge about Hepatitis C. Almost 80% had some or a lot of confidence in the doctor's Hepatitis C knowledge.

Figure 3.7 Level of confidence in GP (n=130)



Women (54%) were significantly more likely than men (35%) to rate their usual GP as important for managing their Hepatitis C ($\chi^2 = 13.7$, $p = .018$).

Participants with no history of IDU (54%) and past IDUs (46%) were significantly more likely to rate their usual GP as important compared to current IDUs (37%), $\chi^2 = 13.7$, $p = .018$.

Have you ever seen a gastroenterologist/infectious diseases physician about your Hepatitis C? (n=219)

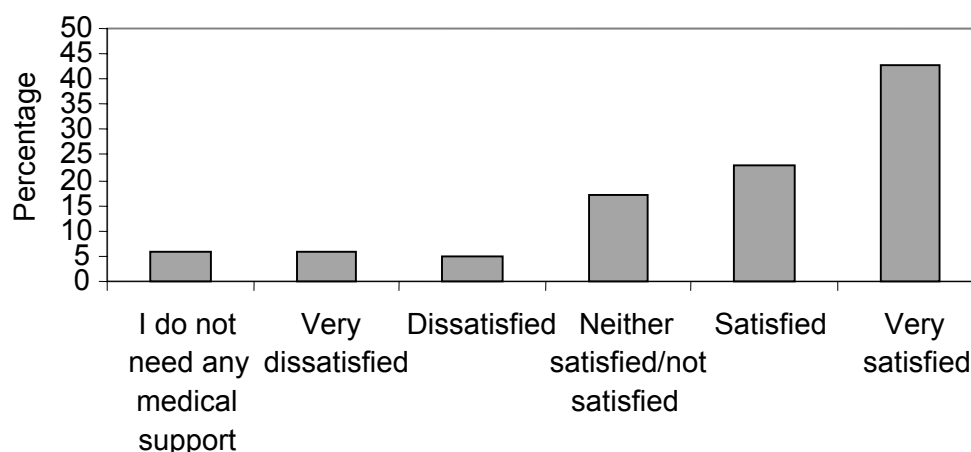
Sixty nine percent of people with Hepatitis C had seen a Specialist Physician about their Hepatitis C. Most of these participants (60%) were currently seeing a gastroenterologist or infectious diseases physician on a regular basis.

About half (49%) of the participants had seen a gastroenterologist or infectious diseases physician within six months of receiving their positive Hepatitis C diagnosis.

Participants diagnosed in the past five years (69%) were significantly more likely than those diagnosed more than five years ago (35%) to have seen a gastroenterologist or infectious diseases physician within six months of their diagnosis ($\chi^2 = 33.1$, $p < .001$).

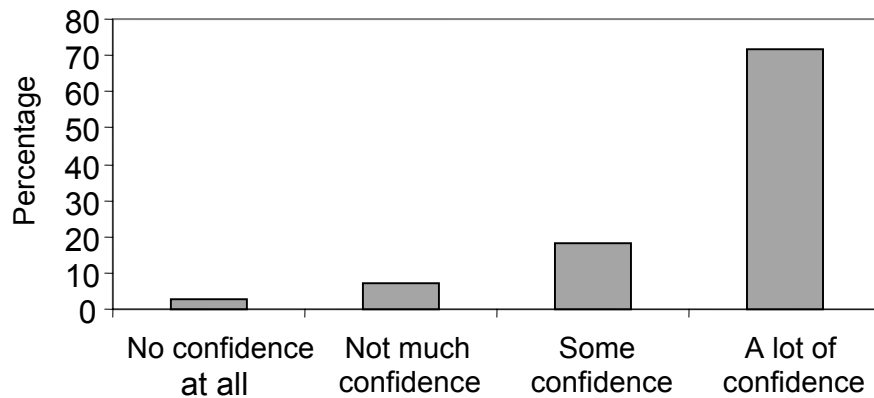
Most respondents (66%) were either satisfied or very satisfied with their current level of care from their Specialist Physician (Figure 3.8).

Figure 3.8 Level of satisfaction with Specialist Physician (n=146)



Nearly three quarters of participants (72%) had a lot of confidence in their Specialist Physician's knowledge of Hepatitis C (Figure 3.9).

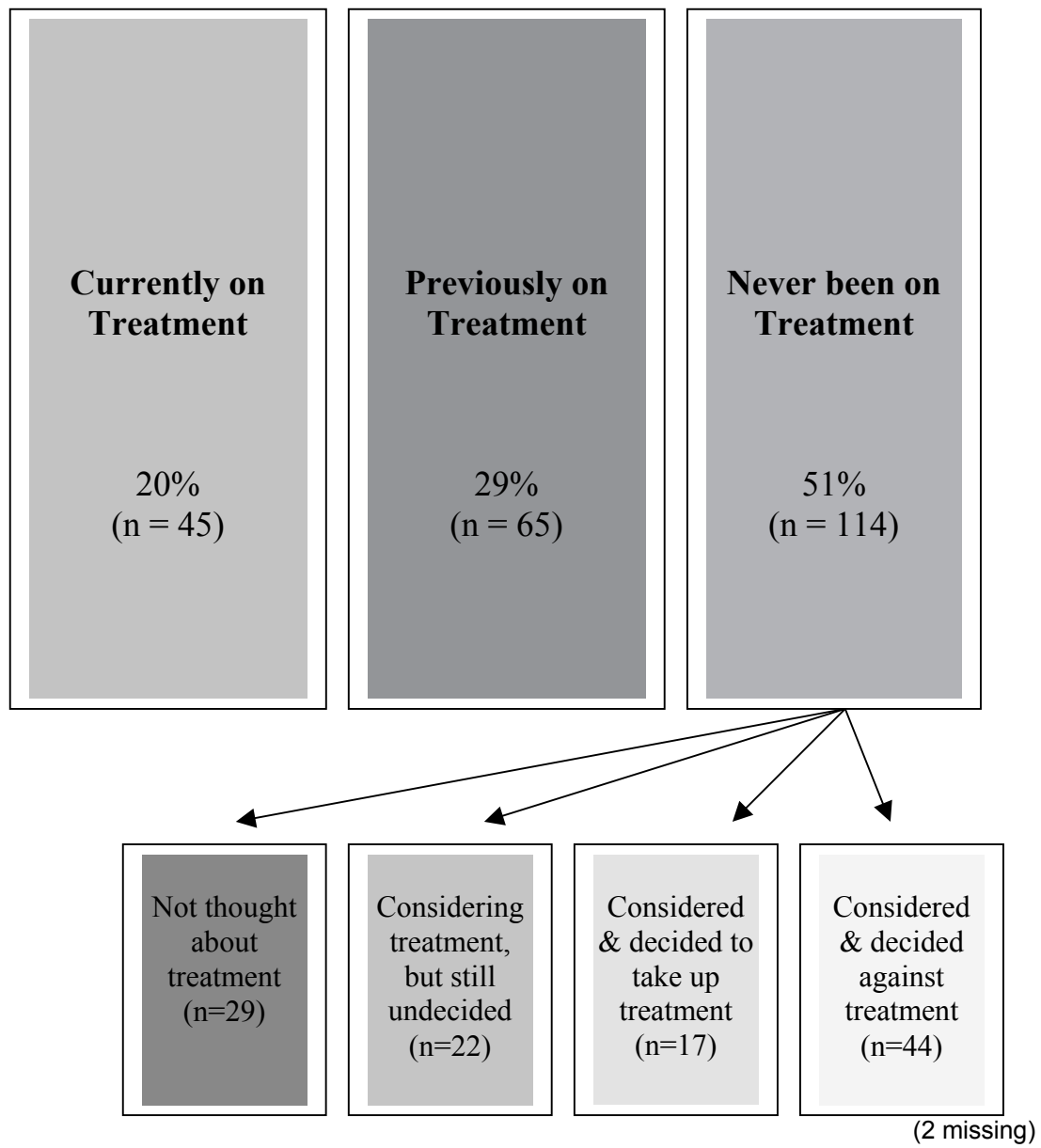
Figure 3.9 Level of confidence in Specialist Physician (n=147)



Are you currently seeing an alternative/natural therapist about your Hepatitis C? (n=222)

Only 13% of participants were currently seeing a natural therapist about their Hepatitis C. Of those who had ever seen a natural therapist (n= 42) for their Hepatitis C, 77% had confidence in their level of knowledge about Hepatitis C. There was no association between seeing a medical specialist and seeing a natural therapist.

Sixty-two percent of respondents indicated that they had not received any information about complementary therapies during post-test counselling.



Currently on Treatment (n=45)

Of the total sample of 224 people with Hepatitis C, 45 (20%) were currently on treatment at the time of the survey. This section describes results relating to these 45 participants.

Men participants (28%) were more likely than women (13%) to be currently on treatment ($\chi^2 = 7.7$, $p = .021$).

Participants diagnosed in the past five years (31%) were more likely to be currently on antiviral therapies for Hepatitis C treatment compared to those diagnosed more than five years ago (14%; $\chi^2 = 9.4$, $p = .009$). Participants whose last liver biopsy showed moderate (40%) and severe (43%) scarring were more likely to be currently on treatment compared to those with minimal or no scarring (17%; $\chi^2 = 23.1$, $p < .001$).

Participants who had previously been told they have cirrhosis (41%) were more likely to be currently on treatment compared to those who had not (15%; $\chi^2 = 13.5$, $p = .001$).

What form of treatment are you on at the moment? (n=43)

Treatment type	%
Currently on pegylated interferon plus ribavirin	77
Standard interferon plus ribavirin	14
Pegylated interferon alone	7
Don't know	2

Where do you go for treatment? (n=43)

Location	%
A public liver clinic	86
A private specialist rooms	7
Community health centre/clinic	7

How far do you travel to receive treatment? (n=44)

Distance (Time and kms)	%
Takes less than 1 hour to travel (one way) to receive treatment	80
Travel less than 15 km	59
Travel between 15km and 50km	32

Most participants (57%) currently on treatment began their treatment within two years of being diagnosed with Hepatitis C (n=44). About half of the participants (47%) had been on their current treatment program less than three months (n=43). Although 39% of participants currently on treatment said their health had improved while on treatment, 36% said that their health had deteriorated with 9% responding that their health had significantly deteriorated (n=4).

Symptoms/side-effects experienced due to treatment (n=41)

Symptom	%
Flu-like symptoms	18
Depression or mood swings	15
Insomnia	14
Diarrhoea	10

Factors in deciding to proceed with treatment

Participants were asked to rate a range of factors they may have considered when deciding to proceed with treatment (see Appendix 2). Participants' responses were recorded on a 5 point scale (ranging from 1 'not important at all' to 5 'very important'. A 'not applicable' category was also included).

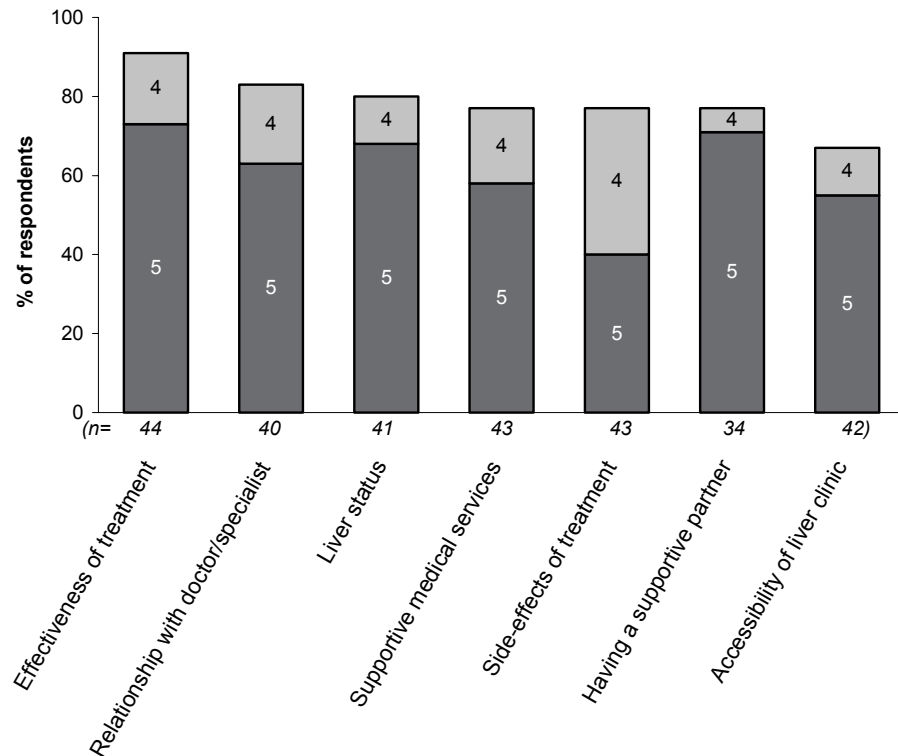
Of the 18 factors offered, Figure 3.10a lists the seven factors considered important by most participants. What is clear from this list is an overwhelming emphasis on treatment issues as the most important factors in deciding about treatment uptake. The only non-treatment related factor recorded is the high importance placed on having a supportive partner. Treatment issues identified as important included relationship with doctor, liver status, supportive medical services, side-effects of treatment and accessibility of liver clinic.

Issues considered not important when deciding to take up treatment (Figure 3.10b) included a range of issues which might be expected to deter people from treatment, such as: the need to use contraception, difficulties managing drug administration, fear of having a liver biopsy, fear of discrimination, costs associated with treatment, and having to commit to a full term of treatment.

Figure 3.10 a & b Factors in deciding to proceed with treatment

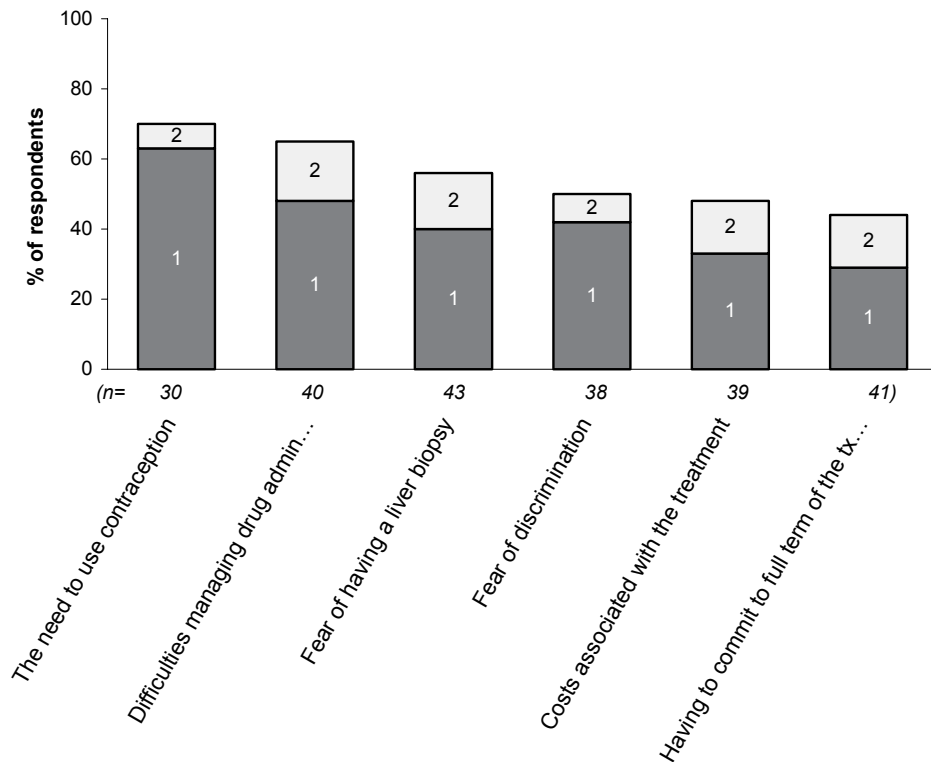
Issues that are important when deciding to take up treatment

(5 point scale, 1 is "not important at all", 5 is "very important")



Issues that are not important when deciding to take up treatment

(5 point scale, 1 is "not important at all", 5 is "very important")



Rate the importance of the following reasons for you going on treatment in order to clear the virus (n=30-44)

Ninety one percent of participants identified preventing long-term liver damage as a very important outcome of treatment. Alleviating symptoms (74%), reducing the risk of Hepatitis C transmission to others (68%), and recommendations from their doctor (52%) were also identified as very important reasons for going on treatment.

Rate the importance of the following resources for helping you stay on treatment for your Hepatitis C (n=27-42)

When asked what was important for helping participants stay on treatment, 81% identified the doctor at the liver clinic, 75% identified the specialist physician and 68% identified a counsellor, educator or drug and alcohol worker as very important.

Fewer participants identified their regular GP (33%), a Hepatitis C support organisation (22%), another person with Hepatitis C (19%), a natural therapist (11%) and the internet (3%) as very important for helping them stay on treatment.

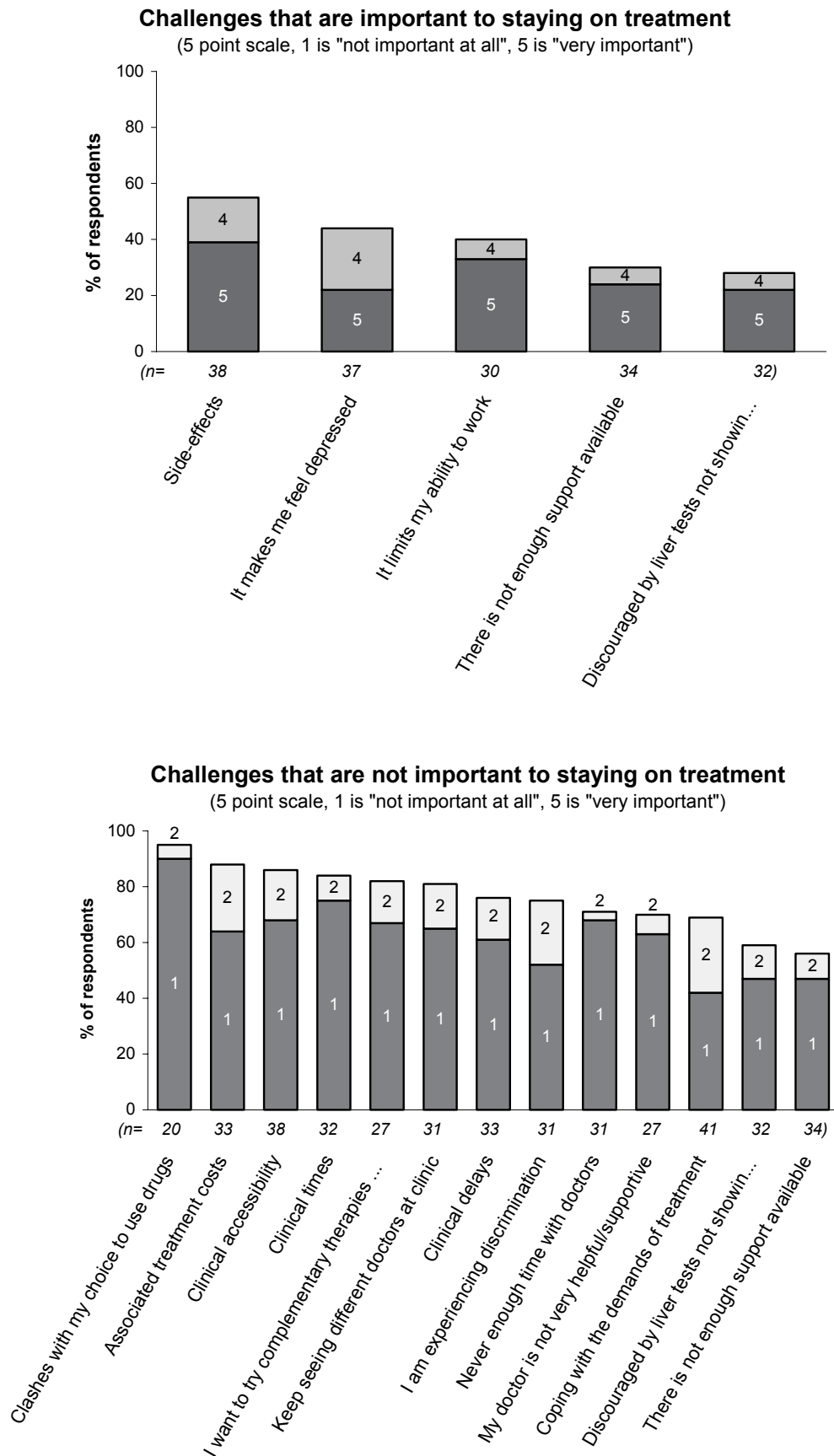
What are the greatest challenges to staying on treatment?

Participants were asked to rate a range of personal, social and treatment related challenges to staying on treatment (see Appendix 3). Participants' responses were recorded on a five point scale (ranging from 1= 'not important at all' to 5 = 'very important'. A 'not applicable' category was also included).

Of the 16 challenges associated with treatment presented, Figure 3.11a lists the five challenges participants considered to be important to staying on treatment. Side-effects associated with treatment and the association of treatment with depression were the two highest rating challenges. However, it must be noted that side-effects associated with treatment was the only challenge rated as important by more than 50% of the participants. The remaining four important challenges were considered so by 43% to 28% of participants. What is striking from these figures is the contrast between the small numbers of participants who rated the potential challenges as important, in comparison to the large numbers rating the same range of potential challenges as unimportant.

Nine of the 16 challenges were considered not important and received the rating of over 70% of participants, (Figure 3.11b). Clinic accessibility, clinic times and delays, associated treatment costs such as blood tests, never enough time with doctors and keep seeing different doctors at the clinic were not endorsed as challenges to staying on treatment. Similarities exist between those currently on treatment with those previously on treatment regarding challenges not endorsed. (See Figure 3.13b for comparison).

Figure 3.11a & b Challenges associated with staying on treatment



Previously on Treatment (n=65)

Sixty five (29%) participants had previously been on antiviral therapies for Hepatitis C, and 55 (86%) of these had completed the treatment course. On average, participants had completed their previous treatment 2.7 years ago (SD = 2.2), and the treatment was successful in clearing the virus for twenty four (45%) of participants.

Most participants began their treatment within 2 years of being diagnosed with Hepatitis C.

Type of treatment (n=62)

Treatment	%
Standard interferon plus ribavirin	71
Standard interferon alone	16
Pegylated interferon and ribavirin	13

Factors in deciding to proceed with treatment

Participants were asked to rate a range of factors they may have considered when deciding to proceed with treatment (see Appendix 2). Participants' responses were recorded on a five point scale (ranging from 1= 'not important at all' to 5= 'very important'. A 'not applicable' category was also included).

Of the 18 factors offered, Figure 3.12a lists the eight factors considered important by most participants. Again, as was the case with people currently on treatment, participants rated treatment issues as the most important factors when deciding to proceed with treatment. Having a supportive partner was the one personal issue that participants rated as important.

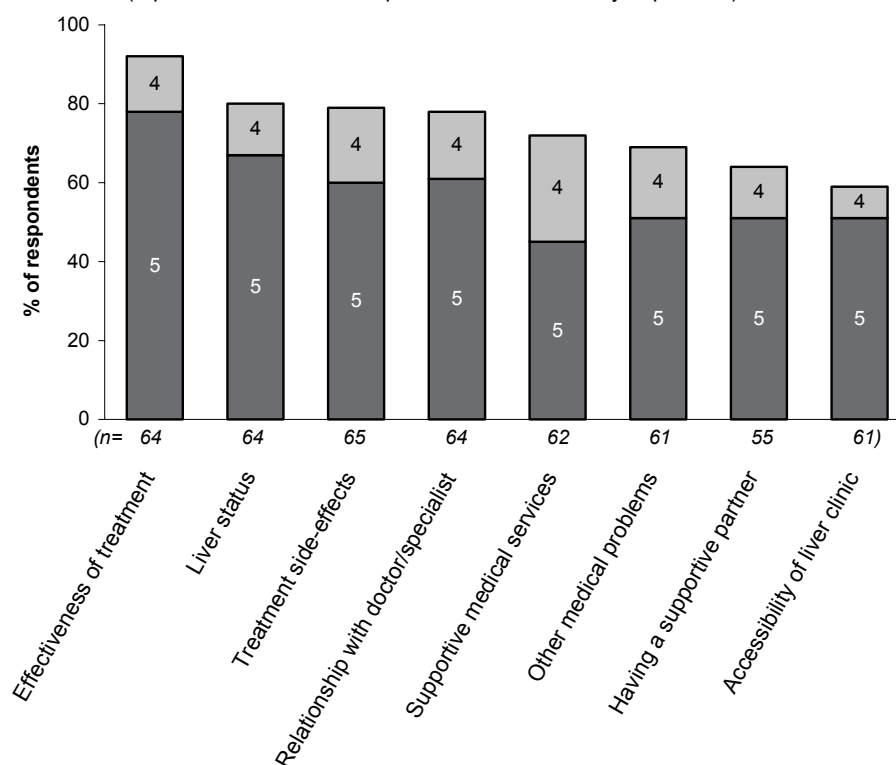
There is a strong similarity regarding factors considered important or unimportant between those respondents who were currently on treatment and those who had experienced treatment in the past.

Issues considered unimportant when deciding to take up treatment (Figure 3.12b) included a range of issues which might be expected to deter people from treatment, such as: difficulties managing drug administration, fear of liver biopsy, costs associated with treatment, the need to use contraception, fear of discrimination and having to commit to a full term of treatment.

Figure 3.12a & b Factors in deciding to proceed with treatment

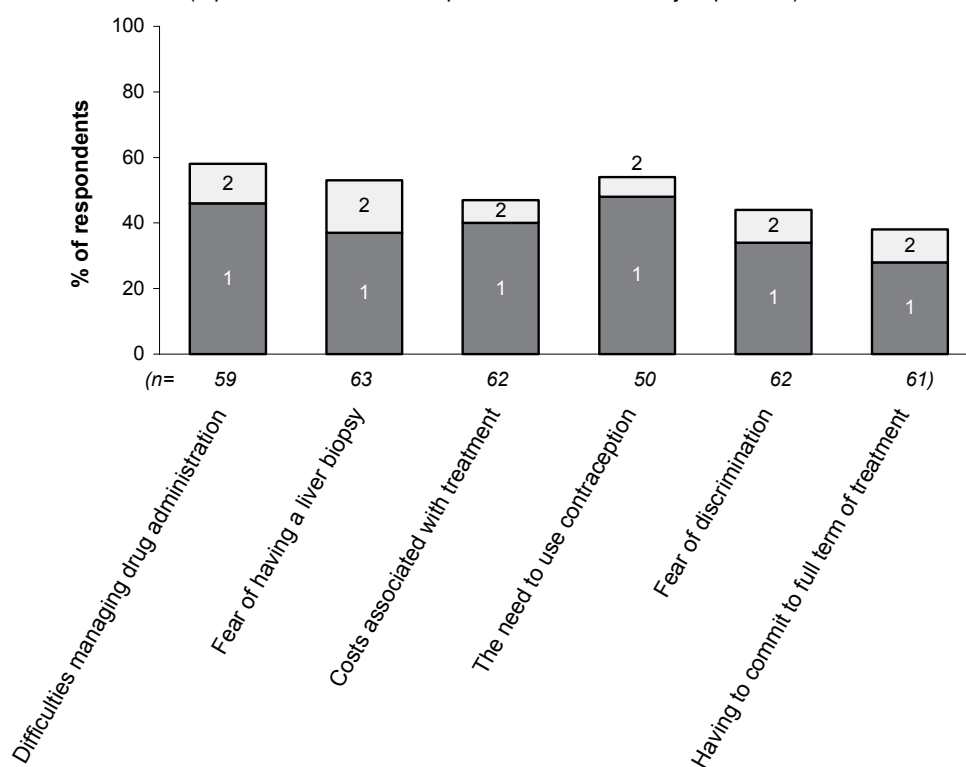
Issues that are important when deciding to take up treatment

(5 point scale, 1 is "not important at all", 5 is "very important")



Issues that are not important when deciding to take up treatment

(5 point scale, 1 is "not important at all", 5 is "very important")



Rate the importance of the following reasons for you going on treatment in order to clear the virus (n=64-65)

Ninety one percent of participants identified preventing long term liver damage as a very important outcome of treatment. Reducing the risk of Hepatitis C transmission to others (71%), alleviating symptoms (70%), and recommendations from their doctor (48%), were also identified as very important.

Challenges to staying on treatment

Participants were asked to rate a range of personal, social and treatment related challenges to staying on treatment (see Appendix 3). Participants' responses were recorded on a five point scale (ranging from 1= 'not important at all' to 5= 'very important'. A 'not applicable' category was also included).

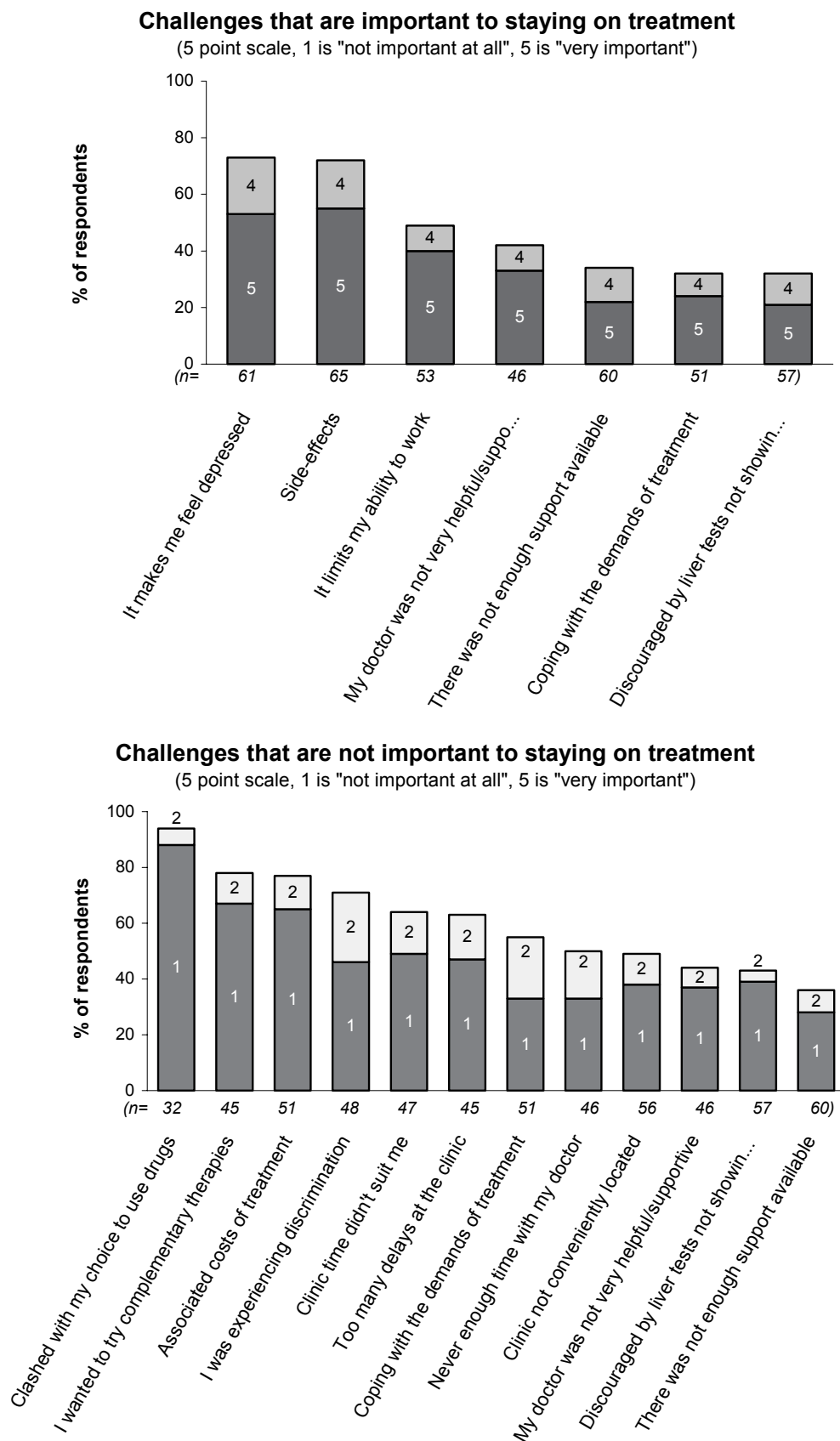
Of the 16 challenges associated with treatment, Figure 3.13a lists the seven challenges considered by participants to be important to staying on treatment. Forty two percent of participants previously on treatment stated that an important challenge associated with staying on treatment was their doctor not being very helpful or supportive. This was rated much lower by participants currently on treatment with only 15% stating it as important and 70% of those currently on treatment rating doctor's support as not important.

Overall the important challenges associated with staying on treatment were rated much higher by those previously on treatment than for those currently on treatment. For example, 72% of participants previously on treatment but only 55% of participants currently on treatment considered side-effects important; 73% of participants previously on treatment and only 43% of participants currently on treatment considered treatment effects on depression as important. A similar relationship can be found for other challenges considered important.

Over 50% of participants previously on treatment rated eight of the 16 challenges as not important, (Figure 3.13b). The listing was an extensive offering of treatment and personal challenges. Experiences associated with liver clinics, such as accessibility, delays at clinics, consulting times not suiting, never enough time with the doctor and seeing different doctors at the clinic were issues considered to be not important by participants previously on treatment and by participants currently on treatment.

Accessibility of liver clinics was an important issue when considering going on treatment for 58% of participants, while 48% indicated that clinic location was not a challenge to staying on treatment. Similarities exist between those currently on treatment with those previously on treatment regarding challenges not endorsed. (See Figure 3.11b for comparison).

Figure 3.13a & b Challenges associated with staying on treatment

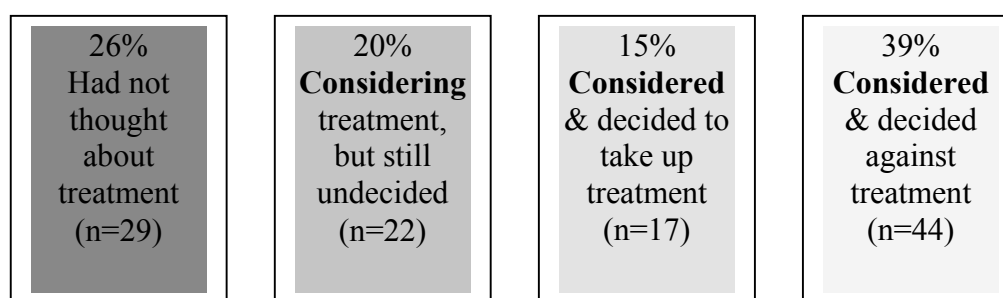


Never Been on Treatment (n=114)

114 (51%) people with Hepatitis C had never undertaken antiviral therapy. Within this group just over a quarter had not given any thought to treatment. The remaining 74% had considered treatment with 39% deciding against treatment. This section focuses on those participants who have considered treatment.

Women participants (54%) were significantly more likely than men (47%) to have never been on treatment ($\chi^2 = 7.7$, $p = .021$).

Current IDUs (79%) were more likely to have never tried antiviral therapies for Hepatitis C compared to past IDUs (50%) and never IDUs (39%; $\chi^2 = 16.5$, $p = .002$).



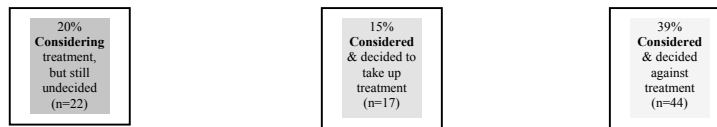
(2 missing)

The main reasons for those who have decided to take up treatment are: (n=17)

Reason to take up treatment	No.
To prevent long term liver damage	17
To alleviate symptoms	13
To reduce the risk of transmission to others	12
The treatment success rate is now much better	9
I am no longer injecting drugs	7
My health has worsened	6
My lifestyle is now more stable	6
My doctor is encouraging me to begin treatment	5
Recommended by my doctor	4
My liver status has deteriorated	3

Most participants (67%) who decided to take up treatment could not identify the type of treatment they were considering.

Information about those who have considered treatment (n=85)



Participants who considered treatment, no matter the outcome (i.e. whether they decided to take up treatment, were still undecided, or decided against treatment) were asked to rate the importance of four reasons in their decision about treatment in order to clear the virus. Preventing long-term liver damage and alleviating symptoms were rated by most people as important.

Important reason	%
Preventing long-term liver damage	85
Alleviating symptoms	67
Reducing the risk of transmission to others	47
Recommended by doctor	21

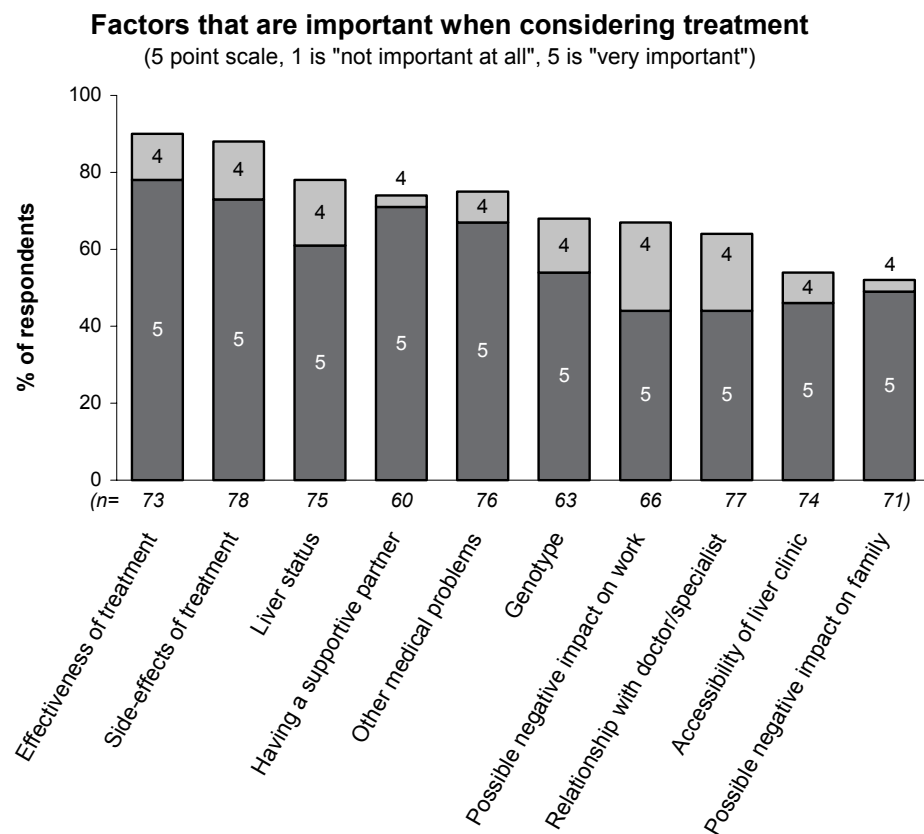
Factors taken into account when considering treatment

Participants who had considered, or were considering treatment (n=83) were asked to rate a range of factors they may have thought regarding treatment uptake (see Appendix 2). Participants' responses were recorded on a 5 point scale (ranging from 1= 'not important at all' to 5= 'very important'. A 'not applicable' category was also included).

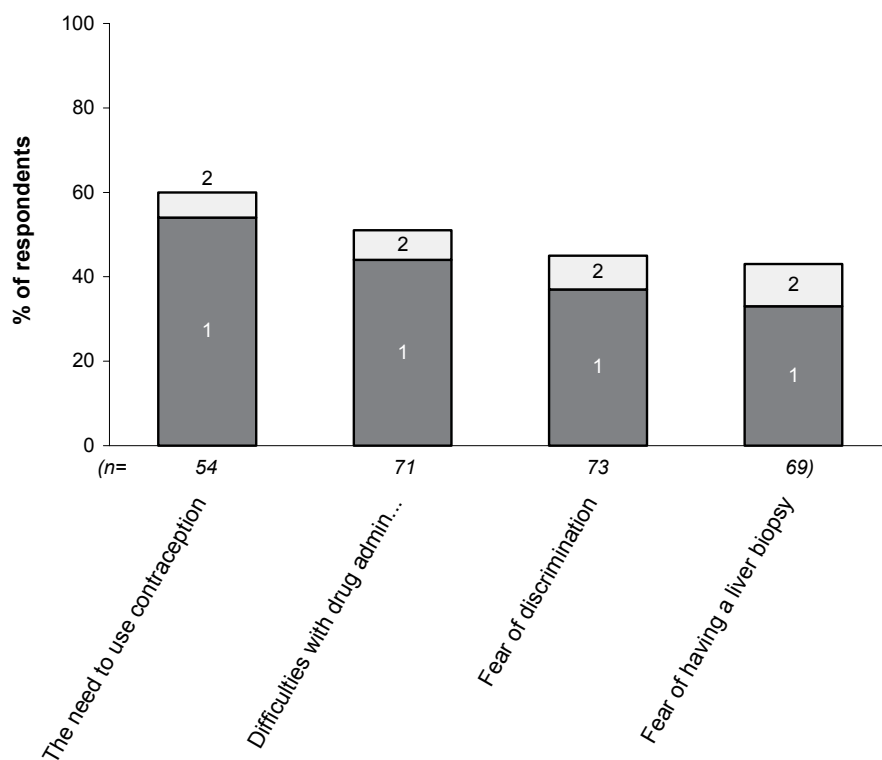
Of the 18 factors offered, Figure 3.14a lists the ten factors considered important by most participants. Of the first six responses listed, five responses are treatment related issues (effectiveness of treatment, side-effects of treatment, liver status, other medical problems and genotype). Having a supportive partner, while listed fourth, recorded a high very important '5' rating of 71%.

Figure 3.14b highlights issues considered not important when deciding to take up treatment and includes the need to use contraception, difficulties managing drug administration, fear of liver biopsy, fear of discrimination. These issues were consistently rated unimportant by those participants currently and previously on treatment, by those who have decided to take up treatment, and by those still considering treatment.

Figure 3.14 a & b Factors taken into account when considering treatment



Factors that are not important when considering treatment
(5 point scale, 1 is "not important at all", 5 is "very important")



Factors taken into account when deciding against treatment

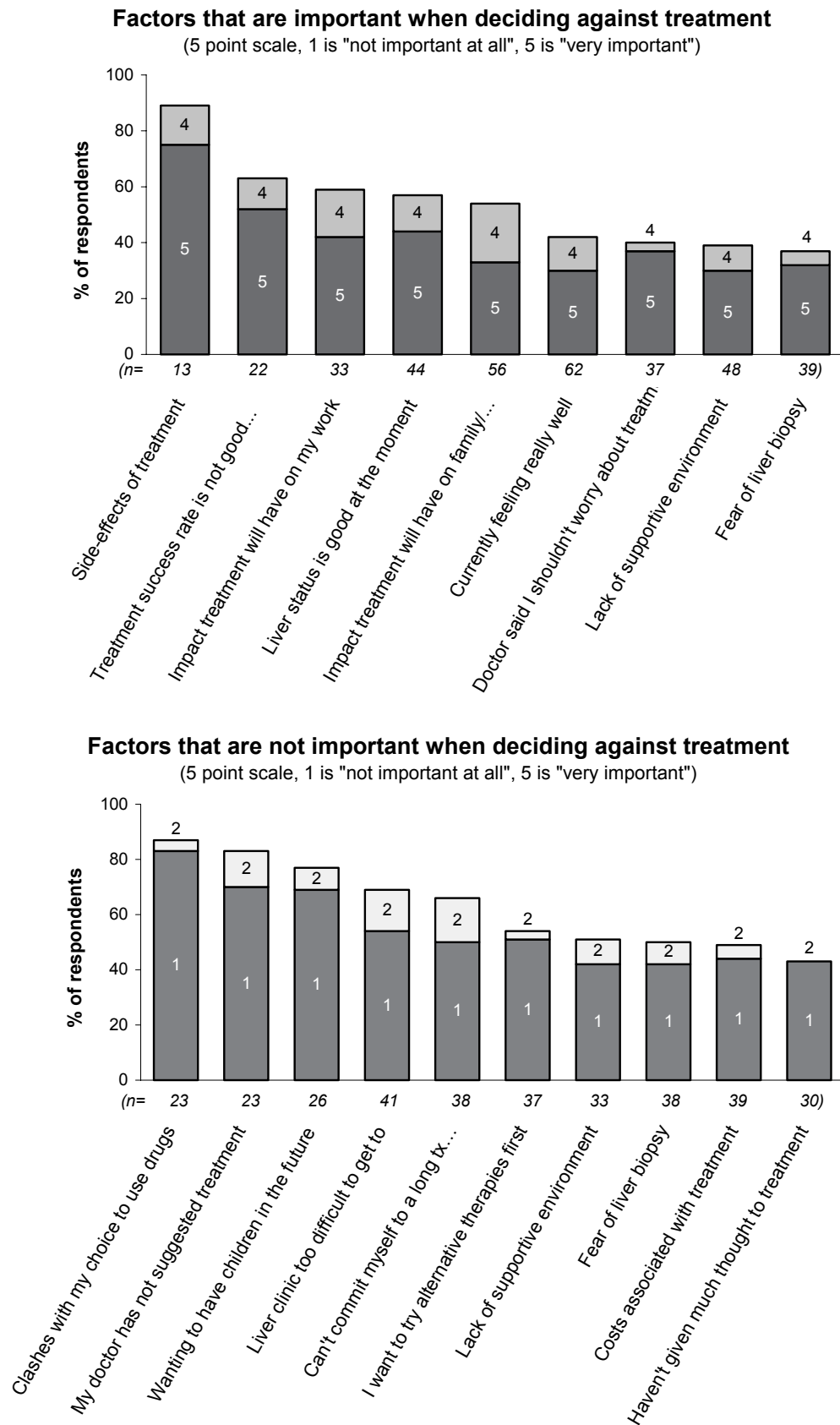
Thirty nine percent (n=44) of respondents who had never experienced treatment had considered and decided against treatment.

Participants who had considered and decided against treatment were asked to rate a range of factors they may have considered when deciding against treatment (see Appendix 4). Participants' responses were recorded on a 5 point scale (ranging from 1= 'not important at all' to 5= 'very important'. A 'not applicable' category was also included).

Of the 18 factors offered, Figure 3.15a lists the nine factors participants considered most important. Side-effects and the belief that treatment success rate is not good enough were important issues in deciding against treatment by 89% and 64% of participants. Over half of the respondents were also concerned that treatment would impact on their work, family and friends.

The large range of issues considered not important when deciding against treatment are presented in Figure 3.15b. Over 80% of those responding to this question (n=23) stated that treatment clashing with their choice to use or inject drugs was not important at all. A message consistently voiced by most participants in the study is that they did not fear having a liver biopsy. For 50% of the participants who decided against treatment, fear of a liver biopsy was rated as unimportant when making that decision.

Figure 3.15 a & b Factors taken into account when deciding against treatment



Chapter 4: General Practitioners

Questionnaires comprising 29 items were sent to 455 GPs in the Northern Metropolitan Division of General Practice. Of these initial questionnaires, 90 were returned, representing a return rate of 20%. To increase the return rate, a supplementary one-page questionnaire was posted to all 455 GPs (see Chapter 2). An additional 130 supplementary (one page, 6 item) questionnaires were returned by fax. The total return rate was therefore 48% (Table 4.1).

One focus group was subsequently held with GPs who had completed the questionnaire and agreed to be involved in a one hour discussion. The focus group brought together GPs with wide variation in practice type and setting. Some of the GPs worked with higher prevalence patient groups than others such as injecting drug users and immigrants from high prevalence regions such the Middle East, Asia and Russia. Some GPs appeared very well informed and up to date on general practice management of Hepatitis C while others were not as confident of their knowledge in this area.

Some of the GPs were not as knowledgeable as others who worked with groups that have a high prevalence of Hepatitis C, so the possibility of missed diagnoses existed. These GPs did not seem to be aware that not all cases of Hepatitis C are related to IDU and those patients from high Hepatitis C prevalence geographical areas could also be affected.

The general view was that Hepatitis C was not common, but all GPs in the focus group had had patients with Hepatitis C. Results from the focus group discussion supported the data from the questionnaire and are presented throughout the chapter.

Table 4.1 Involvement of GPs in care of patients with Hepatitis C

GP Response	29 item questionnaire n=90	6 item questionnaire n=130
Involved with patients with Hepatitis C	83 (92%)	118 (91%)
A patient with Hepatitis C has never consulted me	3	3
I prefer not to manage patients with Hepatitis C	3#	4
Other	0	5

#Reasons given for preferring not to manage patients with Hepatitis C were:

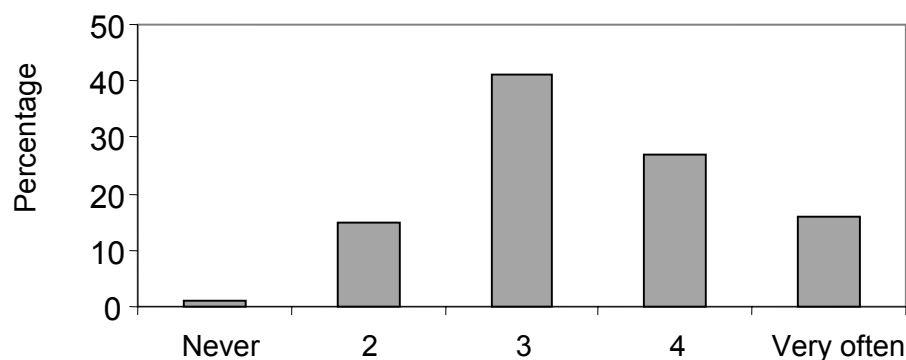
- the association with IDU is difficult to deal with
- concerned about Hepatitis C transmission to staff, self or other patients
- do not have sufficient expertise in Hepatitis C

Results from main questionnaire: (n=90)

Ninety two percent of GPs in this study were involved in the care of patients with Hepatitis C, and 2/3 of these had done so for more than 5 years.

- 77% of GPs had diagnosed a patient with Hepatitis C, with 43% often or very often recommending a patient have a test for Hepatitis C
- Most GPs had cared for patients with Hepatitis C for longer than five years
- 75% of GPs had cared for between one and five patients within the past month
- 85% of GPs had less than 5% of their total patient base with Hepatitis C
- 35% had referred ALL patients with Hepatitis C on to a specialist
- 35% had referred less than half of their patients to a specialist

Figure 4.1 How frequently GPs recommend a diagnostic test for Hepatitis C (n=88)



When asked to rate how often GPs recommended a diagnostic test for Hepatitis C on a scale from 1 (never) to 5 (very often), most GPs (68%) responded with 3 or 4.

Which of the following situations has prompted you to test a patient for Hepatitis C? (n=87)

Situation	%
A history of incarceration	100
A history of IV drug use	91
Elevated ALT level over a period of 6 months	75
Having a partner with Hepatitis C	72
Routine STI screening	66
Hepatitis B infection	63
Elevated GGT/ALP	52
Routine screening	48
HIV infection	35
Patient is pregnant	33
Immigration from high prevalence area	22

Focus group comments

GPs in the focus group offered a number of additional reasons for testing patients for Hepatitis C, which had not been included on the questionnaire:

- Antenatal testing
- Most stated that if they see abnormal Liver Function Tests then they will test for Hepatitis C infection
- Patients requesting test
- Not tested routinely for sexual health and they request the test for Hepatitis C
- Needle stick injury
- Tattoos

In answer to the question **To what degree do you believe the following may inhibit your management of patients with Hepatitis C?** (n=77-81), GPs rated the most challenging aspects as:

Challenging aspects	%
Dealing with non-compliance with attendance	56
Injecting drug issues	56
Non-compliance with treatment	53
Keeping up to date with new medical developments	50
Time to deal with associated psychological issues	44
The side-effects of treatment	38
Time to deal with medical issues	36
Availability of specialist support	35

Less commonly identified factors included:	%
Knowing when to refer patients	25
Lack of other support for patients	24
Difficulty accessing referrals to specialists	19
Cultural differences	14
Access to translator services	13
The use of complementary therapies by patients	12

During the focus group discussion several GPs raised the issue of patient shame over past behaviours as a barrier to presenting for treatment. The discovery of Hepatitis C infection may require disclosure of past hidden behaviours and life events, and requires tactful history-taking by the GP.

To whom do you usually refer your patients with Hepatitis C? (n=83)

GPs overwhelmingly referred patients to a public hospital liver clinic (78%) or to a private specialist (21%). No GPs referred a patient with Hepatitis C to another GP or a community health centre based liver clinic. Only 1% had referred a patient to a complementary health care worker.

Referred patients were required to wait from two to four weeks (37%) or between one and two months (38%) to be seen by a specialist. Patients referred to a public hospital liver clinic (66%) were more likely to have to wait longer than one month to be seen compared to patients referred to a private specialist.

Table 4.2 Likelihood of a GP referring a patient to a Specialist Physician
(n=78-83)

How likely is it that you would refer a patient with Hepatitis C for each of the following?	Likely %	Unlikely %	Unsure %
If the patient developed signs of chronic liver disease	98	2	0
If the patient showed signs of jaundice	98	2	0
If the patient requested a referral	95	2.5	2.5
If the patient developed Hepatitis C-related symptoms	94	4	2
If the patient had ALT levels consistently above 100 U/L	90	1	9
If the patient was pregnant	86	10	4
If the patient's liver function tests became abnormal	85	10	5
If patient wants to start a family	69	21	10
If the patient drinks alcohol heavily	60	29	11
On diagnosis of Hepatitis C	55	37	8
If the patient currently uses IV drugs	51	30	19
If the patient has a psychiatric disorder	45	31	24
If the patient doesn't meet clinical guidelines for treatment	33	42	25

It can be seen from Table 4.2 that 85% or more of GPs would be likely to refer a patient with Hepatitis C to a Specialist Physician where there were clear signs of liver disease, if the patient was pregnant or if the patient requested a referral.

Less common circumstances where referrals would be likely, included if the patient wanted to start a family (69%), if the patient drank heavily (60%), if the patient currently injected drugs (51%), if the patient had a psychiatric disorder (45%), upon diagnosis with Hepatitis C (37%) and if the patient does not meet clinical guidelines for treatment (33%). These findings should be compared with those of the Specialist Physicians, particularly given that over 60% of GPs were confident that they were referring patients on to a Specialist Physician at an appropriate time.

Focus group comments:

Referring patients

Many GPs who do not regularly see patients with a particular condition will use guidelines to make decisions for referrals. This is not just because of a lack of knowledge but good medical practice. There was some variation in referral practices, whereby some doctors seemed to monitor patients more than others.

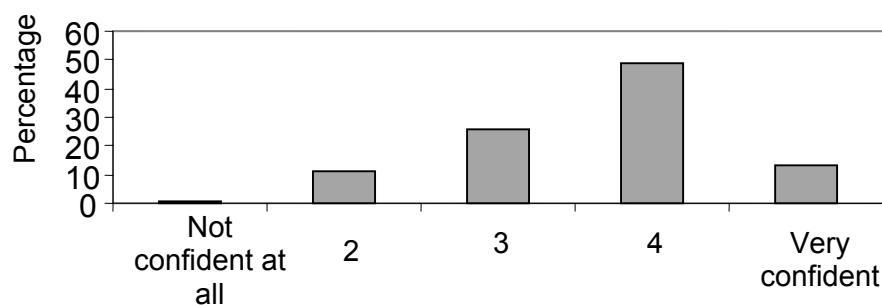
Reasons for referring patients:

- Raised LFTS ALT greater than 150 for around 6 months or more
- Abdominal signs and symptoms
- Some said that they don't see enough Hepatitis C and have to look it up in reference material

Reasons given for not referring included:

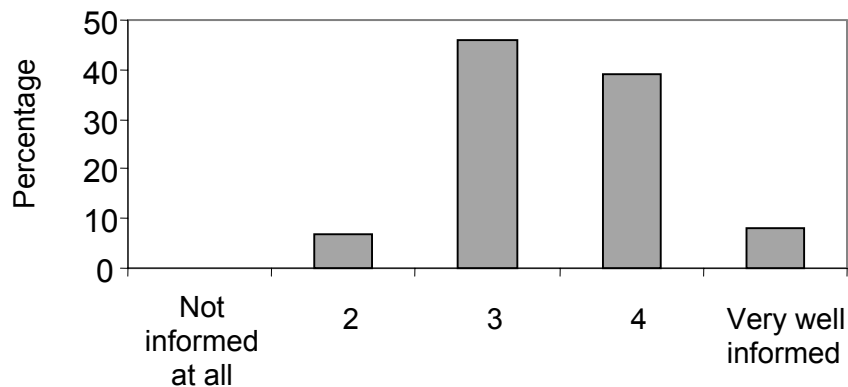
- Patient currently using drugs. One GP said that patients would need to be off drugs before going on treatment.
- One GP said that treatment for Hepatitis C might not be a priority at the time of presentation because of other things happening in the patient's life (and added that this could be reasonable, considering the patient's circumstances).

Figure 4.2 GPs' confidence in knowing when to refer a patient with Hepatitis C to a Specialist Physician (n=88)



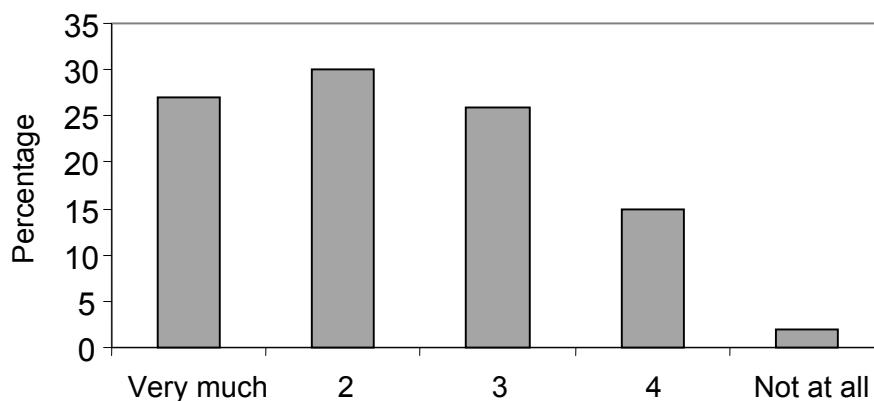
Most GPs rated themselves either 3 or 4 (75%) on their confidence in knowing when it is appropriate to refer a patient with Hepatitis C to a Specialist Physician for treatment.

Figure 4.3 How well informed GPs believe they are about Hepatitis C
(n=88)



Overall, GPs in the study believed they were well-informed about Hepatitis C. Most GPs rated themselves either 3 or 4 (85%) on how informed they were about Hepatitis C. Despite this, 57% rated themselves as having 'much' and 'very much' need to improve their skills in managing Hepatitis C.

Figure 4.4 GPs' need to strengthen professional skills (n=89)



Forty nine percent of GPs had attended a continuing medical education (CME) or continuing professional development (CPD) course relevant to Hepatitis C and almost 80% had completed this course in the past three years. However, most GPs felt they could benefit from further professional development in managing people with Hepatitis C (Figure 4.4).

All GPs rated CME courses as important sources of information about Hepatitis C. Most rated medical journals (79%) as their most important source of information. Other sources included feedback from specialists (68%), professional and clinical practice (47%), educational brochures (39%), lectures and conferences (38%) and colleagues (24%). Very few GPs (4%) rated pharmaceutical industry representatives as an important source of information.

Which of the following would you find useful in helping you keep up to date with Hepatitis C developments? (n=77-80)

Useful Resources for GPs	%
Regular letters from the liver clinic	76
A written guide to symptoms or situations which should prompt testing for Hepatitis C	62
Formal link with a Hepatitis C specialist	58
Lectures and meetings with specialists	56
Receiving regular short bulletins on Hepatitis C	56
Formal share care arrangements	54

About half of the GPs indicated that articles on Hepatitis C in the Australian medical literature would be very useful. A third of GPs stated that internet sites on general practice management of Hepatitis C would not be useful.

Focus group comments

Additional sources of Hepatitis C information identified by GPs:

- GP Division meeting for Hepatitis C
- Source information from textbooks or Internet
- Alfred Hospital internet Site which was described as detailed and useful
- Public Health Unit, Department of Human Services, Victoria
- National Hepatitis C Resource Manual from La Trobe University
- Guidelines were also seen to be helpful in managing Hepatitis C although the GPs were vague on which guidelines were available

The GPs received regular letters from the hospital. For example, St Vincent's Hospital writes regularly to the GPs of patients undergoing treatment for Hepatitis C. One GP expressed surprise that she did not receive many letters in relation to her patient with Hepatitis C. Some GPs commented that they received useful and specific information on patients from liver clinics. Letters to GPs from Specialist Physicians provide an excellent opportunity for educating GPs about Hepatitis C. For example, one GP had a patient who died from hepatoma. He would have liked to have had more detail from the Specialist Physician about this.

Do you manage patients with Hepatitis C in conjunction with a Specialist Physician? (n=82)

The survey found that 79% of GPs answered yes to this question. It should be noted, however, that this is most likely to mean that the GP manages the non-Hepatitis C related complaints of a patient, and either has referred the patient on to, or is aware that the patient has a Specialist Physician managing their Hepatitis C. Shared care, where Specialist Physicians and GPs share the management of a patient undergoing antiviral therapy is very much in its

infancy in Victoria. None of the GPs in this study was involved in formal shared care programs although one had completed training.

Focus group comments:

GPs were asked if they could access a Specialist Physician for more information.

- Most stated that they had not attempted to do this
- Some said they would talk to specialists if they needed to
- Many contacted the hospital registrar at the public hospital liver clinic as a first port of call and found this useful
- Some talk to a private specialist

Chapter 5: Specialist Physicians

Specialist Physicians were invited to complete a 22 item self-administered questionnaire. The questionnaire was mailed to 113 specialist physicians working in the area of Hepatitis C throughout Victoria using the mailing list provided by Gastroenterological Society of Australia (GESA).

The questionnaire covered a range of topics, ranging from sources of Hepatitis C knowledge, involvement with Hepatitis C patients, referral preferences, shared care, reasons for and barriers to adherence to Hepatitis C treatment.

A total of 57 questionnaires were returned representing a return rate of 49%.

Of these 57 specialists, 37 currently managed patients with Hepatitis C. These physicians saw themselves as well-informed and confident in managing patients with Hepatitis C. For most however, patients with Hepatitis C did not form the biggest part of their caseload. The few Specialist Physicians who did not manage Hepatitis C patients believed they did not have infrastructure to support patients adequately.

The specialists surveyed had practiced on average for 16.5 years (ranging from beginning in 1966 to 2003).

Specialist Physicians practiced in:

(n=57)

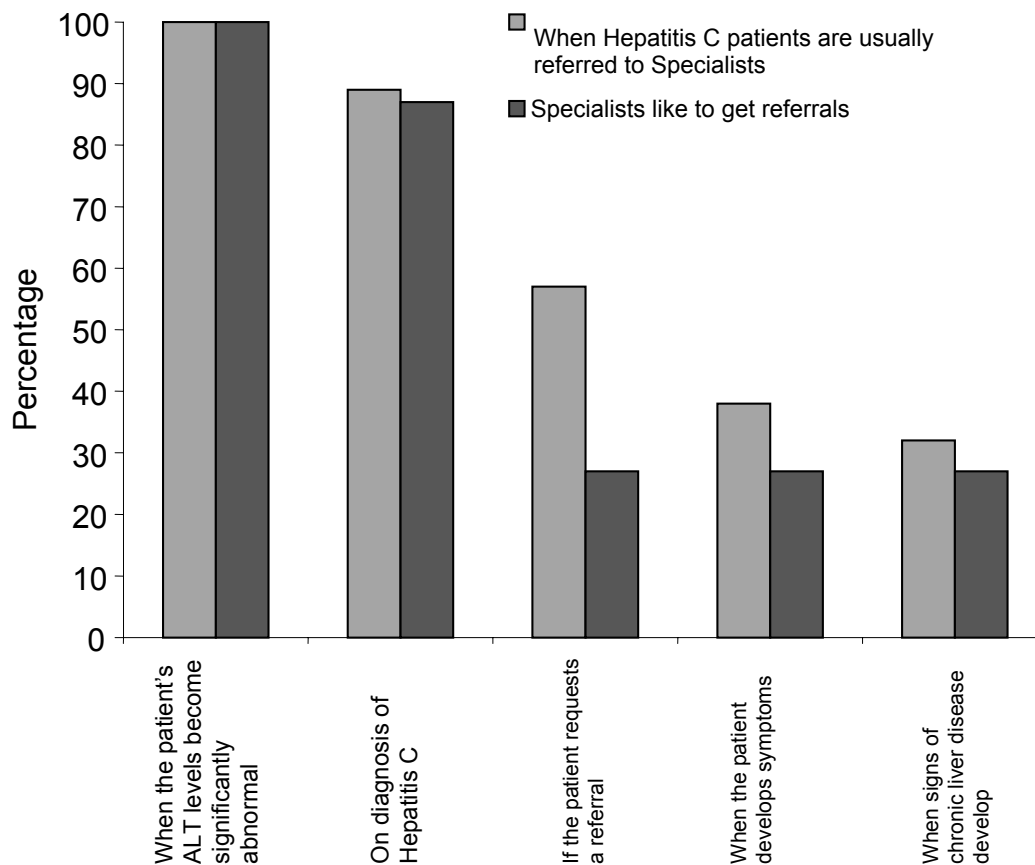
Location	%
Private rooms	77
Public hospital outpatient clinics	65
Private hospitals	21
Community health centre liver clinics	7

Sixty percent stated that they managed or treated patients with Hepatitis C.

Of those specialists who treated patients with Hepatitis C (n=37):

- 56% managed/treated more than 50 patients with Hepatitis C in the last twelve months
- 84% had worked more than five years with Hepatitis C patients
- 57% spent less than 10% of their working time managing patients with Hepatitis C
- 54% of specialists stated that they managed patients with Hepatitis C in conjunction with a general practitioner

Figure 5.1 Comparison between when patients are usually referred to Specialist Physicians and when Specialist Physicians like to receive referrals (n=37)



A match between when patients are usually referred and when specialists like to receive a referral

When the patient's ALT levels become significantly abnormal and at the time a patient is diagnosed with Hepatitis C were the two points in the patient's clinical course when there was a match between when Specialist Physicians noted that patients are usually referred to them and when they like to get referrals.

A mismatch between when patients are usually referred and when specialists like to get a referral

Over half (57%) of Specialist Physicians noted that patients are usually referred to them if the patient requested a referral. A much lower percentage of Specialist Physicians (27%) stated that they liked to receive referrals under these circumstances. Another mismatch was also identified in relation to the point at which the patient develops symptoms, with 38% of Specialist Physicians usually receiving referrals for this reason, in comparison with 27% of those who would like to.

The point at which signs of chronic liver disease develop was rated low (32%) for when specialists noted that Hepatitis C patients are usually referred. Twenty seven percent of specialists stated they would like to get referrals at the time when patients show signs of chronic liver disease.

Specialists are happy to accept a referral from a patient who:

Timing for referral	%	N
Wants to start a family	100	35
Has an ALT level less than 100U/L	100	36
Has a psychiatric disorder	91	34
Drinks alcohol heavily	91	32
Currently injects	74	35

The time of diagnosis was the most preferred point at which specialists would like to receive a patient referral (87%). This matched the time when most specialists actually received referrals (89%). Specialist Physicians considered it too late to receive a referral once a patient had developed symptoms or when a patient had developed signs of chronic liver disease.

Specialist Physicians rated the greatest hindrances to effective treatment to be a late referral, patient's drug use and treatment non-compliance.

How significant do you believe the following issues are for patients adhering to treatment for Hepatitis C? (n=36)

The issues considered by specialists as important (rating 4 or 5 on five point scale) for patients adhering to treatment were:

Important issues	%
Patients lacking commitment to treatment	89
Patients not being ready for treatment	86
Length of treatment	81
The side-effects of treatment	78
Depression associated with treatment	72

The issues considered by specialists as not important (rating 1 or 2 on five point scale) for patients adhering to treatment were:

Unimportant issues	%
Patient experiencing discrimination by health professionals	57
Clinic times not suitable	53
Patient tends to see different doctors at the clinic	50
Cost associated with treatment (<i>time off work, blood tests etc.</i>)	39

To what degree do you believe the following may inhibit effective treatment of patients with Hepatitis C? (n=35-36)

The most common issues considered by specialists as significant for inhibiting effective treatment of patients with Hepatitis C were:

Inhibiting treatment	%
Patients being referred late in their course of disease	77
Non-compliance of patients	64
Associated IDU by patients	63
Lack of staff with Hepatitis C experience	56

Only a few specialists considered the following issues to be 'very significant' issues which inhibit effective treatment of patients with Hepatitis C.

Inhibiting treatment	%
Lack of staff with Hepatitis C experience	14
Lack of access to pegylated interferon	11
Limited numbers of liver clinics	11
Patient access to clinics	11
Frequency of blood tests	8
Availability of translator services	8
Current S100 prescribing regulations	6
Waiting times for liver biopsies	6
Discrimination by health professionals	3
Waiting times for clinic appointments	3
Responding to cultural differences	3

Referral patterns

General Practitioners and Specialist Physicians were not always consistent in referral patterns. For example 75% of Specialist Physicians were happy to accept a referral from a patient who currently injects, while a much smaller percentage of GPs (51%) were likely to refer a patient who currently injected drugs to a Specialist Physician. A patient requesting a referral was rated highly by GPs as a reason to refer a patient. In contrast, only 28% of specialists stated that they would like to receive a referral based on a patient's request.

Chapter 6: Discussion

Of the 242,000 Australians estimated to currently have Hepatitis C, and the 16,000 new cases each year, well under 2,000 people per year in the last few years have undergone antiviral therapy. Despite remarkable improvements in the success rates of treatment for Hepatitis C, there has not been an increase in people taking up treatment. In 2001 and 2002, 1,650 and 1,640 prescriptions for Hepatitis C treatment were used by Australians, primarily for interferon and ribavirin combination therapy (NCHECR 2002, 2003). In 2003, only 1285 prescriptions were written (NCHECR 2004).¹ Given that people with Hepatitis C report significantly poorer health than their fellow Australians including those with other chronic illnesses, why are these treatment figures so low?

The decision to undertake treatment is not made by an individual with Hepatitis C, but rather in collaboration with the GP and the Specialist Physician. All three parties bring a different perspective to the decisions about treatment. In addition, all are constrained in their decision-making by factors which may be beyond their control, and at times, outside their knowledge. Similarly, they may have different reasons which motivate the decisions they make. Not all GPs, for example, have similar knowledge of Hepatitis C or experience in managing people with Hepatitis C, and so they may not all be certain of the best time to refer a patient to a Specialist Physician. Specialist Physicians themselves make judgements on a person's suitability for treatment using a combination of factors such as the person's self-report of their current health, along with test results. They may be required to make the decision about proceeding to treatment with less detailed knowledge of the social support available to the patient, information often more available to a person's regular GP. Figure 6.1 lists a number of broad medical/health and personal issues which have been highlighted in the literature as important factors in the decision-making process when considering treatment. These issues are not mutually exclusive to the person with Hepatitis C, the GP or the Specialist Physician.

Figure 6.1 Issues to be considered before undertaking treatment

- Severity of symptoms
- Disease stage
- Genotype
- Patient's compliance with eligibility criteria
- Likely success
- Ability to manage treatment in current lifestyle issue
- Ability to manage side-effects
- Availability of support

¹ It is likely that this reduction was due to people waiting for pegylated interferon to become available in late 2003.

- Supportive medical service
- Access to medical support
- Access to treatment clinic
- Likelihood of adherence to therapy

This study has found that not all these issues are considered important by people with Hepatitis C, GPs and Specialist Physicians.

It is currently estimated that only 20-30% of people with Hepatitis C will progress to cirrhosis. A dilemma for the clinician is to identify patients who have the greatest chance of developing this severe cirrhosis and who are therefore most likely to benefit from antiviral therapy. An underlying concern is that those who are unlikely to progress to serious liver disease should not be treated unnecessarily (Sievert, 2003). However, the judgement is made far more complex by the fact that liver status does not always predict severity of Hepatitis C symptoms and their effect on quality of life. Decisions about treatment, both from the perspective of people with Hepatitis C and from the health practitioner, are also not always straightforward.

People's reasons for seeking out treatment may not be related to symptom relief. For people currently experiencing treatment and for those who had previously been on treatment, most (91%) stated that they wished to clear the virus to prevent long-term liver damage. Most people also considered reducing the risk of transmission to others, and alleviating symptoms very important. Only half of the participants, either currently on treatment or previously on treatment, indicated that a doctor recommending treatment was an important reason for going on treatment.

People with Hepatitis C: who are they?

The average age of people with Hepatitis C from the current study was 43 years, ranging from as young as 15 years to 63 years of age. While most (81%) of these people were born in Australia; a considerable number were born outside Australia.

Most people (62%) believed they acquired the virus through injecting drug use, however, for many people this risky practice occurred years ago. The average time since participants believed they had contracted the virus ranged from one to 50 years ago.

Nearly a quarter of the sample had completed a tertiary degree and an additional half had completed high school. Just over half of the sample worked either full or part-time, with a worryingly high number (26%) of people indicating that they were unable to work due to illness.

Participants in the study were generally not in good health, with almost 50% rating their health as poor to fair, compared with less than 20% of men and women in the 2001 Australian Health Survey (ABS, National Health Survey Summary of Results Canberra AGPS 2002). Most people had experienced

symptoms and were presently experiencing symptoms which they believed were related to Hepatitis C. Fatigue, lethargy and lack of energy were the most commonly reported symptoms. For at least some of the time most participants (63%) felt isolated from others because of their Hepatitis C.

Most respondents knew their genotype, with half stating they had genotype one (which requires 12 months of treatment) and 34% with genotype 3. Nearly half (46%) of respondents reported that their most recent liver biopsy showed minimal scarring (stage 0-1 fibrosis) which excludes people from treatment.

Diagnosing Hepatitis C

The first step to accessing treatment is acknowledging either the likelihood of having acquired Hepatitis C, or acknowledging that symptoms may indicate an infection, and then attending a health provider to seek advice and testing.

Diagnosis of Hepatitis C is a relatively recent practice since testing only became available in the early 1990s. The average time since participants were diagnosed was only 7 years. In 31% of cases people were tested because their doctor suggested it. In a further 24% of cases people asked for the test. An additional 20% of cases were identified through routine screening such as antenatal testing, testing prior to surgery or a health examination. While the average time since diagnosis was only 7 years, the average time since likely acquisition of the infection was 18 years. The long time between likely infection and diagnosis has typically been reported in other Australian studies of Hepatitis C (Hopwood and Treloar 2003; Gifford et al, 2003, 2004).

In 31% of cases, the respondent's usual doctor suggested testing for Hepatitis C and in 51% of cases a GP ordered the Hepatitis antibody test.

Despite the picture of poor health associated with Hepatitis C, just over half (51%) of the sample had never been on treatment. It is perhaps surprising that in the current study 13% (n=29) of participants had given no thought to treatment, 20% (n=44) had considered treatment and decided against treatment and a further 10% (n=22) were undecided about treatment, suggesting that a number of barriers to antiviral treatment exist. It also implies that a barrier identified in our earlier studies is no longer of such significance. The *Living with Hepatitis C Study* (2001) found 27% of over 400 women had never heard of treatment, and in the *Men, Health and Hepatitis C Study* (2002) an alarming 42% of over 300 men claimed never to have heard of treatment.

Most participants (67%) who had decided to take up treatment could not identify the type of treatment they were considering.

Barriers to treatment

There is a range of factors which may act as barriers to the uptake of treatment. Some barriers are structural, and include access to a GP who is knowledgeable about and supportive of treatment. Others are personal, such as having a supportive partner, friends and family.

Studies have shown that men generally demonstrate poorer health maintenance and less health-seeking behaviour than women (Schofield et al, 2000; Uitenbroek et al, 1996) and so are less likely than women to seek out a GP.

However, studies of self-reported health status have shown that for a range of chronic conditions women have poorer health profiles than men (Waldron, 1983). There is evidence from other studies that many women with Hepatitis C who had never experienced symptoms still saw a doctor for their Hepatitis C. This contrasts with many men with Hepatitis C, who were physically well and were able to place their Hepatitis C to one side of their everyday lives (Gifford et al 2003, 2004). Men were inclined to seek help once symptoms became worrying. These results have important implications for the management of Hepatitis C, where behaviours, such as IDU, alcohol consumption and diet, can have serious implications for disease progression.

Another factor affecting attendance at health services is the fear that those with Hepatitis C may be discriminated against because of their infection. Discrimination towards those with Hepatitis C from health service staff has been widely reported in Australia (Anti-Discrimination Board of NSW, 2001). In addition to their poorer health, women in the *Living with Hepatitis C Study* (2001) also reported higher rates of perceived discrimination from health professionals than men (Gifford et al, 2003, 2004). While this could result from their more frequent access to health services providing more opportunity for discrimination, our earlier qualitative work suggests that women worry more about other's attitudes towards them, while men tended to take perceived discrimination less seriously (Temple-Smith et al, 2004). While the current study focused on the treatment issues rather than accessibility to health care, it is important to recognise that a variety of issues may be keeping a person with Hepatitis C from accessing a health service, which is the first step to treatment.

Other barriers to treatment may be perceptual, and based on erroneous beliefs about the eligibility, costs and discomforts associated with antiviral therapy. In addition, recent years have seen treatment become more effective and less arduous. Those who have had Hepatitis C for a long time may not be aware of these new developments.

Resources

In the current study GPs were considered as one of the most important resources in managing people's Hepatitis C. Over half of the rural residents indicated that their normal GP was an important resource in helping them

manage their Hepatitis C, in comparison to 41% of metropolitan residents. In contrast to this, 21% of metropolitan residents, in comparison to 12% of rural residents, rated their GP as not important at all.

Very few people with Hepatitis C considered natural therapists as an important resource in managing their Hepatitis C and only 13% were currently seeing a natural therapist. This low number may be related to the fact that 62% of respondents indicated that they had not received any information about complementary therapies during post-test counselling.

Treatment

Just over half (51%) of the sample had never been on treatment, 29% had been on treatment in the past and 20% were currently on treatment. Male participants (28%) were significantly more likely to be currently on treatment than females (13%).

The average age of respondents who were currently on treatment was 44 years.

Men participants (28%) were more likely than women (13%) to be currently on treatment. Women participants (54%) were significantly more likely than men (47%) to never have been on treatment. Current IDUs (79%) were also more likely to have never tried treatment compared to past IDUs (50%) and those who had never been IDUs (39%).

The time of diagnosis was an important factor in people's attitudes to treatment, and also suggested that participants who were diagnosed more recently were more likely to be on treatment. Thirty one percent of people diagnosed within the last five years were more likely to be currently on treatment compared to those diagnosed more than five years ago (14%). A shift in referral practice was evident, with those diagnosed more recently having been referred more quickly to a Specialist Physician than those diagnosed a long time ago.

For participants diagnosed more than 5 years ago, 31% were more likely to be dissatisfied with their current level of emotional support compared to those diagnosed in the last five years (15%). This suggests that alongside the developments in clinical treatment, improvements in management and support of patient's emotional needs have been made.

Treatment – People who have never been on treatment

Eighty five respondents who had never experienced treatment were asked which of a list of 18 issues (see Appendix 2) were important when deciding about treatment. Side-effects of treatment was the single issue rated as important by most people who have never been on treatment when making a decision about treatment.

The need to use contraception, difficulties managing drug administration, fear of biopsy, fear of discrimination, and costs associated with treatment were all rated as issues that were not important when considering taking up treatment.

Treatment – People who have decided against treatment

In this study 44 of the 224 study participants had made a decision not to undergo treatment for Hepatitis C.

For almost all of the people who decided against treatment, of the 18 factors offered (see Appendix 4), side-effects of treatment was rated as the most important factor. Treatment success rate, the impact of treatment on work, family or friends, and that liver status is good, were other issues also rated as important by at least half of those who decided against treatment.

A large range of issues were rated as unimportant in deciding against treatment. These included treatment clashing with the choice to use drugs, doctor not suggesting treatment, and wanting children in the future.

Fear of liver biopsy, a reason commonly offered anecdotally by those working within Hepatitis C as an important factor for refusing treatment was rated as not important by about half of those who had decided against treatment.

Accessibility to a liver clinic was an important factor in deciding against treatment for some rural residents. Seven people living in rural areas stated this was very important in making the decision not to proceed with treatment, in comparison to only one metropolitan resident. Interestingly seven other rural residents (in comparison to 16 metropolitan) stated that accessibility was not an issue in deciding against treatment, suggesting that the geographical positioning of clinics was the key.

Treatment – People who are undecided about treatment

Twenty two people of the 224 participants were undecided about treatment. Their results were consistent with others who had decided not to undertake treatment at this stage.

Treatment – Factors in deciding to proceed with treatment

Factors which were important in deciding to proceed with treatment were similar for those who had undergone treatment in the past, and for those currently on treatment. Participants overwhelmingly rated treatment issues as the most important factors when deciding to proceed with treatment. These included the person's perception of the likelihood of success (effectiveness of treatment), liver status, and the relationship with the doctor and the clinic managing the treatment, treatment side-effects, and having supportive medical services. A supportive partner was the one personal issue that participants rated as important.

There are strong similarities regarding factors considered important and factors considered unimportant between those respondents who were currently on treatment and those who had experienced treatment in the past. For people who had experienced treatment in the past and for people currently on treatment, effectiveness of treatment and their liver status were rated as being more important than treatment side-effects when they were making the decision to commence treatment. The relationship with the doctor was also considered extremely important, as was the support from a partner.

Issues considered unimportant or not relevant when deciding to take up treatment, included a range of issues which might be expected to deter people from treatment, such as: difficulties managing drug administration, fear of liver biopsy, cost associated with treatment, the need to use contraception, fear of discrimination and having to commit to a full term of treatment.

For both those currently and previously on treatment, the relationship to their doctor/specialist was important in making the decision to start treatment. For those previously on treatment, 67% of rural residents and 57% of metropolitan residents rated the relationship to the doctor/specialist as very important (5 on the 1-5 scale), and a further 22% and 14% rated it as important. Interestingly, accessibility of the liver clinic was very important to 60% of metropolitan residents, and only 39% of rural residents when making a decision to start treatment.

Treatment – Challenges associated with staying on treatment

Of the possible challenges presented to the participants who had experienced treatment in the past or who were currently experiencing treatment, very few were rated as important by most respondents. In fact, of the 18 items listed, most people currently on treatment did not rate any of them as important.

For those currently on treatment and those previously on treatment, the most important challenges were side-effects of treatment and depression. Interestingly however, these factors were rated as important by more respondents on past treatment than on current treatment, suggesting that the recent introduction of pegylated interferon and improved control of side-effects are showing benefits.

It might be expected that those undergoing treatment would rate as important a variety of structural issues such as proximity to clinic and waiting times. However, there were many issues not considered as important by those currently or previously receiving treatment. These included factors such as treatment clashed with my choice to use drugs, associated treatment costs, desire to use complementary therapies, and clinic times and delays.

Treatment – Resources for helping people stay on treatment

Most people currently on treatment rated treatment associated resources as the most important in helping them adhere to their viral therapy. These resources: their doctor at the liver clinic (81%), their Specialist Physician

(75%) and their counsellor/nurse educator/drug & alcohol worker (68%) were rated by the majority as important in helping them stay on treatment.

Fewer participants identified their regular GP (33%), a Hepatitis C support organisation (22%), another person with Hepatitis C (19%), a natural therapist (11%) and the internet (3%) as very important in helping them stay on treatment.

Forty three percent of rural residents who had experienced treatment rated their GP as very important in helping them stay on treatment, in comparison to 27% of metropolitan residents. Almost 40% of metropolitan residents rated their GP as not important at all in helping them stay on treatment, suggesting perhaps that they were able to access more comprehensive support through the liver clinic during this time.

The GP in Hepatitis C management

Visiting a GP is a critical step in the recognition of the need for testing, the diagnosis of Hepatitis C and in obtaining a referral to a Specialist Physician. GPs are also important in the ongoing management of the chronic symptoms of Hepatitis C and in providing a range of support to those with Hepatitis C. Not all GPs are interested or experienced in Hepatitis C management and their knowledge of treatment options may be variable.

The evidence suggests that not everyone with Hepatitis C is equally likely to access a GP. As referred to earlier, there are differences in the way in which men and women access primary care. Differences also exist between people who currently inject with those who either no longer inject or have never injected drugs.

The GP from the perspective of the person with Hepatitis C

Given that so many participants reported Hepatitis C-related symptoms and poor health generally, it was surprising that only half were currently seeing a GP for their Hepatitis C. People who were currently injecting were even less likely to see a GP for their Hepatitis C. While most people (more than 80%) who were seeing a GP for their Hepatitis C were confident of their doctor's level of knowledge about Hepatitis C, less than 50% of people were satisfied or very satisfied with their current level of care from their GP. People who currently injected rated their GP as less important in managing their Hepatitis C than people who had either never injected or injected at some time in the past. Similarly men rated their GPs as less important in managing their Hepatitis C than women.

From the GP's perspective

A key finding of this study was that over 90% of the 220 GP respondents had been involved in the health care of patients with Hepatitis C. Most GPs had diagnosed a patient with Hepatitis C with almost half 'often' or 'very often' recommending a patient to have a test for Hepatitis C. The main reasons given by GPs for testing someone for Hepatitis C was a history of incarceration, a history of IV drug use, elevated ALT level over a period of 6

months and having a partner with Hepatitis C. These findings highlight the need for GPs to be well informed about all aspects of Hepatitis C management.

While most GPs had cared for patients with Hepatitis C for more than five years, their Hepatitis C caseload formed less than 5% of their overall caseload. Overall, GPs in the study believed that they were well informed about Hepatitis C. Despite this, over half rated themselves as having much or very much need to improve their skills in managing patients with Hepatitis C. This was supported by (50%) of GPs stating that keeping up to date with new medical developments may significantly inhibit managing people with Hepatitis C.

Most GPs believed that dealing with non-compliance in relation to attendance, injecting drug use, dealing with non-compliance in relation to treatment and keeping up to date with new medical developments were key issues that may significantly inhibit managing patients with Hepatitis C. Only 25% of GPs believed that knowing when to refer a patient was a significant factor that may inhibit management of patients.

When asked about referring patients with Hepatitis C to complementary therapists, GPs stated that they had rarely referred a patient with Hepatitis C to a complementary health care worker.

Referral from a GP to the Specialist Physician

From the perspective of the person with Hepatitis C

To access treatment for Hepatitis C a patient requires a referral from a GP to a Specialist Physician. Most people with Hepatitis C in this study had received information about referral to a specialist, and 69% had seen a specialist, 50% of these within 6 months of diagnosis.

There was a change in referral culture evident in the study. Only 35% of those diagnosed more than five years ago had seen a Specialist Physician within six months of diagnosis. By comparison, 69% of those diagnosed within the last five years had seen a Specialist Physician within six months of diagnosis. There was no gender difference evident here.

From the GPs perspective

While 35% of GPs had referred all their patients with Hepatitis C to a specialist, the same number had decided for various reasons to refer less than half of their patients to a Specialist Physician. When GPs did refer patients, they overwhelmingly did so to a public hospital liver clinic.

Most GPs (98%) stated that they were likely to refer a patient with Hepatitis C to a Specialist Physician where there were clear signs of liver disease, or if the patient showed signs of liver jaundice.

Most GPs (95%) were likely to refer a patient to a Specialist Physician if the patient requested a referral.

Ninety percent of GPs stated that they were also likely to refer a patient if the patient had ALT levels consistently above 100U/L, however a further 9% were unsure about the appropriateness of referral at this point.

A patient's pregnancy or a finding of abnormal liver function tests were likely reasons given by 86% and 85% of GPs to refer a person with Hepatitis C to a Specialist Physician.

According to GPs, the likelihood of referring a patient to a Specialist Physician on diagnosis of Hepatitis C was only 55%, with 37% stating that they were unlikely to refer a patient at time of diagnosis.

If the patient drank alcohol heavily, wanted to start a family, currently used IV drugs, had a psychiatric disorder or did not meet the clinical guidelines for treatment, then the likelihood of referring to a Specialist Physician was reduced. Under these circumstances the chance that the GP would either not refer to a specialist, or would be uncertain about what action to take increases dramatically.

When asked if they were seeing a gastroenterologist/infectious diseases physician on a regular basis, 49% of rural residents and 67% of metropolitan residents had done so.

From the Specialist Physician's perspective

The results from the Specialist Physicians showed that they did not always receive referrals at the stage when they would like to do so. They did, however, believe that they received appropriate referrals of patients with significantly abnormal ALT levels and of patients on diagnosis of Hepatitis C. There were some mismatches between GPs and Specialist Physicians in relation to the perceived best time for making and receiving a referral. More than 60% of GPs were confident that they were referring patients at the right time. Despite this, there were clear discrepancies between GPs and Specialist Physicians, particularly in relation to referrals for patients who drank alcohol heavily, patients who used IV drugs and patients who had a psychiatric disorder.

Specialist Physicians considered it too late to receive referrals once a patient has developed symptoms or when a patient has developed signs of chronic liver disease. Specialists were also less in favour of receiving a referral on a patient's request. The results from the Specialist Physicians showed a clear preference for referrals early in the course of the infection, and if possible at the time of diagnosis.

Specialist Physicians' ratings of the greatest hindrances to effective treatment being a late referral, patient's drug use and treatment non-compliance, confirmed this position.

The Specialist Physician in Hepatitis C management

Sixty percent of the Specialist Physicians in this study managed patients with Hepatitis C. These Specialist Physicians saw themselves as well informed and confident in managing patients with Hepatitis C. While just over half had managed more than 50 patients with Hepatitis C in the last 12 months, their time devoted to these patients amounted to less than 10%. Just over half of the Specialist Physicians said they managed patients with Hepatitis C in conjunction with a GP.

In contrast to the practice of almost all GPs in the study, all Specialist Physicians stated that they were happy to accept a referral from a patient who wanted to start a family or who had an ALT level of less than 100U/L. Ninety one percent were happy to accept a referral from a patient who had a psychiatric disorder or who drank alcohol heavily. While 74% of Specialist Physicians were happy to accept a referral from a patient who currently injected, only 51% of GPs stated that they were likely to refer a patient to a Specialist Physician if the patient was currently injecting. A further 30% of GPs were unlikely to refer and 19% stated that they were unsure if they would refer a patient who currently injected. This mismatch between GPs and Specialist Physicians' expectations of appropriate stages for referral is an important finding of this study, and an issue which can be easily addressed.

The issues considered significant by Specialist Physicians in inhibiting effective treatment were a patient being referred late in their course of the disease; non-compliance of patients; associated IDU by patients; and lack of staff with Hepatitis C experience.

Specialist Physicians considered a lack of commitment to treatment; not being ready for treatment; the length of treatment; side-effects of treatment; and depression associated with treatment, all to be important factors in patient adherence to treatment. In fact, the two highest rating challenges for people currently on treatment and for people who had experienced treatment in the past were the side-effects and depression associated with treatment.

The fact that Specialist Physicians interpreted patients' hesitancy to undergo treatment as related to the difficulties of the treatment itself is not surprising, as these are the realities with which they deal on a daily basis. However, patients' results suggest that their decision to undergo treatment is rather based on the likelihood of success and their relationship with those who will support them through this difficult time.

Chapter 7: Conclusion

As described in Chapter 1, the decision to opt for treatment does not lie entirely in the hands of the person with Hepatitis C. Certain eligibility criteria must be met for the medication to be made available under the Pharmaceutical Benefit Scheme. Currently these criteria demand that liver function must be compromised to some extent before treatment will be considered. This appears short-sighted, in light of recent evidence showing the success of early treatment undertaken before liver damage is apparent. A current Australian trial in acute Hepatitis C is investigating whether treatment in the acute stages of infection is effective in clearing the virus (Dore, 2004).

This study offers a unique perspective on treatment from the viewpoint of the people with Hepatitis C, GPs and Specialist Physicians. It has highlighted a number of previously unrecognised issues, many of which could be readily addressed. The study also provides insight into what people consider the most important reasons for undertaking treatment and the most important challenges they are either currently facing or have faced in the past to staying on treatment. Other key findings include:

- GPs' concern over their own Hepatitis C knowledge
- Level of satisfaction of people with Hepatitis C with their GPs' knowledge of Hepatitis C
- Time of diagnoses does affect access to treatment. People who were diagnosed longer ago are less likely to have had treatment than those diagnosed recently
- Mismatch between GPs and specialists in relation to optimum time for referral
- Mismatch between Specialist Physicians and people with Hepatitis C about reasons for treatment compliance
- High rate of GPs managing people with Hepatitis C
- Recent change in culture of referrals to Specialist Physicians
- Average age of treatment is in mid-40s
- More men undertake treatment than women
- Factors people take into account when considering treatment
- Factors people take into consideration when deciding against treatment

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Appendix 1: Overview of recent key Australian social research studies on Hepatitis C which have collected information on treatment issues
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Table 1 gives a brief overview of recent key Australian social research studies on Hepatitis C which have collected information on treatment issues.

Table 1: Key Australian Social Research Studies On Hepatitis C

Study	Year	Sample	Tool	Conducted by
Living with Hepatitis C	2000	462 women with Hepatitis C	Questionnaire, based on info. from 20 interviews with women with Hepatitis C plus stakeholder interviews	Hepatitis Social Research Program, Gifford et al 2003
Men, Health and Hepatitis C	2002	312 men with Hepatitis C	Questionnaire, based on info. from 16 interviews with men with Hepatitis C plus stakeholder interviews	Hepatitis Social Research Program, Gifford et al 2004
A Sense of Belonging	2003	23 people with Hepatitis C 5 focus groups of people with Hepatitis C 21 service providers	In-depth interviews plus focus groups	Australian Hepatitis Council, 2003
The 3D Project	2003	504 people with Hepatitis C	Questionnaire, followed by 19 in-depth interviews	National Centre in HIV Social Research, Hopwood and Treloar 2003

Appendix 2: Issues associated with making a decision about treatment

Personal and social reasons

- Having a supportive partner
- Your age
- Possible negative impact on your work
- Possible negative impact on family
- Fear of discrimination
- The need to use contraception

Treatment issues

- Effectiveness of treatment
- Cost associated with treatment
(*time off work, blood tests, anti-depressant tablets, Panadol etc.*)
- Supportive medical services
- Side-effects of treatment
- Your relationship to your doctor/specialist
- Your genotype
- Liver status (*degree of liver damage/fibrosis*)
- Other medical problems (*i.e. depression*)
- Fear of having a liver biopsy
- Difficulties managing drug administration
- Having to commit to the full term of the treatment

Access to Treatment

- Accessibility of liver clinic

Appendix 3: List of challenges associated with staying on treatment

Personal and social reasons

It limits my ability to keep working
I am experiencing discrimination
There is not enough support available
I want to try complementary therapies instead
Discouraged by liver tests not showing improvement
Treatment clashed with my choice to use drugs (*illicit drugs*)

Treatment Reasons

The side-effects – they make me feel worse physically
It makes me feel depressed
The associated costs of treatment are too great
It is hard coping with the demands of treatment
The clinic is not conveniently located
My doctor is not very helpful/ supportive
Clinic times do not suit me
There are too many delays at the clinic
I keep seeing different doctors at the clinic
There is not enough time with my doctor

Appendix 4: List of issues associated with helping people decide against treatment

Personal and social reasons
Because I am feeling really well
Impact treatment will have on family/ friends
Impact treatment will have on work
Lack of supportive environment (family/friends/partner)
Wanting to have children in the near future
Can't commit myself to a long treatment program
Treatment clashed with my choice to use drugs (illicit)
Treatment issues
Treatment success rate is not good enough
Side-effects of treatment
Fear of liver biopsy
Liver status is good (minimal scarring)
Costs associated with treatment
Liver clinic too difficult to get to
My doctor said that I shouldn't worry about treatment yet
My doctor has not suggested treatment
Because I don't know enough about treatment
I want to try alternative/natural therapies first
Haven't given much thought to treatment

